

## منابع حیطة مطالعات میان رشته‌ای علوم انسانی و سلامت

دوازدهمین المپیاد علمی دانشجویان علوم پزشکی کشور



Medical Humanities meets medical technology

آبان ۱۳۹۸

مَدِينَةُ  
الْمَدِينَةِ

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امروزه طبابت و مراقبت سلامت بدون حضور تکنولوژی متصور نیست. ارتباط میان پزشکان، پرستاران و سایر مراقبین سلامت با بیماران و افراد نیازمند به تنهایی تعیین کننده کیفیت مراقبت و نتایج آن نیست، بلکه تکنولوژی نقشی انکارناپذیر دارد. تکنولوژی‌های نوین تشخیصی و درمانی این امکان را به وجود آورده است که مرزهای مرگ و زندگی، بهنجاری و نابهنجاری و سلامت و بیماری به چالش جدی کشیده شوند. از همین رو رصد، تأمل و نقد جدی و مستمر نقش و جایگاه تکنولوژی در حوزه سلامت بخشی کلیدی از مطالعات میان‌رشته‌ای علوم انسانی و سلامت است. باید توجه کرد مراد در اینجا ارزش‌داوری درباره تکنولوژی نیست، بلکه بررسی همه‌جانبه این پدیده است. از همین رو کمیته علمی حیطه مطالعات میان‌رشته‌ای علوم انسانی و سلامت بر آن شد تا نقش و جایگاه تکنولوژی در حوزه سلامت را مورد توجه جدی قرار دهد و به‌عنوان موضوع امسال در این حوزه برگزیند.

در مرحله اول (آزمون غربالگری) تأکید اصلی بر مفاهیم اصلی و رویکردهای مختلف در **Medical Humanities (MH)**، مفاهیم و تعاریف اصلی در فلسفه تکنولوژی و تأمل در جایگاه تکنولوژی – به‌طور عام – در حوزه سلامت خواهد بود. در مرحله دوم (نهایی) بر موضوع هوش مصنوعی تمرکز خواهد شد. بدیهی است که پرداختن به تکنولوژی در حوزه سلامت نه از منظر مهندسی بلکه از دیدگاه مطالعات میان‌رشته‌ای علوم انسانی و سلامت خواهد بود و منبعی که پیش‌رو دارید در تلاش خواهد بود که مطالب مورد نیاز را برای این مهم فراهم کند. از آنجا که متون برگزیده از نویسندگان مختلفی است تبعاً لحن‌های متفاوتی دارند و مسلماً یکدست نیستند اما اگر پرسش‌های اصلی و کلیدی‌ای در خواندن متون مدنظرتان باشد مطالعه هدفمند و مؤثر رخ خواهد داد. با توجه به عدم وجود مطالب مشابه در برنامه‌های رسمی دانشجویان رشته‌های مختلف علوم پزشکی در این مورد ممکن است نیاز داشته باشید برای فهم برخی از مطالب به منابع کمکی مراجعه کنید. به هر رو هدف کلی نه به خاطر سپردن مطالب بلکه درک و فهم ژرف آنها برای به کار بستن آنها در تحلیل و نقد خلاقانه و بدیع است.

توجه به این نکته ضروری است که برخلاف علوم طبیعی (natural sciences) در علوم انسانی (humanities) تعریف واحد و سراسر است و نظریه‌ای فراگیر و جامع وجود ندارد، بلکه در هر موضوعی مکاتب، نظریه‌ها، دیدگاه‌ها، رویکردها و تعاریف مختلفی وجود دارد. این ویژگی در علوم انسانی نه به معنای تشتت و سردرگمی است و نه به معنای نقضان دانش آن، بلکه به سرشت این علوم بازمی‌گردد. مکاتب، نظریه‌ها، دیدگاه‌ها در علوم انسانی همچون زبانهای مختلف هستند که تلاش برای از بین بردن آنها و ساختن یک زبان واحد نه ممکن است نه معقول. در هر نظریه یا رویکردی در مقایسه با سایر نظریه‌ها و رویکردها، زمینه‌ها، پیش‌فرض‌ها، مسائل مرکزی، مفاهیم کلیدی، نحوه پرداختن به مسائل و استدلال‌ها و براهین متفاوت است. به همین دلیل از شما انتظار می‌رود نه تنها در خواندن متون تلاش کنید هر نظریه یا رویکرد را با توجه به محورهای بالا فرا بگیرید، بلکه در برخورد با هر مسأله با مذاقه و آوردن براهین نشان دهید که

کدام رویکرد یا نظریه برای مواجهه با آن مسأله مناسب‌تر است، چگونه می‌توان آن را در مواجهه با مسأله بکار بست و با بکار بستن نظریه مسأله را چگونه می‌توان صورت‌بندی کرد. در ضمن دانستن اینکه هر نظریه یا مفهوم را چه کسی پیشنهاد کرده است بخش مهمی از مباحث علوم انسانی به همین دلیل در مطالعه متون این موضوع مد نظر تان باشد.

مطالب پیش‌رو در دو بخش اصلی سامان یافته‌اند: بخش اول، مفاهیم اصلی و تعابیر مختلف از MH است که پایه اصلی برای شناخت این حوزه و درک پرسش‌های مرکزی و مسائل آن است. سه مقاله اول به مفاهیم و رویکردهای مختلف به MH اشاره دارد و سه مقاله بعدی تحلیل فیلسوفان پزشکی به نام از MH است. بخش دوم درباره تکنولوژی است که مذاقه در تعاریف مختلف تکنولوژی در فلسفه تکنولوژی خواهد پرداخت، پس از آن آراء یک فیلسوف تکنولوژی در باب فلسفه تکنولوژی پزشکی خواهد آمد و سپس یک فیلسوف پزشکی ویژگی‌های تکنولوژی در پزشکی را خواهد کاوید. در انتها یک مقاله کوتاه در مورد جایگاه هوش مصنوعی در پزشکی قرار گرفته است. لازم به ذکر است مرحله نهایی المپید با محوریت «تحلیل و نقد هوش مصنوعی از منظر MH» برگزار خواهد شد و در مرحله اول (غریبالگری) به منظور آشنایی با این موضوع این مقاله کوتاه در منابع آورده شده است.

در خواندن این متون:

اول- انتظار می‌رود دانشجویان مفاهیم اصلی MH بشناسند و رویکردهای مختلف در این حوزه را بازشناسند و تحلیل کنند.

دوم- آنچه از مفاهیم و رویکردهای مختلف در MH فراگرفته‌اند را در تحلیل و نقد روش‌مند مسائل تکنولوژی در حوزه سلامت به کار بندند.

سوم- انتظار می‌رود تعاریف و رویکردهای مختلف به تکنولوژی را بدانند.

