

Medical Humanities: a vision and some cautionary notes

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This article aims to engender discussion about the nature and future of medical humanities. First, a normative personal vision of medical humanities as an inclusive movement is outlined. Some of the problems that may emerge if medical humanities conceives itself too narrowly are then discussed. The case of the rise of the medical ethics movement is used to show what can happen to a movement that restricts itself too quickly and then the stages of the “death course of a discipline” are described and assayed. The article concludes with a plea for medical humanities to remain a “broad church”, exploratory, pluralistic movement rather than aiming to become a paramedical academic discipline.

My professional life has been spent largely within the ambit of the British National Health Service as a theologian, health care chaplain, manager, citizen representative, and health and social care teacher. In all these roles I have tried to foster and practise interdisciplinary learning and cooperation as a means of humanising and broadening care. I therefore enthusiastically welcome the renaissance of the medical humanities movement in Britain. I see the movement as a renaissance rather than an absolute innovation because within living memory many doctors actually undertook some general arts as part of their medical training; some students have always chosen to take arts subjects as part of their courses at universities such as Cambridge where all first degrees are, at least nominally, in arts. Medicine and health are everybody's business. They are human concerns in the widest sense. They have dimensions which far transcend rational/instrumental technological problem solving. So it is good to see concerted moves towards thicker, more pluriform views and practices in health and health care. These have the potential to enrich all those lives and institutions which are bound up with health. Health care can begin to discover a hinterland that will make it intrinsically more interesting and rewarding.

So much for ringing and sincere affirmation of the rise of medical humanities. In this article, I want to take a critical, speculative look at what I see as the some of the opportunities and dangers facing this nascent movement. I will start by outlining a personal vision of what I think medical humanities might be. This will emphasise breadth and variety of forms. I will then consider the threats to this kind of vision by outlining the potential “death course” of a new discipline. I will draw on the recent history of health care ethics in Britain. This movement has substantial analogies

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to the rise of medical humanities; it may have cautionary lessons to teach, not least in the way that it has become narrowed, specialised, and made routine. This is by way of asking the question: how can a broad, inclusive, energetic vision of medical humanities be maintained in the long run? My prognostications may be, and I hope are, wrong. But my hope is also that, by raising such issues as a critical friend at an early point in the evolution of this new venture, it may be able to avoid unnecessary and harmful narrowing.

A VISION OF MEDICAL HUMANITIES

Medical humanities does not yet have a fixed identity and form, nor has it yet been patented or trademarked. Humanities in principle can embrace all disciplines and people. I take it then that there is still room for a personal vision of a movement with which I would like to travel, as a humanities scholar concerned about health and health care. In a nutshell, I would hope that medical humanities could be:

a loose coalition of concerns, people, disciplines, approaches, practices, and methods that are engaged in a fairly open ended dialogue and exploration of where humanities approaches etc can be illuminative of, or even obstructive to, health and health care.

That is to say, the kind of venture that I would like to be involved with would be a loose, porous, ill defined and inclusive movement of individuals and groups, practitioners, performers, analysts, and theorists, with different backgrounds, skills, perspectives, and interests *on all matters to do with being human and being healthy*. Participants would be related, to a greater or lesser extent, by a number of purposes and hopes. These might include the following:

- The desire to affirm and promote the place, importance, and practice of humanities disciplines and arts in health and social care (performance).
- Commitment to encouraging critical evaluation of, and reflection upon, those activities (research and reflection).
- The wish to promote practitioner and user education that takes account of the insights, methods and pleasures that humanities can provide in enhancing all aspects of health care. (Pleasure and intrinsic worth are not highly valued indicators within an evidence based health care system, but if they are not affirmed as essential marks of arts and humanities, then even arts and humanities shade over into becoming *technologies* rather than preserving their distinctiveness. Stivers notes: “That which is truly qualitative . . . cannot be measured and predicted”.¹)

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Within the context of a diverse network or movement which has some loose common commitments and aims, but no centralised dogma or creed, there might be some shared values.

Firstly, the processes of building up an awareness of the potential importance of humanities in health and health care would be at least as important as any end result that might be achieved. This reflects the commitment to the intrinsic, rather than the instrumental, value of humanities and arts.

