



Not a Humbug: the evolution of patient-centred medical decision-making

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Abstract

This 'Christmas Issue'-type paper uses the framework of 'A Christmas Carol' to tell about the evolution of decision-making in evidence-based medicine (EBM). The Ghost of the Past represents paternalistic medicine, the Ghost of the Present symbolises EBM, while the Ghost of the Future serves as a patient-centred system where research data and tools of decision science are jointly used to make optimal medical decisions for individual patients. We argue that this shift towards a patient-centred approach to EBM and medical care is the next step in the evolution of medical decision-making, which would help to empower patients with the capability to make educated decisions throughout the course of their medical treatment.

EBM is not dead, to begin with. There is no doubt about that whatsoever, and unless we realise its necessity, nothing wonderful can come of the story of which we now write. For rather than being dead, EBM has merely evolved due to the experiences and necessities of life in such a way as old Ebenezer Scrooge, who changed to better his ways in the spirit of human goodness. Like Scrooge, physician and other medical decision-makers may yet avoid the frigid existence of cost and standardisation alone, and instead may embrace the general welfare and wishes of patients. For while the cost of medical care and the opinions of physicians are certainly important in any medical decision, these represent but an incomplete picture of medical care, which must grow to adopt the desires and values of patients associated with their treatments and outcomes. To further illustrate this point, we channel the spirit of Charles Dickens, where his work in 'A Christmas Carol' proved how a man who had been corrupted by the hardships of life could change for the better. Where Scrooge was able to become as good a man as the old city of London had ever known by peering through the window of Christmases Past, Present and Future, we portend that medical decision-making may take a similar path and evolve in favour of incorporating patient wishes alongside the views of physicians and underwriters.

Ghost of the Past: paternalistic medicine

"I told you these were shadows of the things that have been [...] that they are what they are, do not blame me!"—Stave 2, *A Christmas Carol*¹

At the dawn of the 20th century, medicine remained an archaic science often unavailable to any except the wealthy. Even in this early state, there existed a burning desire to improve life, where doctors and early philanthropists sought to improve public health, and reduce the aches and pains of the weary masses. In spite of these noble intentions, however, they were bound by the

limitations of their available knowledge and financial exchequer. Considerations of money and cost were important to any medical decision—it is not the purpose of this tale to suggest it is not—yet a belief existed in decades past that the improvement of health was a sacred and noble task, demonstrated by the adoption of the Hippocratic Oath by many western medical schools in the 19th century. The medical decision-making process at the turn of the 20th century was not perfect, however, as such decisions were made in an ad hoc manner. It is here that the 'gut feelings' of doctors dominated the decision-making processes in lieu of establishing standards. Within such a world, physicians operated within the realm of their own experiences and beliefs, with no standards to govern the behaviour of those trusted to cure the ills of the people. This contributed to the negative outcomes so feared among much of the population, and inevitably forced a change to the emergence of EBM and standardised treatment regimens. In various fields of medicine, especially in the fields of prevention and screening, the new methods of an optimised cost-benefit approach gained popularity, and served as the early harbingers of EBM. These are the shadows of things that have once been—they are what they are, but they may serve to benefit the public, insurers and doctors of the future through an evolution of this critical paradigm (figure 1).

Medical decision-making developed out of an inherent desire to ensure a high quality of medical care and best practices for all humans. In the early history of mankind, quality medical care was not necessarily provided to those in need, as doctors did not always know the optimal medical solution to treat various maladies, and resorted to unsubstantiated 'cures' such as mercury, bloodletting and other painful and not always effective procedures to treat their patients. Such treatments often generated more harm than good to the health of their patients, and often produced a mistrustful and sceptical public.² In such a system, medicinal practice was generally paternalistic in nature, where older physicians were trusted based on their experience instead of relying on established standards for best medical practices or scientific data.