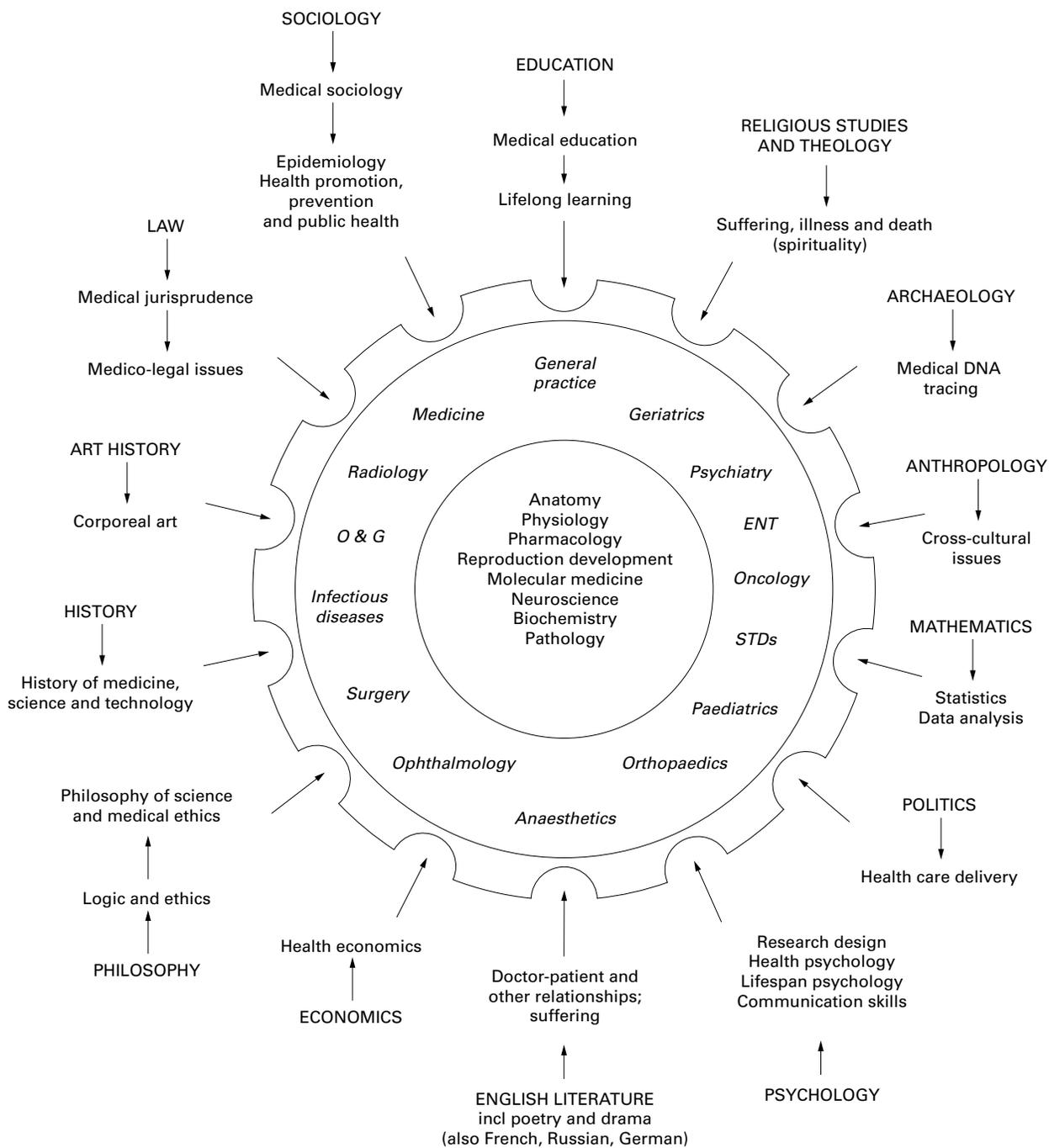
چهارم- انتظار می‌رود مفاهیم و رویکردهای نظری به تکنولوژی در حوزه سلامت بشناسند و آن را در نقد تکنولوژی در سلامت به کار گیرند.

لازم به ذکر است کمیته علمی، این حیطة را چنان طراحی کرده است که نیل به این اهداف در فرآیندی چندماهه میسر است که هم تلاش شما را می‌طلبد و هم کمیته علمی می‌کوشد با فراهم آوردن فرصت‌های آموزشی- در قالب وبینار و کارگاه- در غنی‌سازی و ارتقاء آن می‌کوشد. بی‌تردید مسابقه‌انگاری و فروکاستن آن به چند آزمون این کوشش علمی را مخدوش خواهد کرد.

با آرزوی موفقیت برای شما دانشجویان عزیز و به امید آینده پررونق مباحث MH به همتان.

کمیته علمی حیطة مطالعات میان‌رشته‌ای علوم انسانی و سلامت

دوازدهمین المپید علمی دانشجویان علوم پزشکی کشور



## The Field of Medical Humanities

**Part I**  
**Medical Humanities:**  
**Basic Concepts and Approaches**

# Rethinking Medical Humanities

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**Abstract** This paper questions different conceptions of *Medical Humanities* in order to provide a clearer understanding of what they are and why they matter. Building upon former attempts, we defend a conception of *Medical Humanities* as a humanistic *problem-based* approach to medicine aiming at influencing its *nature* and *practice*. In particular, we discuss three main conceptual issues regarding the overall nature of this discipline: (i) a problem-driven approach to *Medical Humanities*; (ii) the need for an integration of *Medical Humanities* into medicine; (iii) the methodological requirements that could render *Medical Humanities* an effective framework for medical decision-making.

**Keywords** Medical Humanities · Medical decision-making · Theories of medical deliberation · Triangular reflective equilibrium

## Introduction

In the last few decades, the development of life sciences has been characterized by a paradigm shift that calls for rethinking the contribution of humanities to medicine. This is mainly due to two reasons: 1) the rise of molecular explanations of illness and disease has changed the way in which diagnosis, prognosis and therapy are understood; 2) theoretical reflections on medicine are lagging behind the advancements of biomedical sciences. Within this context, academics, practitioners and citizens alike have raised many concerns regarding the overall direction and shortcomings of medicine and healthcare. Clinical medicine, they argue, ought to be considered as standing along a continuum in which molecular explanations, diagnostic tools, therapeutic approaches and patient care all interact for the purpose of exploring and making sense of the human experience of disease and illness (Brody 1985; Boniolo 2011).

The promise of the discipline that goes by the name of *Medical Humanities* (henceforth MHs) is to vindicate the fundamental importance of this broader understanding of medicine. MHs' aim, in fact, is the opening up medicine and healthcare to different educational and cultural opportunities for the purpose of producing some benefits that are both *intrinsic* and *instrumental* (Evans and Greaves 2002). Respectively, MHs are expected to (i) enable

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practitioners to plunge into the numerous perspectives within the humanities (literature, history, philosophy, sociology, etc.) that can foster a deeper understanding of what medicine is and attempts to, and (ii) to improve the quality of the humane relationship among doctors, clinical professionals and patients. The advancement of this field has prompted many initiatives in most of medical schools both in the US and in Europe and is gradually gathering momentum in clinical research and practice. Nevertheless, immediately after its rise in the 1960s, many controversies have arisen about the way in which MHs should be understood and characterised as a recognised discipline (Evans and Greaves 2010).

Our contribution aims at bringing into question different conceptions of MHs proposed thus far. By doing so, our work aims also at providing a clearer understanding of what MHs are and why they matter. While this will not close the discussion about their identity, nonetheless, we will defend an approach to MHs that might be considered a step further in the process of clarifying its status. In particular, we discuss three main conceptual issues regarding the overall nature of MHs: (i) a problem-driven approach to MHs; (ii) the need for an integration of MHs into medicine; (iii) the methodological requirements that could render MHs an effective framework for medical decision-making.

