

EDITORIAL INTRODUCTION

The patient, the illness, the doctor, the decision: negotiating a 'new way' through person-centered medicine

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Abstract

Medicine has a unique understanding of the physical, psychological, spiritual and social dimensions of what it is to be human and nowhere within modern medicine today is the need for greater cognition more acutely necessary than in the understanding of the patient as a *person*. Concerns with medical humanism, which are increasingly apparent within global healthcare services and policymaking, far from detracting from continuing progress in medicine's scientific character, enable a far more effective practice of medicine than each can possibly do in isolation from the other. The argumentation for augmentation of this nature enables a re-assertion and a re-establishment of some of the core tenets of medical philosophy and theory that have become progressively lost in over a century of positivistic empiricism. It is argued that unlike the 20th Century which was concerned with rapid scientific progress, the 21st Century should be characterised by a concern with both science *and the whole person*. In order to achieve such a vision in practice, a continuing articulation of medicine's scientific nature via the evidence-based medicine (EBM) movement and a continuing articulation of patients' rights through the person-centered care (PCC) movement, should no longer compete for audition in separate arenas or when together in the manner of a dialogue of the deaf. Rather, the more philosophically tenable components of each model should embark upon a process of *coalescence*, enabling shared clinical decision-making to be able to take account of a range of human concerns as well as being actively informed by accepted and reliable science. Although such a process will not of itself correct the current crisis in medicine – a crisis of knowledge, care, compassion and costs – it will play a highly valuable part in returning to clinical practice radical concerns for the proper care of the patient and the overt soul of the clinic. Without such progress, healthcare standards will continue to slide, inexorably it seems, to the lowest common denominator that is legally tolerable. The humanistic dimension of medicine is not an optional extra. On the contrary, its application is what separates the physician from the veterinary surgeon. The trajectory we describe can be summarily interrupted in accordance with the new World Health Organisation imperatives, by the development and implementation of person-centered medicine, an emergent model of modern clinical practice.

Keywords

Crisis, chronic disease, epidemiology, evidence-based medicine, humanistic framework, integrated care, patient autonomy, patient-centered care, person-centered care, relationship, shared decision-making, standards, veterinary medicine

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Introduction

As we write, nowhere within modern medicine is the need for greater understanding more acutely necessary than in its philosophy of the patient as a *person*. Far from being an esoteric or peripheral area of specialised academic interest, the personhood of the patient is a human reality that

remains utterly foundational to the clinical encounter and to medicine's ongoing mission, progress and destination. In fact, medical humanism, that quintessential aspect of accomplished clinical practice, is one of the most exciting and immediately relevant areas of medical discourse and research in which currently to be engaged. To some colleagues, a concern with medicine's humanism in a time

of astonishing therapeutic and technological progress may seem odd, even thoroughly questionable. How is it that such concerns with humanism, which some argue belong to a former age of the profession, should be allowed to surface in a manner that might risk a detraction from the continuing quest for scientific progress and application? But the concern with humanism is not a preoccupation at the expense of medicine's accumulating science base - on the contrary, it is an active quest for integration, an integration between the two fundamental components of medicine within medical theory: the sciences of medicine and the arts of medicine, the latter enabling the fullest and most effective application of the former. This argumentation for augmentation is one which at its core is devoted to a properly 'holistic' care of the sick, that is, to a Medicine of the Whole Person [1,2]. We do not therefore argue for the achievement of integration in purely theoretical or conceptual terms, in the manner of a tokenistic acknowledgement of medicine's history and traditional form, but rather for a functional integration in current best practice of the two foundations of medicine in a manner which has immediate implications for the practical operationalisation of important visions of effective clinical practice and for the Profession of Medicine in ethical terms. We need, then, both to re-assert and re-establish the core tenets of medicine following the damage that has been occasioned to professional practice by a century of positivistic empiricism. One core tenet of medicine is the clinical relationship and, within it, the person who is ill and the person who is called to assist the ill patient and accompany him on his illness journey. These, then, are the *persons* at the centre of care.

The 21st Century as the Century of the Patient

It has very recently been argued that the 21st Century should become the 'century of *the patient*' (italicisation ours) [3]. Is this a simple rhetorical statement by individuals with a personal attachment to the flavour of current healthcare and consumer fashion or a real possibility to which clinical professionals more generally should give closer attention, even a much fuller commitment? While warning of the pervasive nature of *fashion*, against which medicine is hardly immune, we argue that the notion that patients should be afforded this new and particular level of visibility and importance in modern healthcare is, in fact, entirely coherent and worthy of much greater, even urgent, consideration.

