

EDITORIAL INTRODUCTION

Person-centered Medicine: advancing methods, promoting implementation

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Introduction

In recent years, the World Health Organisation, the World Medical Association, the World Organisation of Family Doctors, the World Psychiatric Association, the International Council of Nurses, the International Alliance of Patients Organisations and the Institute of Medicine of the National Academies of Sciences of the United States of America, along with a wide range of other major professional and patient societies of global clinical importance, have collectively articulated increasing and widespread concern at a deepening crisis within medicine – a crisis of knowledge, compassion, care and costs [1,2]. The common observation is one of a growing distortion in the priorities and ethos of medicine, where a reductive focus on disease processes and organ systems alone has led to the compartmentalisation of knowledge, the fragmentation of services and to documented increases in a frank neglect of patients' concerns, needs and values [1]. When this phenomenon is considered alongside increasing healthcare resource scarcity in the face of a relentless increase in healthcare costs, together with an exponential rise in the incidence and prevalence of chronic and comorbid disease [3], we arrive at an astonishing picture of the current status of health services in our world today and to a startling realisation of the size and extent of the rapidly growing challenge with which we have now come face to face. Since to do nothing is no longer an option, there are

increasing and understandably urgent calls from policymakers across the globe for a response to this dilemma in the form of new approaches to the provision of healthcare services that aim to reverse the de-personalisation in clinical practice and increase its knowledge base, while attempting actively to contain or reduce its rapidly unsustainable costs. This is a challenge of staggering complexity.

It is difficult to understand how a combination of de-personalisation, unsustainable cost, scientism and a Taylorian approach to dealing with sick and suffering persons *cannot but* result in a toxic product of health system instability, medical error and burnout and malpractice suits. And to say that such a scenario retains serious implications for core medical professionalism and the patient experience of illness and health is merely to state the obvious. That something, then, must be done – and done quickly – appears so incontrovertible an assertion that it is at last, gratifyingly, beginning to stimulate the development of a number of national initiatives in response. One of the most prominent of these has occurred in the United States of America and another is in the process of occurring within the United Kingdom. There are others occurring elsewhere. The US and UK examples are initiatives on such a scale as to have direct and imminent implications for the development of person-centered medicine and we therefore discuss these here, within the context of this Editorial Introduction, in

welcoming readers to Volume 1, Issue 3 of the *International Journal of Person Centered Medicine*.

The Patient-Centered Outcomes Research Institute (USA)

In the US, a move towards a greater personalisation of healthcare services has been given recent impetus by the creation of the Patient-Centered Outcomes Research Institute (PCORI) [4] as a function of the 2010 Patient Protection and Affordable Care Act [5]. The overall aim of the PCORI is to provide patients and their healthcare providers, family and caregivers, with the information required to make choices that are aligned with their desired health outcomes and where such choices are consistent with their values and preferences.

The governance of PCORI is overseen by a wide ranging multi-disciplinary group of experts including physicians, nurses, health services researchers and, importantly, patients themselves, but prominently includes a range of other agencies, including those from hospitals and healthcare systems, insurers, the pharmaceutical, technology and diagnostics industries and also the Veterans Administration, the Agency for Healthcare Research and Quality, the National Institutes of Health and the Federal Government itself. In terms of developmental activity, PCORI has constituted a methodology committee with established expertise in epidemiology and biostatistics, health services research more generally and also genomics and translational sciences, with the aim of developing the scientific basis of patient-centered outcomes research.

The mission statement of the PCORI has been advanced as: 'PCORI helps people make informed healthcare decisions - and improves healthcare delivery and outcomes - by producing and promoting high integrity, evidence-based information that comes from research guided by patients, caregivers and the broader healthcare community'. Such a mission, thus articulated, will be undertaken within the broad framework of four questions: (1) Given my personal characteristics, conditions and preferences, what should I expect will happen to me? (2) What are my options and what are the benefits and harms of those options? (3) What can I do to improve the outcomes that are most important to me? (4). How can the healthcare system improve my chances of achieving the outcomes that I prefer?

In order to answer these questions, PCORI will assess the benefits and harms of preventive, diagnostic, therapeutic or health delivery system interventions to inform decision-making, highlighting the comparisons and outcomes that matter to people. It is set to take full account of an individual's preferences, autonomy and needs, focussing on outcomes that people notice and care about such as survival, function, symptoms and health-

related quality of life. Additionally, it will incorporate a wide variety of settings and diversity of participants to address individual differences and barriers to implementation and dissemination. Furthermore, it will investigate optimizing outcomes, while addressing burden to individuals, resources and other stakeholder perspectives [4,6].