### Arranging the space for different *disciplines* within MHs

A cursory analysis of the literature on MHs shows a substantial lack of consensus as to their aims and scope as a discipline. Within this state of affairs, however, it is generally agreed that MHs are expected to (i) embrace all the disciplines contributing to the conceptual analysis of medicine (MHs as a *multi-faceted conceptual framework*), and (ii) to foster a depth of human and humane understanding of the professional-patient relationship (MHs as an *existential framework*). Many of the controversies arising from the analysis of MHs as a discipline are currently framed in terms of finding a common balance between the two distinct purposes just sketched. On the one hand, some authors ascribe to the two-fold nature of MHs the unique capacity of dealing with the all-embracing nature of medicine (Meites et al. 2003, Ahlzen 2007, Crawford et al. 2010). Under this interpretation, different disciplines - from history and philosophy of medicine, bioethics, psychology and sociology to arts, poetry and literature - are in fact wrapped up together in the light of fostering a significant understanding of the human experience of illness. On the other hand, other authors prefer to see MHs as consisting of different movements, “which may overlap, but are distinct in their aims, methodologies and participants” (Downie 2003, 37). These different strands of MHs, they argue, are hardly reconcilable within a unified conception that is actually compelling (Campo 2005).

Unsurprisingly, many scholars have emphasized the need of harmonizing these contrasting ‘modes of understanding’ MHs (Puustinen et al. 2003, Ahlzen 2007). For instance, one way of reconciling the interaction between conceptual and existential reflections on medicine has been found in the dichotomy between ‘multidisciplinarity’ and ‘interdisciplinarity’ (Evans and Macnaughton 2004) – i.e. the way in which different disciplines should interact with regard both to the cross-border issues pertaining to MHs and the preservation of distinct scientific and academic expertise. While the dichotomy between *conceptual* and *existential* approaches to MHs has to be thought as an epistemic dichotomy, the one between ‘multidisciplinarity’ and ‘interdisciplinarity’ seems to point to the methodological criteria necessary for reconciling different disciplines within MHs. Problems arise in fact as to the way in which the interaction of experts and competencies from different fields should be conceived. Those who describe the interplay of expertise at the basis of MHs as *multidisciplinary* put a strong emphasis on the idea that their most effective contribution to knowledge can be gained only by preserving

specific disciplinary identities. Every individual discipline participating in MHs is seen, under this interpretation, as a self-contained domain with its own distinguishable subjects, questions and methods. Though this is not meant to deny that any discipline includes some questions that can be better answered through the awareness coming from different disciplines, supporters of the multidisciplinary view maintain that looking for the continuities between fields is likely to result in an endless and conflict-ridden process that might waste the potential of independent and recognised disciplines within the humanities (Pattison 2003). On the contrary, different authors have argued that the general purpose of MHs supports a rather diverse view (Evans and Macnaughton 2004). Namely, the view that *interdisciplinarity* - the search for possible interactions between expertise as to relevant subject matters that cut across different disciplines - represents the best way to foster a humanistic contribution to medicine both at the theoretical and the practical level. Interdisciplinarity, according to these authors, concerns a deeper engagement among disciplines, and more particularly “with subject matter that somehow both straddles the disciplines and falls between them – aspects of a question which [any discipline] neither might pursue, or even recognise, in isolation” (Evans and Macnaughton 2004, 2).

In principle, we agree with Evans and Macnaughton (2004) as to the general need of abandoning stiff disciplinary boundaries within MHs and of embracing an approach where scholars coming from different disciplines can make their ideas, competences and experiences interact profitably. Nevertheless, interdisciplinarity also has its own weaknesses. Arguably, it would entail the necessity to engage with the search for common dictionaries, subjects and methods in order to avoid ambiguities and confusions stemming both from the different meanings of some terms in different disciplines and from the different methods that characterize them. Though such a goal might be highly desirable, we think that it is virtually impossible to achieve due to the specialisation that different fields within the humanities have undergone in the past and are currently undergoing. This is what makes interdisciplinary approaches to MHs unlikely to be successful at the academic and the educational level. In addition, considering the task of a mutual agreement on fundamental issues as necessary in light of such a variegated community of experts, would have to be grounded on better reasons than the mere potential academic recognition of the field (Evans and Macnaughton 2004).

In the light of the methodological issues arising from different ways of making sense of the interaction among disciplines within MHs, we suggest abandoning the dispute between multidisciplinary *versus* interdisciplinarity. What appears to be relevant is neither the language deployed by disciplines to answer some questions nor the search for an agreement on core issues between experts. Rather, as argued by Popper (1963) while discussing the status of scientific disciplines, what counts as necessary is the capacity to deal with problems under analysis. In other words, though resolving an issue might imply the need to resort to competencies coming from different fields, this does not seem sufficient ground for the construction of cross-disciplinary knowledge and expertise. This appears to be especially true in the case of MHs whose questions usually cross the borders of many disciplines but are nevertheless solvable notwithstanding the lack of agreement on disciplinary boundaries at the academic level. Therefore, we argue, a *problem-based approach* that preserves distinct expertise and competencies, while at the same time looking for successful cooperation in the light of the outcome might be much more likely to produce better results than the attempt to create a sort of hybrid knowledge within MHs. Whatever problems medical professionals are confronted with, MHs can provide them with more thorough conceptual and existential understandings of the situation, resorting to different contributions coming from a variety of disciplines. In this respect, their role appears to be fundamental. Under the problem-based approach, professionals should in fact (i) collect all the stimuli coming from several disciplines participating in MHs; (ii) tailor such knowledge as taught at medical school in the process of

seeking a solution to a particular issue; and, thus, (iii) produce an interlock between distinct disciplinary perspectives, depending on what the problem within a context demands them.

The problem-driven approach to MHs just sketched should not be seen as something to be established once and for all. Rather, it is precisely conceived as a revisable and flexible framework for different modes of interaction between medicine and humanities within clinical practice. The search for interdisciplinarity has raised many concerns due to the expected difficulties faced in the process of harmonizing distinct academic expertises. This search, we argue, has diverted the attention of scholars in the field from the fact that there exist ways of reconciling diverse perspectives, abandoning the goal of creating common languages and methods. A problem-based approach, on the contrary, seems to point to revisable and provisional ways of making this interaction practically possible - something, we argue, that could serve better the purpose of solving the difficulties arising from medical decision-making. However, the capacity required of practitioners in making such interactions possible needs to be better examined if we want to seriously take up the challenge of providing them with useful resources coming from MHs. Abandoning discipline-based perspectives, while looking for the contribution that any of them can bring to problems in clinical practice seems to be a process much more complex than the mere exposition of humanities during medical education. We will turn to this issue later in our work. Before trying to make sense of it, however, we wish to continue our discussion of current understandings of what MHs are.

### **Arranging the role for MHs within the *practice* of medicine**

Besides the issues presented above, a further layer of analysis concerning the identity of MHs deals with their implications in the study and practice of medicine. As to the former, many authors (e.g. Grant 2002) have stressed the relevance of the *educational* role of humanistic reflections on medicine. MHs ought to play, on this view, an active role in the educational curriculum of medical practitioners in order to ensure the centrality of conceptual and existential understandings along with biomedical ones in their profession. As to the latter, however, different scholars have underlined the importance of the *assimilation* of a humanistic conception in the practice of medicine. Under this interpretation, MHs should be conceived as a benign form of self-ruled governance to which every professional subscribes (Evans 2008). This understanding of MHs' practical role sheds light on the fact that the impulse to heal, palliate, comfort, and console cannot be externally imposed through education. Quite the contrary, MHs can contribute to medical practice only if practitioners authentically assume the relevance of humanizing the delivery of care.