Ghost of the Present: evidence-based medicine and the birth of shared decision-making

"Will you decide what men shall live, what men shall die?"—Stave 3, *A Christmas Carol*¹

Decades of tireless study produced the brilliant medical schools and physicians of today, bearing forth a standard of living that had been previously unimaginable for the masses (figure 2). However, this shift in intellectual and medicinal prowess grew in parallel with a rise of EBM, where patient's wishes were often met with a

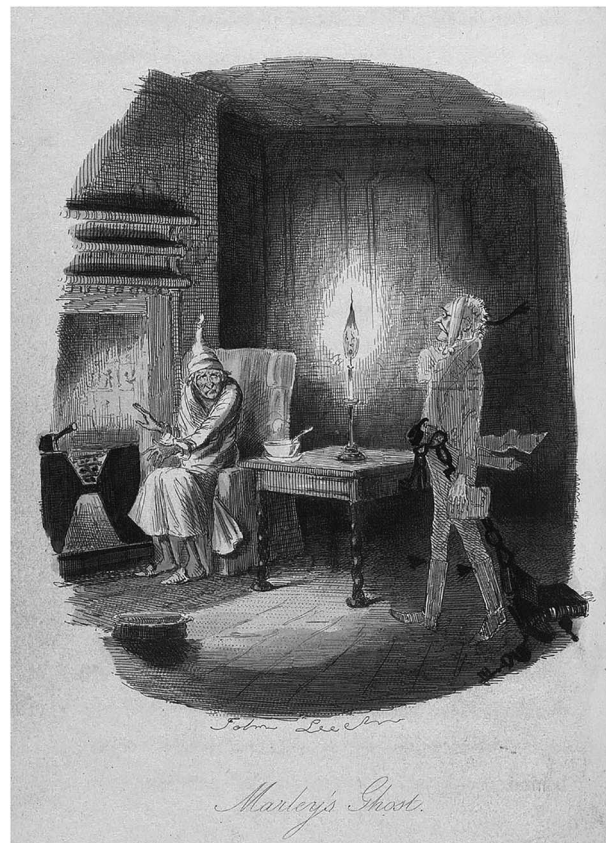


Figure 1 Scrooge is confronted by the Ghost of Jacob Marley, and begins his journey to learn the error of his ways.

modern equivalent of 'Bah, Humbug!'. In this way, the blizzard of time wore away at medical decision-making's youth to fashion it into a tight-fisted hand at the grindstone, where clinical standardisation came to dominate the wishes of the masses in most decision-making. Such decisions serve as the fruits of a discerning body of affirmed healers tasked with the challenge of using available medical expertise to treat the human condition. Given this, though the spirit of EBM is one that is intended to place the values of patients at the heart of any medical decision, these wishes often fade against the desires of physicians and underwriters. However, the wonderful truth of this story is that standardisation may progress yet again to include the strengths of a clinically structured decision-analytic approach towards medical decision-making that gives voice to patient beliefs, opinions and preferences, and offer a happy and healthy solution for all.

The concept of EBM, which evolved in 1990, emphasises the use of evidence from well-designed and well-conducted research in healthcare decision-making by 'finding, appraising, and using contemporaneous research findings as the basis for clinical decisions'.^{3 4} According to Timmermans and Berg,⁵ the term was originally used to describe an approach to teaching the practice of medicine and improving decisions by individual physicians, however, it rapidly expanded to include a previously described approach that emphasised the use of evidence in the design of guidelines and

policies that apply to populations ('evidence-based practice policies'). It has been suggested that an improved understanding of EBM by general practitioners contributes to better-informed decision-making by physicians and their patients.⁶ However, the vast majority of clinical pathways are developed based on expert panels of academic and community physicians who come to consensus based on current best evidence regarding efficacy, toxicity and cost.⁷

Criticisms that EBM denigrates clinical expertise, ignores patient values, or promotes 'cookbook medicine', all arise because of a failure to appreciate the focus on inclusion of patient values, which has always been emphasised in the traditional framework, and of EBM.⁸ However, to our knowledge, and based on the literature review, patients' preferences, values and concerns have not been adequately represented in the development of treatment and medical decision guidelines despite the inherent bottom-up approach provided by EBM, which calls for the integration of patient evidence, clinical expertise and patient choice.^{9 10} This represents a direct misuse of the principles of EBM, which should integrate patient wishes into any medical decision.⁹

While the development of EBM was intended as a tool to help doctors make sense of evidence in the context of individual patients' problems and preferences, few healthcare providers know how to use patient preferences and values to guide evidence-based decision-making. This leaves many to criticise EBM as not



Figure 2 Scrooge meets the Ghost of Christmas Present, and learns how his decisions negatively impact others.

responding to patient wishes in a variety of contexts, which is explicitly against the original spirit of the methodology.¹¹ Despite considerable promise, the pursuit of patient-centred medicine faces special challenges stemming from the cross-disciplinary nature of decision-making. Unfortunately, these challenges have thus far remained underexplored.¹² While EBM greatly improved the quality of care and extended life expectancy of the global population over the course of the 20th century, much can still be done to improve the quality of healthcare by making it more patient centred as we continue our journey through the 21st century (figure 3).¹¹