Secondly, the medical humanities movement would prize diversity of forms. It would aim to affirm, stimulate, and develop all those who are likely to be affected by it (potentially anyone who might be a patient or carer) and to be maximally inclusive. It should aspire to be a “broad church” of many languages and kinds of performance and analysis, in which bridges are built and conversations occur that reveal things to participants that they could not have learned within their own original limits and worldviews.²

By the same token, thirdly, homogenisation and regularisation of thought, method, and practice would be actively resisted. The willingness of theorists and performers within medical humanities to live with ambivalence, complexity, and ambiguity, reflecting the diversity of human existence, might be a distinctive hallmark of this movement within the health care domain.

Thus, medical humanities would aspire to become and remain a humane contribution to the humanisation of health and health care in the broadest possible way. It would affirm common, if diverse, humanity. It would aim to enhance and affirm human existence and to remain relevant and accountable to humanity understood in the broadest sense. Medical humanities would add value and values of many different kinds (aesthetic, moral, sensual)—not just financial or crudely measurable—to life and health at a number of different levels.

To make these aims and values a little more concrete, perhaps some of the observable and distinctive “vital signs” or effects of medical humanities might be as follows. Equal space and respect would be accorded to practitioners, performers, theorists, and analysts from the various relevant arts, humanities, and medical practices and disciplines. Attempts would be made to try to break down barriers between these different groups and perspectives; work would be undertaken to build effective channels of communication, dialogue, and debate. Interdisciplinary understanding and cooperation, while difficult and time consuming, would be privileged and prized. There would be active attempts to bridge gaps between “professionals” and experts in both the humanities and health care and the users or consumers of their efforts. People and institutions would be helped to take their own ordinary experiences and perceptions more seriously, to value them more highly, and to articulate them more fully and diversely so they could learn from them. Individuals and groups would be encouraged to express their feelings and experiences more clearly and critically so that their lives and choices were enhanced. Attempts would be made to help create critical and imaginative space for all, both users and workers in health care, so that the common imagination was enriched and diversified. Furthermore, there would be evidence of positive engagement with the necessary passion and risk that allows creativity to take place and the “transfiguration of the commonplace” to occur in “everyday epiphanies”.³

A valuable byproduct of all this might be that team work and human relations would be enhanced, reflection upon practice would be enriched, and the rhetoric of partnership and respect between different groups and individuals should become more real—and also more critical. It should not be expected, however, that arts and humanities will contribute in predictable, controllable, and measurable ways to external “targets” set by ratiotechnocratic imperatives. This would be to distort the intrinsic values and meanings of the whole humanistic enterprise.

The corollary of this kind of utopian, normative vision of a diverse medical humanities is that certain features should be

avoided at all costs. Thus medical humanities should not be narrow, exclusive, or cliquish, with just a few “insiders” and many outsiders. It should avoid the temptation to become highly professionalised and expert dominated so that ordinary people and workers feel unable to understand or participate in it. Furthermore, it would be important for it to affirm what people are already doing and to help them to do it better, rather than making them feel ignorant or inadequate because they do not have certain kinds of cultural baggage or pleasures.

Intellectualisation and academicisation would have to be resisted if performance in arts were to continue to be integrally valued. At the same time, it would be important for the movement not to foster anti-intellectualism or contempt of health care or academic professionals.

It would be easy for medical humanities to cease to be a dynamic movement and become another bit of health care training syllabus, representing yet another demand on precious time. If medical humanities, either in training or service delivery settings, becomes just “one more damned thing” that performers, workers or users have to take into account, then it will have failed. Similarly, if people come to dread the mention of the term, cannot understand the jargon or activities of its proponents, are bored, or perceive the movement to be a bit of detached, encapsulated nonsense which is part of one discipline’s empire building aspirations, it will have lost much of its validity and interest.