Then how should the relationship between humanities and medical practice be conceived? With regard to this point, Evans and Greaves (1999) have summarized the debate into two main positions: (i) *the additive view*, according to which medical practice should be 'softened' by sensitive practitioners who have had training in the humanities and (ii) *the integrative view*, according to which the status, goals, methods and procedures of clinical medicine should be reshaped by the broader understanding of a patient's condition that, coming both from existential and conceptual reflections within MHs, is authentically endorsed by professionals. In keeping with this distinction, it is our intention to point out the second as the necessary, though more ambitious, way to conceive MHs. On the one hand, the integrative approach would bestow on MHs the capacity to make medical practitioners more aware of several conceptual and existential implications that their role entails. The search for integration of humanistic and scientific knowledge on medicine is, in fact, likely to produce, through education, the extended understanding of medicine voiced by scholars within MHs. By

reuniting technical and humanistic perspectives within medical training, an integrative approach aims at fundamentally refocusing medicine both at the level of its understanding and its practice. In doing so, this view is meant to compel professionals to bring within the models of illness' explanation the experiential nature of suffering. On the other hand, a merely additive conception is undesirable for at least two reasons. First, it could leave fundamentally unchanged current understandings of the condition of being sick as a mere biological phenomenon. The addition of training in the humanities within medical curricula would not, in fact, make necessary any reappraisal of medicine's explanatory models. Otherwise stated, the additive view is merely concerned with complementing medical education with the conceptual apparatus of the arts and humanities. The sole exposure of future professionals to these alternative perspectives of medicine, however, is likely to produce only a contrast between 'humanistic' and 'evidence-based' approaches to medicine rather than a thorough reconsideration of medicine's objectives. Second, such an additive approach to medical education would ascribe to individual responsiveness to academic stimuli the fulfilment of MHs potential to ameliorate medicine and its practice (e.g. the practitioner-patient relationship). These are the main reasons why we hold the view that the engagement with MHs should be deeply *integrated* within medical education and, by result, form and transform the clinical encounter. The realisation of an integrative approach, we argue, could embed the *humanae litterae* within the knowledge base of medicine, hence vindicating the idea that medicine has risen as the science for suffering humans, keeping material and experiential natures irreducibly fused (Evans and Greaves 1999).

### Framing different conceptions of MHs

What, then, are MHs? To sum up, there seems to be a two-dimensional space - call it *MHspace* - that covers different formulations of MHs. As far as we know, all authors working in the field of MHs could find their own position in such a space. The *MHspace* appears to be constrained by two main dimensions concerning: 1) the aims and scope of MHs as an academic enterprise dealing with conceptual and/or existential understandings of medicine and the methodological issues arising from their interaction - i.e. MHs as an *interdisciplinary* or *multidisciplinary* endeavour; 2) the specific impact that MHs should have on medical education and the governance of healthcare - i.e. should MHs be merely supplemental to the so-called "medical gaze" (Foucault 2010), or should they be expected to *integrate* with medicine and reshape its nature? Generally speaking, therefore, MHs seem to gather all those *conceptual* and *existential* approaches that, starting from the perspective of humanities, aim at having a bearing on the *study* and *practice* of medicine.

As to the attempt at making sense of MHs according to this two-dimensional characterization, our opinion is that a comprehensive and conclusive definition of MHs is neither possible nor desirable. We believe, in fact, that the search for conclusive conceptions of the interaction between expertise standing behind MHs would not settle all the issues arising from the use of such a distinctive label. Accordingly, we claim that MHs should be *differently characterised if analysed within the context of medical education, academic debates, or healthcare practice*. However, we suggest that MHs could generally profit from an approach that is oriented to the way in which inputs coming from different fields can act together in the light of a *concrete problem* that has to be solved. It is not of course within the scope of our work to reconcile all the expected instantiations of any humanistic approach to medicine. We believe that, for the aims of this work, the recognition that MHs occupy a multidimensional space rather than being a homogeneous academic and practical endeavour is enough. One of

the promises of MHs lies precisely in their capacity to encompass different objectives and yield lots of different benefits. As summarized by Pattison (2003, 36), MHs can, in fact, simultaneously aim (i) at opening up medical and healthcare education, (ii) at establishing a counter-culture protesting against the exclusion of certain bits of knowledge from medicine, (iii) at transforming the nature and practice of medicine, and finally (iv) at providing some academic and funding opportunities to under recognised disciplines.

Although there exists no definite answer to the question regarding which of these objectives should be given a priority, we want to follow the suggestion made by Ahlzén (2007) about what the task of medicine is and how the humanities should primarily contribute to its fulfilment. Medicine, according to the author, is the “activity that aims at healing and ameliorating suffering due to disease and at the prevention of this suffering” (388). Integrating the humanities into its understanding and practice should therefore aim at compensating the weaknesses and shortcomings that, within current developments of medicine, make the activity of mitigating suffering mistaken or unsatisfactory. This approach, the author concludes, would immediately reveal the deeply positive influence that MHs could have on medicine. Otherwise stated, Ahlzén (2007) argues that MHs should concentrate “on core issues like the disease concept, the diagnostic process, and the idea of treatment” (388) if they want their contribution to be rapidly acknowledged as valuable. With a conceptual apparatus strongly relying on biomedical sciences at its core, the development of medicine has thus far overlooked all the existential dimensions of medicine that concur to the shaping of its nature and, consequently, of its practice. Our contribution wants to take up the challenge of providing MHs with a stricter characterization of their potential to transform the nature and practice of medicine. Nevertheless, we believe that rather than focusing on the wide conceptual apparatus that forges the *nature* of medicine, one should primarily focus on how its *practice* is actually mediated by the very same concepts and value-choices at its core. Knowledge that helps us to understand a complicated situation and can guide us in decision-making by evoking insights from experience, does not automatically flow from conceptual reflections into practice.

The remainder of our work will accordingly explore further the contribution of humanities to medicine with a particular focus on how MHs can ameliorate the practice of medicine. In order to achieve this goal, we will focus on the potential bearing that humanistic approaches to medicine might have on the fundamental locus where all the grounding concepts and assumptions in medicine are instantiated in the form of structural constraints of a practical activity. Otherwise stated, the last part of our work will analyse, through the lens of the humanities, the doctor-patient relationship as the crucial encounter where biomedical knowledge, conceptions of medicine, and individual values all contribute to the decision-making process aiming at promoting and fulfilling the tasks of medicine as a human activity.

### **Methodological foundations and medical decision-making**

In this section of our paper, we propose a characterization of MHs as a tool for deliberation encompassing all the approaches that, coming from the humanities, could contribute to the improvement of the interaction between practitioners and patients. The widespread appeal and desire to promote the importance of humanizing medicine poses, in fact, an important question about how to conceive decision-making under the banner of MHs. By making reference to deliberation, our work aims at specifying the widespread appeal within MHs to an idea of medical decision-making that we shall call *alliance* between clinicians and patients. This approach, we argue, is likely to produce the benefit of enabling individuals to make choices that are informed by their experiences, values and beliefs. Creating such alliance, however,

entails the elaboration of viable methods and strategies for the engagement of patients, which have been so far overlooked by scholars in the field of MHs. Achieving the goal of constructing such an environment for patients' decisions lacks a methodological outline of MHs as a tool for deliberation in healthcare. To this issue we now turn.