Ghost of the Future: patient-centred decision-making

"Men's courses will foreshadow certain ends, to which, if persevered in, they must lead," said Scrooge. 'But if the courses be departed from, the ends will change.'—Stave 4, A Christmas Carol¹

If existing medical decision-making practices do not adopt a structured and patient-centred approach, we fear that many in our society will continue to suffer in a costly and unhealthy manner, and arrive at a suboptimal end. The sole focus of structured medical decision-making cannot by itself resolve the various issues facing

the common man, and may continue to neglect the will of patients in the midst of life-changing treatment. Thankfully, these are only the shadows of things that might be, where such dark ends may be overcome by adopting a patient-centred approach to EBM. The rich history of Western medicine has offered plentiful experience in how different systems may foster various benefits to the masses, where now it is up to all within EBM to live in the Past, Present and Future by embracing the lessons that they teach in order to improve the delivery of medical care. Considerations of morbidity and mortality should always be present in such decisions, yet a focus on patient welfare and inclusion of patients' values and preferences in decision-making is what makes all the difference.

Physicians are taught to make decisions through the integration of evidence, inference and experience. The architecture of such decision-making is inherently structured around principles of EBM, yet it does not fully embrace the inputs and opinions of patients throughout the delivery of medical care. Where the further inclusion of patient wishes in medical decision-making is next in the evolution of EBM, future medical decision-making should be redesigned to offer pathways for the inclusion of both, qualitative information (ie, patient wishes or external information) and formal decision support



Figure 3 Scrooge meets the Ghost of Christmas Future, and learns of his fate as a tormented lost soul if he chooses not to become a better and more caring man.

systems, to assist in the visualisation of trade-offs inherent in the decision-making process, where appropriate. Such options and improvements to the existing architecture for medical decision-making would potentially help healthcare providers and patients make more informed decisions about a variety of clinical issues, especially when multiple treatment options are available with various degrees of risks and benefits.

This could be accomplished in many ways, including through the utilisation of decision support systems to promote the practice of EBM,^{6 13} and the use of qualitative efforts aimed at including patients in the decision-making process to overcome issues with medical miscommunication. However, currently used quantitative decision support systems and qualitative frameworks for patient engagement are limited in number and quality, with a primary emphasis on improving quality of care by helping clinicians improve the evaluation, assessment and treatment of patients, and to advise them on options in terms that patients can understand.^{14 15} With an ever-increasing knowledge base of medical and treatment options, and growing pressures for time, physicians need tools to aid in offering patients sound advice in an efficient manner while engaging patients in the decision-making process. In the future, medical decisions can evolve to become more patient centred, and can incorporate values and belief systems important to

patients. Such patient centredness will be especially important in situations where patients have a true decision paradigm in which more than one treatment option may be available to them (such as end-of-life care, choosing between more than one treatment option especially in cases of elective surgery, choosing most appropriate birth control method, etc).¹⁶ We argue that this shift towards patient-centred care, possibly through redesigned decision-making architecture inclusive of patient wishes, is the next evolution in medical decision-making. While a variety of approaches and methods both qualitative and quantitative are available to advance medical decision-making and EBM, the overall process in which decisions are made should ultimately give patients voice and make them agents of change in their own healthcare decision-making process. Shared decision-making is the future of medicine,¹⁷ where patient-centric decision-making will replace the traditionally hierarchical and paternalistic approaches to providing medical care.

Scrooge learned the errors of his ways, and sought to evolve his business and lifestyle to become as good a friend, master and businessman as the city of London had ever known. He was able to use the best principles of underwriting to continue his business, yet could also keep the good of the common man in his heart, which made all the difference for those in need, such as Bob

Cratchit and his son, Tiny Tim. Those committed to EBM are now at such an impasse, and must decide for themselves what the best way forward for medical decision-making is while recapturing the spirit of patient wishes for medical treatment. For us, we hope that such people are able to heed the lessons of Past, Present and Future, to evolve in such a way that makes use of decision analytic structure while keeping patient wishes at the centre of all action. For in such a system, it may be said that such underwriters and doctors are able to make use of their existing skills while upholding the business of humanity and public health.

We only slightly modify the words of Tiny Tim (who did not die due to his sickness, thanks to Scrooge) in wishing Happy Holidays to everyone, and wait in excitement for the things that may yet be.

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