The meeting of the group of physicians, patients and academics which led to the articulation of the sentiment we detail was convened in order to mark the signing, one year ago (12-17 December 2010), of the Salzburg Statement on Shared Decision Making [4]. Essentially, the Statement called upon clinicians to: (i) recognise that they have an ethical imperative to share important decisions with patients; (ii) stimulate a two-way flow of information and encourage patients to ask questions, explain their

circumstances and express their personal preferences; (iii) provide accurate information about options and the uncertainties, benefits and harms of treatment in line with best practice for risk communication; (iv) tailor information to individual patient needs and allow them sufficient time to consider their options & (v) acknowledge that most decisions do not have to be taken immediately and give patients and their families the resources and help to reach decisions. Moreover, the Statement called upon patients themselves to: (i) speak up about their concerns, questions and what is important to them; (ii) recognise that they have a right to be equal participants in their care & (iii) seek and use high quality health information. Moreover, the Statement called on policymakers to: (i) adopt policies that encourage shared decision-making, including its measurement, as a stimulus for improvement & (ii) amend informed consent laws to support the development of skills and tools for shared decision-making.

Why did the *dramatis personae* in Salzburg consider the formulation of the Statement so necessary and timely? Drawing on their own explanation, it was because much of the care to which patients have potential access is delivered by clinicians and depends in large measure on the willingness of clinicians to provide it. These clinicians, the Statement architects have contended, are slow to recognise the extent to which patients wish to understand their clinical condition(s) and the decision options available to them and where clinicians are perhaps less habitually concerned with the elicitation and use of patient preferences and widely agreed standards of best practice. The difficulty that patients and their families experience in engaging with health professionals as part of shared decision-making should therefore be addressed, whether such difficulties arise from lack of confidence in questioning health professionals or from a limited understanding about health and its determinants with an inability to identify sources of information which are reliable and easily understood.

Despite the documentation of these observations, which of themselves surely call for urgent change, it is easily possible to underestimate the cultural resistance to change among health professionals, policymakers, patients and the public more generally and while shared decision-making is gaining momentum within the USA and the UK in the manner we have described previously [5-7], it has recently been concluded that in order to resolve such tensions and to progress the patient involvement function, "we have to negotiate a new way" [3]. What, then, is this 'new way' and how is it to be negotiated? How do we stimulate a shift within the Profession of Medicine, so that a 20th Century characterised by astonishing scientific progress, but concomitant de-humanisation and de-personalisation, can be replaced by a '21st Century of the Patient', preferentially concerned with both science *and persons*? That is to say, how do we create a new age, as it were, and a new set of new methods and a new model of practice that neglects neither science nor humanistic provision, but which brings both together in a manner of

integration that empowers Medicine in a way that each, operating singly, *simply cannot*.

Person-centered Medicine

With these salutary questions in mind, we contend that the defining characteristic of medical care in the 21st Century, in order to make it ‘The Century of the Patient’, should be the relentless pursuit of a model of care which enables continuing and affordable advances in biomedicine and technology to be applied within a humanistic framework that recognises the importance of applying science in a manner which respects the patient as a *person* and which takes full account of his values, preferences, aspirations, stories, cultural context, fears, worries and hopes and which responds to his emotional, social and spiritual necessities in addition to his physical needs. This is person-centered medicine [5-7]. As we have argued previously, such a model of practice cannot be developed and operationally realised through a continuing articulation of medicine’s scientific nature alone via the evidence-based medicine (EBM) movement, nor through the growing emphasis on a primacy of the patient through the patient-centered care (PCC) movement. We believe that these two movements, which have both contributed substantially to important discourse within medicine and healthcare over several decades, should cease to continue to compete for audition in separate arenas or, when in rare confrontation, in the manner of a dialogue of the deaf. Rather, these schools of thought must surely begin to speak *una voce* and it is for this reason that we have called recently and loudly, with Hartzband and Groopman [8] among others, for their ‘coalescence’ [6]. We do not pretend that such a coalescence will be philosophically, methodologically or even politically very simple. There is, in fact, a great deal of further thinking to be done in this context, as Loughlin has recently pointed out within a characteristically astute and detailed paper [9]. However, to await international philosophical consensus on a *precise* definition of personhood or to indulge in extended reflection on what *precisely* constitutes, for example, the ‘centre of care’ may be considered inexcusably neglectful of the urgent necessity to confront the ongoing de-personalisation and de-humanisation of healthcare that Hass [10] believes to be the most important subject in bioethics worldwide today. Certainly, there can be no practice without theory, but provisional understandings of given schools of thought on matters such as personhood and the infrastructure of the clinical consultation can provide the basis for interim methodological development and testing through process and outcome measurement of the effectiveness of developed models of care such as PCM, as part of and following their trialled implementation. The alternative is stasis, if not paralysis - and neither such state can be understood as progress in any intellectual or practically useful sense in our view.