As showed above, we defend a notion of MHs as a *humanistic problem-based approach to medicine aiming at influencing its nature and practice*. In this section, we specify further this perspective by analysing some methodological requirements that MHs should meet when conceived, in particular, as a full-fledged framework for medical deliberation. In a recent paper, Barilan and Brusa (2012) have suggested a model for ethical deliberation that builds upon Rawls' (2005) *Reflective Equilibrium* (henceforth RE). Famously, RE has been conceived as "a deliberative process in which we reflect on and revise our beliefs about an area of inquiry, moral or non-moral" (Daniels 2011, 1).<sup>1</sup> The use of RE might be as specific as the moral question, "What is the right thing to do in this case?" or the logical question, "Is this the correct inference to make?" Alternatively, the inquiry might be much more general, asking which theory or account of justice or right action we should accept, or which principles of inductive reasoning we should use. This is the main reason why the expression 'method of RE' refers both to the process of making an inference or a decision and the method itself. Barilan and Brusa (2012) propose a modified version of RE called *Triangular Reflective Equilibrium* (henceforth TRE) that could allow for the interaction in medicine of inputs coming from conceptual and existential reflections. In particular, the authors direct their attention to the possibility of reshaping RE in a way that could better accommodate medical decision-making in socio-psychological as well as narrative and rational terms. For this reason, they characterize TRE as a threefold method (and process) grounded on (i) *descriptive narratives*, (ii) *considered judgements*, and (iii) *rational arguments*.

According to this model, deliberation starts with a *descriptive narrative* of a situation. This individual 'construction of reality' is the underlying substratum that shapes and gives rise to beliefs and value-laden judgements that then are consolidated in the form of *considered judgements* - i.e. the initial responses to a problem that are the "product of intuition, cultural background, personal or professional experiences or some other conscious or subconscious psychosocial mechanism" (Barilan and Brusa 2012, 306). At this stage of deliberation, the individual narrative is immediately subjected to the criticism coming from *rational argumentation*. This phase of TRE is expected to make deliberation as fruitful as possible, since deliberants are engaged in a discussion that aims at improving, refining and purging from errors their beliefs and judgments. This is not meant of course to conform the uniqueness and irreplaceability of individual narratives to any superimposed way of experiencing disease and illness. Rather, as the authors explicitly claim: "TRE produces awareness of diverse narratives while pursuing the level of integration necessary for critical reflection" on a medical decision (Barilan and Brusa 2012, 313). In other words, TRE is expected to exert every effort to facilitate the interaction between inputs coming from individual narratives of a situation and the critical reflection upon it that the deliberant can gather from the interaction with other people.

Arguably, TRE addresses some of the central issues pertaining to how deliberation in medicine could be actually improved by an analysis of its method. In particular, it sheds light on the necessity to open clinical decision-making to humanistic reflections on medicine that go beyond mainstream bioethical reflections. Nevertheless, we believe that their contribution only partially succeeds in achieving this goal. As argued by Boniolo (2012), one central question that remains to be answered in current general debates on deliberation pertains to the different ways in which deliberative rules and methods should be practically instantiated (see also Boniolo and Di Fiore 2010). In particular, deliberation requires participants to be "quasi-

peers,” meaning that a minimum sufficient common knowledge is necessary for models of deliberation to fruitfully foster an *alliance* between its members. If this condition is not met, the whole process of deliberation might be impaired by unbalanced degrees of knowledge. In other words, under Boniolo’s view, deliberation entails ideally that a minimum of shared knowledge is correctly delivered to all deliberants. In the case of the doctor-patient relationship, we argue that this could imply communication of information to the patient, as well as the careful consideration of the ways in which different patients might dissimilarly make sense of and act upon the same information.

In the light of this, we maintain that the approach based on TRE should be modified in order to have what we might call TRE<sup>+</sup> (TRE plus). After descriptive narratives are taken into account and considered judgments are subjected to rational scrutiny, the deliberative canon defended by Boniolo (2012) can suitably contribute to tackling any potential imbalance of knowledge in the process of deliberation. His canon is mainly divided into two parts: the presentation of the *status quaestionis*, and the construction of a *justification* for choosing what is considered best by deliberants. In the case of medical practice, the *status quaestionis* might amount to an initial phase in which the decisional landscape is presented by the physician in a form that is as much as possible neutral (note that the display of patient’s *individual narrative* and the scrutiny of *considered judgements* have already been undergone). This stage could be then followed by the disambiguation of the terms used in which patient’s inquiry and questions, encouraged by the physician, play a central role. Finally, different solutions are presented by the practitioner and *justified* to the patient. At this point, the clinical pathway preferred by the professional is presented. This line of action is then subjected to *rational argumentation* and critical reflection by the patient (as in the TRE model) who engages with the physician in concluding the deliberative process. We argue that the outcome of this renewed version of TRE is indeed a valuable one. Whether the patient decides to conform to the suggestion of the professional or not, his/her choice for any clinical course seems to have been enriched by the engagement in this open-ended dialogue.

How does all of this relate to MHs? As shown above, TRE<sup>+</sup> could be considered a suitable method both for medical deliberation and for the individual process of making sense of the experience of illness. In the previous section we have also argued that one of the main purposes of MHs is the construction of a supportive framework in which medical decision-making is enriched by conceptual and existential understandings of medicine. Apart from the impact that bioethical reflections have had in the last 40 years (Brody 1985), however, humanistic approaches to medicine are somewhat lagging behind in the process of providing practitioners with an expanded perspective on their professional activity. Whether patients are confronted with choices that have ethical implications or not, their moral and cultural background always plays a pivotal role in informing the decisions they are about to make (e.g. the decision to undergo a treatment rather than another, the decision to comply with medical prescriptions, etc.). The individual description of a situation ought to be, in fact, considered as the value-laden narrative – encompassing a set of moral values as well as a spectrum of beliefs about the world – that predetermines opinions, judgments and understanding alike. If MHs want to be acknowledged as an established supportive framework for decision-making in healthcare, actually reshaping and improving the nature and practice of medicine, the methodological analysis presented in our work appears to be essential. This is the main reason why we put forward TRE<sup>+</sup> as a method that could accommodate the different perspectives characterizing MHs as an academic enterprise within medical practice. TRE<sup>+</sup>, we argue, could constitute the common methodological domain in which the different disciplines contributing to MHs could finally explore the “potentially synergistic character” (Ahlzén 2007, 386) of their contribution to medicine. TRE<sup>+</sup> is likely to produce an expanded awareness of the

human condition within the doctor-patient relationship, resulting from the engagement with all the different disciplines participating to MHs. This is what we might deem to be a first step towards the problem-driven approach to MHs. With such a methodological view in mind, in fact, MHs could really enhance physicians' capacity to deal with (i) the individual understanding of disease and illness as a contextualized and self-construed phenomenon, and (ii) the rational discernment of the subjective perception of a situation to better support medically relevant decision-making.

There exist similarities between our model for patients' engagement in medical deliberation and what is currently presented under the general title of "shared decision-making" between the professional and the patient. By looking at a systematic review of intervention for its implementation (see Légaré et al. 2012), one might in fact easily conclude that our way of characterising MHs as a framework for medical deliberation shares the same objectives of the shared decision-making endeavour. We maintain that our proposal should not be understood in opposition or as an alternative to this approach. We rather suggest our contribution as affirming the potential for MHs to enhance strategies for shared decision-making. In particular, we believe that canons of deliberation like the one presented in our work might answer some of the questions about methods and procedures (Stiggelbout et al. 2012) for clinicians and patients to make decisions together, hence fostering the emergence of better practices of shared decision-making.