The Health and Social Care Bill 2011 (UK)

In the United Kingdom, the Health and Social Care 2011 Bill, introduced into the British Parliament on 19 January 2011 and currently proceeding through the legislative process, similarly promises an invigorated national health service (NHS) 'built around patients, led by professionals and focussed on delivering world class healthcare outcomes' [7]. A core feature of the Bill is a greater empowerment of patient choice and the creation of mechanisms to allow local people to become personally involved in the design of services, thus, theoretically at least, enabling them to take a direct role in shaping and improving the NHS, making services more patient-centered and responsive as a result.

The integration of services as part of care provision is strongly advocated by the Bill, an extremely important emphasis, given that integration represents the most effective method for caring for the increasing number of people with chronic and comorbid conditions [8,9]. Here, the creation of health and wellbeing boards will be of pivotal significance, structures which are intended, in part, to facilitate the integration of health and social services and to ensure the achievement of public involvement, not least through the engagement of the new boards in commissioning activities.

A 'choice mandate' is included within the Reform, aimed directly at embedding the 'no decision about me without me' principle within clinical service delivery. Naturally, this does not refer simply to affording patients the choice of a specific provider of their care from among those competing to do so, but also refers to the need radically to increase the active participation of patients in the clinical decision-making process itself, a key component of person-centered medicine (PCM). The level of political commitment to the success of the Bill is illustrated by the UK Prime Minister's personal pledge to position integration at the heart of the NHS reforms.

If these policy prescriptions are ultimately translated into operational reality, then the likely outcome will be greatly welcome. Indeed, it is a decade since the NHS Plan (2001) announced the policy intention for a 'patient-centered NHS' [10], with little having been achieved within the reality of operational health services delivery since that time [11], despite additional declarations of policy intent and also a renewed emphasis on personalisation from the medical regulator [12,13].

The US and UK initiatives are extremely welcome and signify an evolving political commitment to the re-humanisation of currently de-humanised healthcare services. As such, they have clear relevance to the emergence of PCM and, indeed, have the potential to accelerate its progress. We have, however, four observations to make in relation to these developments. The first relates to nomenclature, the second to service design, the third to scientific medicine and clinical decision-making and the fourth to costs and implementation.

Nomenclature

Our *first* observation focusses on nomenclature. We find it disappointing that the US initiative and also the evolving UK legislation both continue to talk in terms of the person as a patient and not the patient as a person. As we have recently discussed [2], the matter of nomenclature is certainly not something which can be based on simple aesthetic preference or even traditional usage, but is rather a deeply philosophical matter and must therefore be attended to as such. We contend that the patient should be understood as an embodied, purposeful, thinking, feeling, emotional, reflective, rational human individual, always in action, responsive to meaning, whose life in all spheres points outward and inward, who has the capacity to love and be loved and whose spiritual dimension, frequently ignored, enables him to understand, through transcendence, the meaning of his own life within his internal milieu and externally. [14,15]. The patient is a person because he has *personhood* which, as Schaffner has argued, signifies human agency and authenticity in all levels of being and contexts [16].

Although casually and habitually employed within everyday medicine, the word 'patient', is therefore of itself highly limited in its essential descriptiveness, implying a lack of autonomy, which is to say it indicates or even promotes passivity and dependency [17]. When the word 'patient' is employed within the prefix 'patient-centered' in discussing models of care provision, additional problems become manifest, given that the nature of such care implies an individualisation that excludes the person of the physician, whose interests should, we argue strongly, be properly integrated within the process of *shared* decision-making [18,19]. Moreover, 'patient-centered care' implies an 'obligation to care for (patients) on their own terms' [20], with a clinician seemingly relegated to the status of a simple provider of goods. Such a system, if it were to (be allowed to continue to) evolve unchecked, would become, in reality, 'patient-directed care'. Such a model is a frank impossibility within the philosophical framework of medical professionalism, which excludes all such notions, as indeed it has similarly and entirely correctly dispensed with the formerly extant systems 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 [18,21,22].

It is for all of the reasons given above that we continue to argue vigorously for a substitution of nomenclature that in its construction explicitly recognises both the patient and the clinician(s) alike as *persons*. The term 'patient-centered' and the model of care to which it is attached seem to us, then, to be properly superseded by the description 'person-centered' and thus by the model of care to which person-centered medicine itself explicitly describes. There are some early indications that such argumentation is being assimilated by policymakers. The Scottish government within the United Kingdom, for example, now refers to *person-centered* medicine [23], rather than *patient-centered* medicine [24] and the number of Medline citations employing the prefix 'person' in the context of care provision is rising substantially each month.