We will know that medical humanities as a vibrant, pluralistic, experimental, risky movement has died when it: excludes varieties of disciplinary perspective and performance, has qualified exponents who are experts and who do not need to consult people in other disciplines, and becomes an autonomous discipline in its own right which licenses its own practitioners in some way. At that point, most likely, medical humanities will also have become dominated by health care workers specifically trained in the discipline; these latter will then become disconnected from real interdisciplinary work, barring humanities academics and performers from their own activity and thought. At this point, medical humanities will have gained the world and the financial support that it needs, but lost its soul. Part of the essence of humanities is the sense of intrinsic value and non-measurable worth that may allow the emergence of pleasure, unexpected insight, and even wisdom. These features are basically incommensurable with the “McDonaldised” world of measurement, predictability, control, and guaranteed efficacy.⁴

This brings me to lessons that can be learned from what was once the health care ethics movement and thoughts about the “death course” of disciplines. If medical humanities is to avoid routinisation, exclusivism, narrowing, specialisation, professionalisation, and the other ills described above, it may be important for it to glance over the wall to see what has become of health care ethics over the last few decades.

HEALTH CARE ETHICS: A CAUTIONARY TALE

In many ways, the rise of the medical humanities movement is very similar to the early stages of the rise of health care ethics. In the 1960s and 1970s a few medical professionals and arts academics such as philosophers and theologians became interested in the lack of medical ethics teaching and discourse. By definition, all these people were amateurs in a field whose edges and parameters were not yet established. They were driven as much by interest as by necessity and were all equally motivated to find ways of enriching discourse around medicine and health care. Necessarily, they had to make the effort of trying to understand different disciplinary perspectives and to be committed to working together. The early pioneers of health care ethics were theologians, philosophers, doctors, nurses, health care chaplains, and others. Medical groups in different centres of health care education were

similarly diverse and health care ethics teachers and researchers might come from a variety of disciplinary backgrounds, practical and theoretical. There was, if I recall correctly, a real sense of mutual exploration and excitement as interdisciplinary health care ethics research and education made its first tentative steps towards inclusion in the curriculum, and towards becoming more central to health care in general.

Twenty five years later, health care ethics is a well established part of the curriculum for professionals of all hues, and ethics is talked about constantly within health care settings. Most health care and research institutions now have ethics committees and formal ways of deliberating about ethical issues. It is hard to remember how little regarded ethics was as recently as 40 years ago. While rejoicing at the prominence accorded health care ethics as a field today, it is important to note that this has perhaps been won at some cost. Much has been gained, but some valuable things have also been lost.

Because health care ethics is now a recognised disciplinary speciality, there is little room now within it for enthusiastic amateurs who do not know its sources, forms, and conventions. Increasingly, health care ethics teachers and researchers have specialised in it at postgraduate level over years. It has therefore become professionalised, creating a contrasting “laity” of people who cannot be recognised or defined as health care ethicists. Indeed, the jargon and conventions of health care ethics are now so well defined that many people would recognise it as a specialised language which they cannot and do not speak, rather like legal jargon and concepts. Similarly, the area has, like palliative care, become medicalised. It is increasingly common for health care professionals to be taught health care ethics by other health care professionals who have specialised in the area. This pays dividends in terms of relevance and applicability, but risks screening out the possibility of real interdisciplinary struggle for understanding and multiple perspectives.

Health care ethics has acquired the dignified paraphernalia of formal journals and an “official” literature. This announces that it has become “academic”. The loss here may be a failure to recognise that non-academic perceptions, approaches, utterances, and performances can have real value. The jewel in the “crown” of centrally established health care ethics is the creation of defined agreed curricula for students and trainees. It is this kind of clarity, however, that may cut health care ethics off from interdisciplinary messiness and open ended exploration. Health care ethics is obviously closely related to matters of law and procedure in health care. But focusing in a procedural, componential way on well defined decisions and problems separates this discipline from curiosity about wider, more complex issues of human existence, wellbeing, and flourishing. Thus, health care ethics fails to be curious about the wider world and the human condition. It can easily become cut off from its hitherto contributory disciplines such as history, theology, and philosophy, which frame particular issues and problems in a wider human context. Here the capacity of health care ethics to define its own agenda may be fatal, for it is no longer obliged to address ideas and concerns from other areas of life and academia than those which its practitioners deem relevant by their own lights. Instead of engaging in demanding and creative interdisciplinary encounters, health care ethics is likely to become more self regarding and autonomous. As it becomes increasingly coherent, lapidary, smooth, and self confident, it is in danger of eliminating all loose ends and radically different approaches to the big questions and issues of life.