In conclusion, we argue that the method of TRE<sup>+</sup> could enable MHs (interpreted as a humanistic problem-driven approach to medicine aiming at influencing its nature and practice) to be a full-fledged background framework for decision-making in clinical practice. On the grounds of the fruitful combination between a canon of deliberation and a renewed version of RE, TRE<sup>+</sup> could map the team effort that characterizes MHs (as an academic endeavour) by providing medical deliberants (i.e. patients and professionals) with a common scheme of reasoning to resolve problems with they are daily confronted. This, we maintain, is likely to produce an *interaction* and *integration* between humanistic gazes and medicine that scholars in the field of MHs are currently seeking (Annoni et al. 2013).

## Conclusion

Our proposal has referred to current understandings of *Medical Humanities* as incomplete attempts to re-make sense of medicine from the perspective of humanities. If we analyse medicine as a human activity, humanities appear to play a crucial role. This, we argued, makes MHs – conceived in many possible different ways, according to the context – a promising field of study that could produce significant benefits for the practice of healthcare (Petersen et al. 2008). By incorporating and promoting the adoption of a shared method within a particular instantiation of this approach, however, our work has been also intended to shed new light on the persistent uncertainty surrounding the contribution of humanities to medicine. MHs are currently facing the challenge to turn into a full-fledged discipline. There may be many issues arising from medical decision-making that might not be resolved through an approach that focuses narrowly on disciplinary boundaries. In the light of this, we argued, a straightforward approach to the capacity of finding solutions to particular problems could result in a more immediate improvement of medicine from the perspective of humanities. In some cases, such strictness might be particularly desirable on the grounds of the importance of preserving distinct scientific and academic expertise. MHs entails grappling with such methodological issues arising from the purpose of combining 'humane and humanizing' reflections on medicine with the daily course of healthcare delivery. In the case of medical decision-

making, we argued, this goal could be achieved through the employment of TRE<sup>+</sup>, as a shared standard of reflection and deliberation at the level of the patient-professional relationship.

Of all kinds of relationships, the ones between patients, doctors and all the different agents involved in medicine are those that we value the most. The rationale behind the approach of MHs to healthcare is (among other things) that of fostering a renewed understanding of this relationship, which ought to be capable of re-making sense of it in more humane terms. Our opinion is that achieving such an ambitious goal entails the construction of a methodological domain in which different people can practically *interact* and produce valuable outcomes that discipline-based approaches would not be otherwise able to bring forth. Our work aimed, accordingly, at taking a step forward in the process of investigating the nature and potential of the interlocking of disciplines that goes by the name of *Medical Humanities*, in order to provide them with the minimal coherence that is required to a full-fledged theoretical framework for medical decision-making. There may be many controversies at the academic level, arising from a sharp methodological approach to MHs. Some people might welcome such an attempt; others might feel uncomfortable with it. Nevertheless we believe that, despite this risk, the potential of TRE<sup>+</sup> for the practical implementation of MHs within medicine is very significant and that such opportunity should not be squandered.

## Endnote

1. It is worth mentioning that Rawls intended RE as the theoretical movement of ‘going back and forth’ from judgements and ‘contractual circumstances’ to our principles of justice for the aim of tailoring the latter to match our considered judgments ‘duly pruned and adjusted’ (Rawls 2005, 20). Otherwise stated, in Rawls’ original intentions RE is a method for the assessment of the validity of a theoretical framework, such as his theory of justice, and not as a means to make practical, concrete decisions.

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# Defining the Medical Humanities: Three Conceptions and Three Narratives

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**Abstract** The definition of ‘medical humanities’ may be approached via three conceptions—the humanities as a list of disciplines, as a program of moral development, and as a supportive friend. The conceptions are grounded by linking them to three narratives—respectively, the history of the modern liberal arts college; the history of Petrarch and the *studia humanitatis* of the early Renaissance; and the life of Sir William Osler. The three conceptions are complementary, each filling gaps in one or more of the others. Getting clearer on a definition of ‘medical humanities’ is practically important if this field is to take its rightful place within health professions education and practice.

**Keywords** Medical humanities · Humanities · Osler · William · Petrarch · Studia humanitatis

## Introduction

While the oldest programs in medical humanities within US medical schools date back to the 1960s and 1970s, defining “medical humanities” remains a challenge. The absence of a widely-agreed-upon definition may be of little practical importance if the medical humanities is the sort of thing that “we know when we see.” A good deal of the pedagogical literature on medical humanities, however, is based on the belief that the field is currently marginalized within the academic health professions, and ideally deserves a greater role. That belief hints that a clear definition is essential to further progress.

During most of my own career in medical humanities, I held an unreflective “list of disciplines” conception of the field. I found it sufficient to view medical humanities as some combination of its relevant disciplines—ethics and philosophy, religious studies, history, literature, and so forth. My gaze was expanded upon joining the Institute for the Medical Humanities at the University of Texas Medical Branch in Galveston. The Institute was established in 1973 and its graduate program, offering interdisciplinary MA and Ph.D. degrees in medical humanities, was begun in 1988. I then became aware of two other

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conceptions, the “program of moral development” and the “supportive friend.” I suggest that all three conceptions must be taken into account if we are to evolve an adequate definition. I will also suggest that the best way to address the three conceptions is to put each in the context of a historical narrative.

Each of the three conceptions could just as well be a conception of *the humanities* as well as *the medical humanities*. I will, however, restrict my discussion to the latter as my main interest is teaching and research within medicine and the other health professions.

### Other efforts at definition

One might expect that a good place to look for a definition of “medical humanities” is in the first number of a journal of that title. However, when *Medical Humanities* was spun off from the *Journal of Medical Ethics*, no formal definition was offered. Greaves and Evans instead offered two “formulations,” an “additive view” and an “integrated view.” The former entailed sprinkling a bit of humanities over the top of an essentially unchanged biomedical enterprise, while the latter contemplated a more fundamental and critical role.<sup>1</sup>

Writing in *Academic Medicine* in 2009, Shapiro et al. posited an “ongoing lack of clarity on what exactly the medical humanities comprise, and how they should be integrated into medical education.” They proceeded to offer a narrowly “pedagogical” definition: the medical humanities use the methods and concepts of one or more of the humanities disciplines, teach students critical reflection aimed toward a more humane practice, and are by nature interdisciplinary and collaborative.<sup>2</sup>

Another approach was suggested in 2008, when Evans identified three “manifestations” of medical humanities: as an academic field of intellectual inquiry, as a dimension of medical education, and as “...a source of moral and aesthetic influence upon the daily praxis of organized clinical health care”.<sup>3</sup>

The American internist and poet Raphael Campo was less deferential when he titled an essay, “‘The Medical Humanities,’ for Lack of a Better Term.” Campo concluded, “Despite some public exposure...no conception of ‘the medical humanities’ compels, caught somewhere between manifesto, mushiness, and marketing lingo”.<sup>4</sup>

In short, there appears to be sufficient evidence for definitional ambiguity, to justify further attempts at clarification.

### Three conceptions

I will present my three proposed conceptions of medical humanities—as a list of disciplines, as a program of moral development, and as a supportive friend—indirectly through three narratives. The first conception, I would claim, is the implicit conception operating in most discussions of academic programs in medical humanities, at least in the

<sup>1</sup> Greaves D, Evans M. Medical humanities [editorial]. *Med Humanit* 2000; 26:1-2.