We have argued that in order to achieve such a functional integration of the sciences of medicine and the

arts through which such sciences are properly applied to individuals, all directed towards the creation of a more complete model of clinical practice, a *fifth* reconstitution of EBM will be necessary [6], in combination with an accompanying change in the philosophies of the patient-centered care model, where each is prepared to give ground to the other in order to achieve a successful result in the direct interests of patients themselves. This process is certainly far from a so-called paradigm shift, implying disconnection between what has been the *status quo* before and what is now advanced as the ‘new way’. Rather, we propose a Hegelian synthesis, suggesting continuity and development, an approach evolving out of what has been the status and history of ideas previously [9,11]. In accordance with such a proposition and system, EBM should now acknowledge at the very least the futility of a philosophical position which argues for clinical practice to be *based on*, rather than *informed by*, the results of methodologically limited epidemiological study designs, a thesis that has been seriously questioned over some two decades of philosophical and clinical argumentation and which retains the potential to bring EBM into direct conflict with patient preferences and values, risking violations of patient autonomy within the ethical framework of medicine [12,13]. Likewise, PCC should increasingly reject consumerist models of healthcare, through which clinicians are regarded as functional providers of goods, in favour of the recognition that *two* persons inhabit the centre of the clinical consultation, not simply the patient himself as a consumer or director of care. As we have argued previously, medical professionalism excludes all such notions of consumerism and patient-direction in the same way as it has now dispensed with all notions of ‘physician-directed care’ in the classical forms of paternalism and autocracy within the clinical consultation. Indeed, the doctor-patient relationship is quintessentially *dialogical* and *not individualistic* in nature [14,15], therefore precluding a primacy of either doctor or patient and eschewing such conflictive structuring in favour of *shared decision-making between people*.

It would be absurd of us to claim that the coalescence of the more philosophically rational components of the EBM and PCC movements is all that is required to resolve the current crisis of knowledge, compassion, care and costs within modern medicine [6,11]. It is not. The deficiencies and deficits of modern health services extend beyond the problems of de-personalisation and de-humanisation of clinical practice itself, major those these are, and encompass utilitarian considerations of cost-effectiveness, the problem of workforce morale and so-called ‘burnout’, Taylorian approaches to healthcare service provision that treat patients not as persons but rather as statistical units and objects of treatment, all of which factors, collectively, are actively contributing to a descent of the standards of clinical care and medical professionalism to the lowest common denominator legally possible. A radical interruption of this worrying and alarming trajectory is urgently required as has indeed been called for by the

World Health Organisation itself, especially within the context of dramatically increasing chronic and comorbid illness globally [16]. Each one of these principal components of the current crisis in medicine will need to be attended to as a function of itself. But insofar as clinical practice is concerned, it seems to us imperative that policymakers, patients and clinicians alike must take urgent steps to re-introduce into clinical practice the humanistic dimensions and framework that have become largely lost over the last one hundred years. This humanistic framework of medicine within which advances in science are most effectively and properly applied within medicine is not an optional extra – *it is utterly indispensable*. Indeed, both clinicians and veterinary surgeons employ science, but physicians employ science within a humanistic context. If the humanism is lost or absent, then the implications for the standards of care and for medical professionalism itself become rapidly clear [17]. It is here that the potential for the model of person-centered medicine is most vividly illustrated. It is with these considerations that we welcome readers to the final issue of Volume 1 of the new journal.

Conclusion

We have structured the current issue of the *Journal* into 7 parts. In the first we publish five papers which contribute further perspectives to the evidence-based medicine debate. Six papers follow in the second section, which is devoted to evaluations of the role of PCM and PCM-type interventions within the context of chronic illness. In the third section we focus on mental health and in the fourth section, three papers explore developments in patient empowerment and satisfaction. The fifth section is concerned with progress in clinical communication with a further five papers in the sixth section discussing general aspects of person-centered healthcare. We conclude the Issue with three letters concluding earlier correspondence on the reliability of clinical trials and statistics in clinical care.

In closing the first Volume of the *IJPCM*, we take the opportunity to communicate to colleagues within the health services research community and in Medicine and healthcare practice more broadly, some details of the Fifth Geneva Conference on Person-Centered Medicine, which has been scheduled to take place from 28 April – 2 May 2012. The relevant details can be studied on the page which follows. We urge colleagues to consider attending the conference to contribute to the ongoing debate in the field and to assist the development of person-centered medicine as an emergent model of modern clinical practice [6,7].

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