Service design

Our *second* observation focusses upon service design. Both the US and UK reforms envisage reconfigurations of service delivery into more integrated forms than may currently be observed. We commend the communication of such visions for service re-design and have recently argued strongly in favour of a definitive move away from impersonal, fragmented and decontextualized systems of healthcare towards personalised, integrated and contextualised models of clinical practice [1,2]. The methodologies with which to enable such an operational shift remain, however, poorly described and are in urgent need of definition and development. Indeed, it is for this reason that, in the UK, The Royal College of General Practitioners has recently developed an integrated care strategy for patients on which it is currently consulting widely. The College's vision is for a model of clinical service delivery that consists fundamentally of well co-ordinated systems of care across differing services and levels of care which 'place patients central to the design and delivery of care and meet their needs...' [25].

The involvement of patients themselves in the development of such models of integrated care is vital, along with their family and friends. In the context of chronic disease, which is the major healthcare challenge of our time [3], patients often become 'expert' in the understanding of their condition(s) and of what works and is appropriate for them. It is only through the active engagement of patients and their family and friends in this way that we are likely to see the development and delivery of services that are realistically person-centered, producing high levels of satisfaction as a result. As Ham has emphasised, 'the journey towards integration needs to start from a focus on service users and from different agencies agreeing what they are trying to achieve, rather than from

structures and organisational solutions' [26]. We hope to see, therefore, as the work of PCORI progresses and as the provisions of the UK Bill unfold, an explicit commitment in practice to patient involvement in service design, re-configuration and shared clinical-decision making and to the concomitant development of methods to facilitate such active and functional involvement.

Scientific medicine and clinical decision-making

Our *third* observation focusses upon scientific medicine and clinical decision-making. By placing a prominently overt emphasis on *patient*-centered care, the PCORI in the US [4] and the current legislation in the UK [7] both risk a rhetorical and perhaps actual, *over*-emphasis on the importance of the patient choice and caring function within modern health services at the expense of a proper and sufficient emphasis on the vital importance of the place of agreed science. We are absolutely clear that while caring and compassion, so absent from modern clinical medicine, are urgently in need of re-integration into everyday practice, they cannot and must not be allowed to undermine the science of medicine – and *vice versa*. It is for precisely this reason that we have argued strenuously for a correct balance to be achieved and maintained between these two foundational components of good medical practice: the science of medicine and the humanistic framework within which it is properly applied. While evidence-based medicine (EBM) over-emphasises the value of science within the consultation and patient-centered medicine (PCC) risks over-emphasising the value of patient choice, creating an essential dichotomy between their respective philosophical positions as a result, we continue to maintain that the model of person-centered medicine brings both of these fundamental aspects of medicine directly into a functional harmony, so that rather than being held apart in the manner of polar opposites, the so-called art and science of medicine are properly yoked together [1,2,27-30].

Healthcare resource utilisation and person-centered medicine

Our *fourth* and final observation relates to costs and implementation. Both the US and UK healthcare reforms emphasise the need to attend urgently to economic regulation of healthcare expenditure as part of the process of expanding access to healthcare in the USA and maintaining universal coverage in the British NHS [4-7]. Currently, there is a commonly held view that person-centered approaches, while morally and professionally desirable, are typically associated with increased, rather than decreased, resource utilisation [1,2]. From their

particular perspective, it is entirely understandable that health service administrators will demand evidence that person-centered approaches can reduce hospitalisation and length of stay and other such events and indices of resource utilisation, while maintaining or increasing patient and clinician satisfaction in parallel. Indeed, as resource allocation remains static or decreases, where cost containment strategies become more and more aggressive and as demand continues to rise – especially within the context of chronic disease – it is inevitable that the availability of such evidence will be a prerequisite for an authorised implementation of PCM approaches. It is relevant to note here that assertions that PCM approaches are by their nature inevitably more resource-intensive are becoming less intellectually sustainable as a function of the increasing availability of early proof of principle studies showing PCM-associated decreases in utilisation [1,2,31,32]. Health economic analyses of the effects of PCM interventions have therefore now become urgently necessary in order to constitute a larger body of literature than that which currently exists on this topic and from which more definitive conclusions can be drawn in order to assist the commissioning of care and facilitate implementation processes.

Advancing methods, promoting implementation

Increasing the person-centeredness of clinical services through promoting the re-humanisation of medicine, will take time – there is unlikely to be an 'overnight revolution' in the current model of medical practice. In this context, moving the vision of PCM into an operational reality will require a greater emphasis on the development of appropriate methodologies with which PCM principles can be applied in 'hands on' everyday clinical practice. A first step must be the communication of a more developed and widespread understanding of the person-centered medicine philosophy and model itself. Here, it will be central to increase the awareness within global health systems of the classical definition of PCM as a medicine *of* the person (of the totality of the person's health, including its ill and positive aspects), *for* the person (promoting the fulfilment of the person's life project), *by* the person (with clinicians extending themselves as full human beings, well grounded in science and with high ethical aspirations) and *with* the person (working respectfully in collaboration and in an empowering manner through a partnership of patient, family and clinicians) [33,34]. In clinical practice, this definition proceeds to operationalization via its translation into the creation and maintenance of a relationship between *people*, the persons of the patient and the clinician(s), engaged in a mutual and dialogical process of shared decision-making, focussed on the patient's best interests, employing empathy and compassion within a relationship of engagement, responsibility and trust [2].