One cannot easily imagine Aristotle or the great humanistic therapeutic philosophers of Greece being very impressed by health care ethics today.⁵ Their questions about life and practice were developed out of a total view of human existence and its possibilities. It is difficult to think of their being content to deliver or take a module in procedural health care ethics, however well they might be paid, however grandly titled their

chairs and however exalted their place in the academy. For such thinkers, the particular and the problematic had to be situated within a much larger picture about potential and meaning that covered all of life and the entirety of social and institutional arrangements. This breadth of vision seems to be singularly, if inadvertently, lacking in established health care ethics today.

Do we in the medical humanities want to go the same way?

DEATH COURSE OF A DISCIPLINE?

Maybe the medical humanities movement has no real choice. Perhaps all new, interdisciplinary, pluralist movements must ultimately shrink into established autonomous disciplines. It may then be possible to suggest that every new movement has a kind of “death course” which follows a trajectory from innovation to establishment then death and the need for a new kind of endeavour to fill the gaps that are left by its exclusions. Here I draw on Max Weber’s basic idea of *charisma*, which allows innovation to enter into the world and then to be gradually normalised and “routinised”, to sketch the “ideal type” stages of the death course of a discipline.⁶

Stage 1 Birth/spinning ideas and dreams

At this point there is a movement on the part of some enthusiastic amateurs from various different disciplinary and professional backgrounds who feel that there are important foci and exclusions that need to be addressed and explored in order to address reality more fully and in a more interesting way. Their discussions and actions are necessarily cooperative and interdisciplinary. These people will feel themselves to be on the edge of, or between disciplines. Their mood is likely to be one of excitement, enthusiasm, commitment, uncertainty, and frustration that others do not share their concerns and priorities. They will network intensively and informally, value the support and interest of all, have few if any resources, and possess huge evangelical passion.

Stage 2 Childhood/gaining a hearing

If the innovators have been successful in communicating their excitements and concerns to others, there are likely then to emerge a select few champions of the new movement. These are influential members of professional and other groups who advocate the importance of the movement’s ideas and practices. At this point some material resources are likely to emerge in the form of funding for pilot projects and posts that will allow further exploration. The mood of those concerned is likely to be one of elation and excitement that things are beginning to move. The original progenitors will feel that their efforts are being rewarded and that they are being taken seriously, while advocates feel pleased that they are associated with important innovations that will make a difference in the world. There are no specialist experienced teachers or researchers in the area, so discourse necessarily remains experimental, interdisciplinary, and fragmented at this stage.

Stage 3 Adolescence/finding identity

At this stage the new movement begins to establish its identity and boundaries. More people at different levels become interested in the area, then gradually there emerge what might be called “knowledgeable types” who feel they belong firmly within the ambit of the movement even if their own starting point was outside it. A sprinkling of academic posts begins to emerge, pioneering courses start to run, and maybe a journal comes into being with the name of the movement enshrined in its title. The protagonists are still enthusiastic and excited, but they are increasingly confident that their concerns are becoming central. Academic and other authorities start proactively to seek out the new “experts” in the field to find out how they can make use of their insights and experience. Centres emerge and interdisciplinary, interinstitutional contacts

seem increasingly irrelevant and difficult to retain as the network of interested groups and individuals grows beyond face to face contact.

Stage 4 Adulthood/establishment and proliferation of the discipline

The final stage of emergence of a new discipline is when it firmly establishes itself in various centres and becomes ubiquitous within curricula for particular groups. It will seem to newcomer initiates to the discipline that it has always been there and that there is nothing very new about it. By this point, doctorates are being awarded in the subject, teachers who have specialised solely in the discipline and not in one of its feeder tributaries are being appointed to integrate it throughout the curriculum at all levels, chairs are being awarded to pioneers specifically within the discipline and an authoritative canon of literature and other material deemed central to the discipline emerges. Now the discipline is thoroughly professionalised, and reasonably well funded. It will have identified its boundaries and conventions, and will have started to license expert practitioners who are deemed competent. The people who first had the ideas that have led hither are probably near to retirement and covered with glory and gratitude by second and third generation experts in the field. Their mood is one of satisfaction. Meanwhile, interdisciplinary networking and pluralism of concern, perspective, performance, and focus has all but collapsed as participants in the discipline need only to talk and compete with other self identified members of their own tribe. A new laity sits frustrated, disempowered, and possibly bored in the wings, waiting for some new ideas to come along that will allow them to express ideas and concerns which seem to be absent from the newly solidified disciplinary field. Thus, there is a need for a new movement or discipline to be born . . .