<sup>2</sup> Shapiro J, Coulehan J, Wear D, Montello M. Medical humanities and their discontents: definitions, critiques, and implications. *Acad Med* 2009; 84:192-198.

<sup>3</sup> Evans HM. Affirming the existential within medicine: medical humanities, governance, and imaginative understanding. *J Med Humanit* 2008; 29:55-59.

<sup>4</sup> Campo R. A piece of my mind: “the medical humanities,” for lack of a better term. *JAMA* 2005; 294:1009-1011.

US. I was therefore intrigued to find the second conception entrenched at the University of Texas Medical Branch in the description of the goals of its graduate studies program.<sup>5</sup>

#### First narrative: the history of the modern liberal arts college

Once upon a time the Anglo-American culture had an image of what it meant to be a liberally educated person. Such a person had read certain books, had heard certain pieces of music, and had seen representations of certain works of art. The person was able to discuss intelligently and thoughtfully all of these works, that represented the great moments in the history of Western culture. Indeed it sometimes seemed as if the very idea of “Western culture” was as a sort of grand conversation. The conversation had begun long before the individual was born, and would continue long after the individual died. One aspired, during one’s lifetime, to be a meaningful participant in the conversation.<sup>6</sup> The greatest of each generation actually changed the conversation, introducing original and novel ideas; most were content merely to participate and to keep the conversation going.

The role of a college education became clear against the backdrop of this idea of culture-as-conversation. The goal of a liberal arts education was to prepare one for full, active participation in the conversation. The education was designed, first, to expose one to all the correct books and ideas, and second, to train one in the intelligent way to discuss them.

The view of the grand conversation began to fray as life and the university both became more and more specialized. Increasingly one found oneself participating not in a grand conversation across the entire culture, but in narrow conversations intelligible only to specialists within certain disciplines. Attending to the narrow conversations seemed the best route both to technological progress and to individual career advancement. As time went on, other problems with the old idea of the culture-as-conversation also arose. People became much more aware whose ideas, whose books, art, and music, had been excluded from the canon that defined the “liberal” education.

As narrow disciplinary conversation replaced broad cultural conversation, the role of the liberal arts in a college education gradually lost its meaning and significance. Things had arrived at such a pass by the 1990s that the presidents of 15 of the most prominent liberal arts colleges in the northeastern US had to admit that they did not know the meaning of the term “liberal arts education.” They were forced to hire a public relations firm to remedy their deficiency. Not surprisingly, given that the presidents of the colleges could not define the idea, the public relations firm couldn’t either.<sup>7</sup>

#### Second narrative: Petrarch and the “*Studia Humanitatis*”

Once upon a time there was a poet now commonly known as Petrarch (Francesco Petrarca, 1304–1374). Petrarch surveyed the world around him in fourteenth-century Italy and observed a society in considerable ferment. The reign of the landed aristocracy with their agrarian way of life was quickly being supplanted by a mercantile, urban society. The ships that landed at the wharves of the Italian cities brought more than goods from foreign ports; they brought accounts of strange countries and peoples previously unknown to Europeans.

<sup>5</sup> <http://www.utmb.edu/imh/GraduateProgram/gp.asp?show=Rationale> (accessed October 31, 2009).

<sup>6</sup> Rorty R. *Consequences of pragmatism*. Minneapolis: University of Minnesota Press, 1982.

<sup>7</sup> Proctor RE. *Defining the humanities: how rediscovering a tradition can improve our schools*. 2nd ed. Bloomington: Indiana University Press, 1998.

Petrarch took a special interest in educating the youth, and he assumed that the university ought to prepare students with the *wisdom* needed to live successfully and to provide civic leadership in changing and challenging times. But when he surveyed the university curriculum of his day, a product of late medieval times, he saw technical cleverness but no wisdom. The subjects emphasized—mathematics, law, logic, and metaphysics—seemed designed to show off technical reasoning skills rather than to address the demands of a changing society.

Petrarch's own wide reading had, he thought, made clear where the youth could find the role models they needed for wisdom and civic virtue. The heroes of ancient Greece and Rome, he believed, had led those sorts of inspiring lives. Moreover, as a poet, he believed that classical Latin was the purest and most elegant language with which to express profound moral truths and to tell the stories of heroes. Compared to the debased medieval Latin then used in the universities, classical Latin seemed a world apart.

Rather than the disciplines stressed in the traditional medieval curriculum, Petrarch recommended that students study poetry and literature, languages, history, ethics, and rhetoric. Rhetoric would assure that the curriculum had a strong interdisciplinary tilt. Classical rhetoric had two goals—first, to apply reason to determine the right course of action; and second, to then arouse the passions of the listeners to motivate them strongly to perform the right action. Rhetoricians would employ any discipline that could help toward either goal—law, logic, moral philosophy, knowledge of empirical facts—without being tied down by the methods of any single discipline.

Petrarch had personal as well as pedagogical reasons for stressing the heroes of the ancient world and the classical Latin that some spoke and wrote. Living as he did at the time of the Black Death and of major social unrest, Petrarch had suffered many tragedies and losses in his own life. Of all authors, he found that the writings of Cicero, the Roman orator and philosopher, seemed to speak to him most directly. Cicero wrote of his own losses and sufferings and of how the stoic philosophy seemed to provide succor and relief in grief. Petrarch took very much to heart both Cicero's stoicism and the latter's personal example of steadfastness in the face of grief and suffering.

In the near term, Petrarch and his followers were amazingly successful. Across Europe the university curriculum was slowly transformed in keeping with Petrarch's "humanism"—or the *studia humanitatis*, a term he adopted from one of Cicero's orations. In many ways this new curriculum saw the end of medieval times and the beginning of the Renaissance in Europe.

Sadly, as more decades passed, the new Renaissance humanism came to resemble more and more the curriculum it had sought to displace. From seeing classical Latin as the ideal language to convey poetic messages of wisdom and virtue, scholars turned to seeing classical Latin as the goal of study in itself, and engaged in endless debates about grammar and declension. Having turned outward toward engagement with society and the social issues of the day, the university curriculum gradually turned inward as technical cleverness again took over and as academics addressed each other in terms quite apart from the interests of anyone but their fellow scholars.<sup>8</sup>

Third narrative: the life of sir William Osler

Once upon a time William Osler (1849–1919) was born in the Canadian backwoods and gradually ascended to medical school professorships in Canada, the US, and England. He

<sup>8</sup> Bouwsma WJ. The culture of Renaissance humanism. Washington: American Historical Association, 1973.

was a key designer of the medical curriculum at Johns Hopkins that ultimately became the model for all US twentieth century medical teaching. He became the best known and most widely respected English-speaking physician of his day. He was the last person to attempt (by all accounts, successfully) to write a single-authored textbook of internal medicine.

Osler is respected not only for his medical and scientific knowledge but also for his wide knowledge of the classic works of our culture. He liberally sprinkled quotations from the great books of the past throughout his essays and orations.

Osler spent each day in a busy round of activities including caring for patients, autopsy investigations, teaching, and writing. Evenings were frequently spent socializing with his colleagues and students. The time set aside for reading classic literature approached with night. Osler devoted his bedtime reading to this pursuit and recommended strongly that his students follow suit, often loaning them works from his own extensive library.