There is, however, much work to do here in terms of methodology before this framework can become realistically manifest within clinical medicine and healthcare more generally.

It is in terms of methodology and momentum that the work of the International College of Person Centered Medicine (ICPCM) retains such pivotal significance. In addition to the ongoing work on person-centered integrative diagnosis, person-centered clinical guidelines and person-centered treatment planning, new initiatives include the formal launch, on 1 May 2012 in Geneva, of the International Conference and Publication Series on personalised approaches to healthcare, a major programme of work dedicated to the debate and development of person-centered approaches to clinical practice for a wide variety of common conditions. Additionally, work will shortly commence on the preparation of a major 40-chapter textbook intended to constitute a seminal text for use within undergraduate and postgraduate clinical curricula and by the health services research community worldwide. Furthermore, discussions are imminently to commence on arrangements for the compilation of a mini-series of clinical guides and toolkits detailing practical advice for the teaching and practice of person-centered medicine across the most prevalent of the long term conditions.

We predict that the development of PCM models of care will initially result in their partial or full implementation within specific healthcare environments, where 'best practice' examples, appropriately evaluated in terms of clinical outcomes and cost benefits, then become available for wider study and assimilation within health systems. Increasing the person-centeredness of health services, then, is likely to prove a slow process, but one which has the potential to gather momentum if coherent and integrated models of practice for specific clinical conditions are developed and are accompanied by the relevant health economic calculations showing clear evidence of cost-benefit. It is precisely this momentum that it is now so important to maintain.

Conclusion

There is only one form of medicine, despite the arguments over its base. EBM's initially strident insistence that quantitative scientific data derived from epidemiological and methodologically limited study designs should form the *base* of clinical practice has been seriously questioned following extensive philosophical and clinical argumentation and critique [2]. With such absolutism effectively now defunct, arguments have appeared which commend a 'modest foundationalism' in substitute [35]. These models, however, despite their noble aspirations aimed at philosophical resolution, remain problematic in claiming for medicine largely singular visions predicated upon the specific viewpoints of individual schools of thought. Thus, those colleagues working within narrative

theory and practice will argue for *narrative-based* medicine, while others working within the field of values will argue for *values-based* care, even others will promote *relationship-based* practice. We maintain that medicine does not have or in fact need a base [2], but that it is, in accordance with Montgomery's thinking [27-29], a rational practice based on a scientific education and sound clinical experience; in other words, not just a body of scientific knowledge and a collection of well-practised skills, but rather a conjunction of the two: the rational, clinically experienced and scientifically informed care of sick people [27]. Thus, good medical practice remains *informed* by biomedical and technological advance, *enriched* by narrative, *guided* by values and preferences and *centred* on the clinician-patient relationship as a dialogue between persons - rather than being trapped in a given epistemic cage and defined by any one particular source of knowledge for decision-making. It is here that Tonelli's casuistic approach, with its concepts of warrants for the informing of decision-making (which we have previously discussed [2]) is fundamental, given that warrants generally include both factual and value elements. The simplistic notion that good shared decision-making incorporates facts provided by the physician and values provided by the patient not only demeans physician and patient alike, but leads to an inevitable (and unnecessary) conflict between facts and values, physicians and patients (M. R. Tonelli, personal communication). The casuistic approach acts to preclude such tensions, seeking to understand and respond to the needs of the patient as part of the complexity of the decision-making process. Further elaborations and debates on the above will take place within subsequent issues of the *Journal*.

In terms of the current Issue of the *IJPCM*, we have structured the text into four principal subsections. In the first, we publish the 10 remaining papers which complete the documentation of the proceedings of the Third Geneva Conference on Person Centered Medicine. In the second, we publish 23 regular articles which present original results and wide ranging discussion from a variety of experimental and other studies of direct relevance to the ongoing development of learned discourse in the field. In the third, we publish a book review focussing on key aspects of medicine and spiritual care in the ageing person, concluding, in the fourth subsection, with 4 letters to the Editor which continue and extend the debate on the strengths and limitations of clinical trial-derived data in the care of the individual. We welcome, as always, a frank scholarly exchange and debate on the papers published and look forward to presenting readers in December 2011 with Issue 4, which completes the first academic volume of our new periodical.

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