And so the cycle, which probably takes about 30 years to complete, might start again. If health care ethics had been broader in its concerns and remained a loose interdisciplinary movement concerned with all aspects of human meaning and value (something it might have done had it had a wider philosophical view of its own purpose) then it might have been unnecessary for medical humanities to be born. Perhaps medical humanities in its own time will have to move over to allow the concerns and practices that it has excluded to find voice and attention within the sphere of health and health care.

But could there be an alternative to re-inventing imperfect new disciplinary wheels? Maybe it might be possible to learn from the experience of the past and to take the time to ensure that a broad movement does not degenerate into a relatively narrow discipline. How this might be done cannot be the subject of this paper. There are, however, organisations like the Bournville Trust in Birmingham that resolutely built change and restructuring into their initial constitutions and have tried to keep a broad base of interests solidly engaged with their work. It is desirable that those presently championing medical humanities should have the vision to continue to participate in a broad, diffuse, pluralistic, loose ended, intellectually exciting, and practically stimulating interdisciplinary movement rather than seeking to solidify into an academic discipline whose language is a kind of Esperanto which none but inmates of the medical humanities tribe understands.

CONCLUSION

This field might be seen as having the potential to be a number of different things. Firstly, it might be regarded as a practical and academic health care discipline waiting to be bulked up so that it can take its place in the formal medical curriculum and pantheon of research area. In this way, it might be little more than an important but not particularly threatening extension of medical and health care education. Secondly, it could be a

kind of counterculture where people can protest intellectually and practically about the unsatisfactory nature of health and health care—a place where the excluded bits of human experience and meaning are given value and celebrated. Thirdly, medical humanities might represent more political hopes for changing the nature and practice of health and health care; thus it is seen as a transformative activity—a kind of cultural “militant tendency” situated within the heart of health care to subvert, diversify, and improve it. Finally, and most cynically, it might be thought to be an opportunity for under recognised and underfunded arts academics “on the make” to provide themselves with honour, relevance, and cash to dignify and enrich themselves.⁷

I do not see why medical humanities should not simultaneously be all these things, and more. (Even academic aggrandisement has its place in providing energy and motive for getting things moving.) I have argued in this paper that medical humanities needs to remain a living, messy coalition or movement. It should not then be attenuated into being yet another independent quasi-academic autonomous discipline, basically cut off from the sources of energy and interest that inspired its existence in the first place. It is vital that medical humanities remains as wide and therefore as humane as it possibly can be. It needs to prize and retain all types of disciplinary approach, performance, analysis, and worldview. Our concern and study is humanity itself. Nothing other than the broadest approach can possibly do justice to this subject, particularly in relation to health care.

Retaining breadth, different interests, and interdisciplinary networking will be demanding costly, time consuming, frustrating, and sometimes conflict ridden. I know this from experience. Anything less than a firm resolution to do this at this point in the history of medical humanities will, however, deliver this fascinating initiative into the morbid fate of becoming a conventional, respectable, fundable, paramedical academic discipline.

When medical humanities has come to be recognised as useful, fulfilling a respected and valuable purpose, when its outcomes can be specified and measured, it will have achieved much. In becoming useful, however, some of its humanity may have departed. Surely we can do better than that. And it may be that in the ragtag group of artists, scholars, and health care professionals who try to keep faith with this broad vision, refusing to push each other off some mythical piece of turf which none of us can ever really own, we will learn more of intrinsic worth from the process of trying to stay with each other than we could ever gain from doing a degree in medical humanities. I'm for the journey, however uncomfortable, not the syllabus, however tidy, or the research grant, be it never so large.

I do not want to decipher the mystery. I want questions and not answers. I want the sea and not the harbour.⁸

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