Insofar as we can read Osler's inner thoughts, he appears to have been similar to Cicero and Petrarch in finding a stoic philosophy most congenial as a way to deal with life's challenges and vicissitudes. Both the losses he personally suffered, and the anguish he faced daily in the lives and deaths of his patients, could be rendered more tolerable by the wisdom of classical literature.<sup>9</sup>

Today, Osler's memory is still celebrated within American medical institutions, as demonstrated by the activities of the American Osler Society and its branches.<sup>10</sup>

### The three narratives and the three conceptions

The first narrative relates in two ways to the conception of medical humanities as a list of disciplines. First, it shows why the bureaucratic demands of an American university setting would tend toward this conception. Imagine that you were dean of a medical school, that the medical school was located on a university campus that contained a liberal arts college, and that you wanted to build a medical humanities program from scratch. The most natural way to go about it would be to visit in turn each of the departments in the liberal arts college to ask what it might contribute, which of its faculty had special interests in medicine and health issues, and so on. Second, it also shows why the "list of disciplines" approach is bound eventually to be unsatisfactory. Ultimately it can give no account of the shared mission of the medical humanities, of why *these* disciplines and not some others were chosen.

The second narrative is, of course, a prequel to the first, as movie critics might put it. The second narrative leaves off the story of the role of the humanities in education around 1550–1600, and the first narrative picks up the story again around 1850. The fact that the second narrative traces the concept of "humanities" back to its historical roots offers one possible justification for adopting its related conception, medical humanities as a program of moral development. A second justification is found in tracing analogies between the challenges facing the medical educator today, and those that Petrarch faced in his fourteenth-century world. These analogies include the need to teach some presumably unchanging principles of wisdom in the face of rapid expansion of the empirical knowledge base, incorporating training in the moral virtues within the curriculum, and the goal of making education responsive to the challenges of the real world.

<sup>9</sup> Bliss M. William Osler: a life in medicine. New York: Oxford University Press, 1999

<sup>10</sup> <http://www.americanosler.org/> (accessed October 31, 2009).

Today William Osler might seem a dated figure. In some of his essays, quotations from and allusions to literary classics are liberally sprinkled as decoration, in much the same way that gingerbread adorns the exterior of Victorian houses. This would seem to be an example of the unsatisfactory “additive” formulation of the medical humanities. Yet, as we have noted, the Oslerian model of the liberally educated physician appears to have had remarkable staying power.

To better understand the attractions of a stoic philosophy for such diverse figures as Cicero, Petrarch, and Osler, we might return to the original formulation of *studia humanitatis* in Cicero’s oration *Pro Archia* (In Defense of the Poet Archias, 62 BCE). This oration was a pleading in court in defense of the Greek poet who had been one of Cicero’s own teachers. A relevant passage reads:

And these studies [*studia humanitatis*] nourish youth, delight old age, adorn prosperity, offer refuge and a solace in adversity; they delight at home, nor do they embarrass one abroad; they accompany us overnight, as we travel, and into the countryside.

Here, it seems, the orator is painting a portrait of the humanities as a boon companion or supportive friend. The books that have spoken so meaningfully to one throughout one’s formative years remain there to offer wisdom, comfort, and solace, even when one may have been abandoned by one’s human companions. The reason why Osler found these works his ideal bedtime reading (“they accompany us overnight”) becomes clearer.

### Three complementary conceptions

The three conceptions of the medical humanities are each individually incomplete and require the others to fill critical gaps.

As noted within the first narrative, it is hard to avoid some recourse to the “list of disciplines” conception in describing the scope of the medical humanities. Yet the narrative itself also shows why the conception is ultimately uninformative. It cannot explain where these disciplines came from or what they have in common.

The second narrative completes the first by taking the story back to the historical origins of the humanities in the Renaissance. The conception of the medical humanities as a program of moral development reminds us that the ultimate goal is to make a difference in the world of practice, and to do so guided by wisdom and virtue. Yet the second narrative also sounds its own note of warning. It reminds us how strong is the tendency of academics (in their commendable pursuit of rigor and method) to divert a field of study away from its original goals of engagement in the wider world, and to reduce it to the refinement of academic methods for their own sake.

If the second narrative corrects the first by reminding us of the humanities’ historical origins, why do we then need the third narrative as well? Perhaps a part of the reason that the Oslerian ideal has had such remarkable staying power in today’s world is the way that it recaptures the pure *joy and love* we feel for our favorite books, how opening one of them after a period of absence is like revisiting an old friend. The third narrative, in turn, fails on its own to explain the *critical and reflective* function we believe that the medical humanities can serve. As a rule, we seek comfort and solace in our bedtime reading, not acute intellectual challenge. Yet intellectual challenge is essential if the humanities are truly to contribute to health professions education and practice.

**Conclusion: does it matter?**

I have proposed three complementary conceptions of the medical humanities, each tied to a narrative. I believe that the narratives matter; they are not mere seductions to get a distracted reader to pay attention. The narratives remind us that the conceptions of the humanities are linked to ways of living our lives and of addressing problems in the real world.

In a similar vein, I propose an answer to the question with which I began. Defining “medical humanities” more clearly and precisely may be difficult and multifaceted, but it does matter that we continue the exercise. As part of the pedagogical “manifestation” of the humanities, we seek to educate future health professionals who adopt a more critical and reflective stance toward their work and toward the knowledge that informs it. We must, ourselves, model that critical and reflective attitude toward our own field if we wish this educational endeavor to be successful.

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# ‘The Medical’ and ‘Health’ in a Critical Medical Humanities

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**Abstract** As befits an emerging field of enquiry, there is on-going discussion about the scope, role and future of the medical humanities. One relatively recent contribution to this debate proposes a differentiation of the field into two distinct terrains, ‘medical humanities’ and ‘health humanities,’ and calls for a supersession of the former by the latter. In this paper, we revisit the conceptual underpinnings for a distinction between ‘the medical’ and ‘health’ by looking at the history of an analogous debate between ‘medical geography’ and ‘the geographies of health’ that has, over the last few years, witnessed a re-blurring of the distinction. Highlighting the value of this debate within the social sciences for the future development of the medical humanities, we call for scholars to take seriously the challenges of critical and cultural theory, community-based arts and health, and the counter-cultural creative practices and strategies of activist movements in order to meet the new research challenges and fulfill the radical potential of a critical medical humanities.

**Keywords** Medical humanities · Health humanities · Medical geography · Geographies of health · Critical theory · Arts and health · Activism · Patient advocacy

## Under scrutiny: medical humanities and health

In the last 10 years, the number of disciplines, subjects, methodologies and individual researchers and practitioners working or associated with the medical humanities has grown

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considerably. As befits an emerging field of enquiry, there is on-going debate about its future direction (Ahlzén 2007; Evans and Greaves 2003, 2010; Evans and Macnaughton 2004; Macnaughton 2011; Pattison 2003), complicated by the fact that it “is an area of scholarship, education and creativity peopled with those who primarily, secondarily or in no way associate themselves with the field” (Shafer 2009, 3). Tracing its roots to medical education – and to a territory also fertilized by medical history and bioethics – the medical humanities are most frequently thought of as a means of mobilizing the arts and humanities in the context of medical practice and pedagogy. However, contemporary medical humanities research, while having its focus firmly on matters medical, broadly construed, is not calculated exclusively towards improving the *practice* of healthcare, but also, crucially, on better understanding its conceptualization and representation (Carel and Cooper 2012), its regulation through government and other policies (Metzl and Kirkland 2009), its history (Foucault 1994; 2002), and the complex ways in which cultures influence and are influenced by “medicalized” accounts of human endeavour (Murray 2008; Woods 2011). Despite claims that the medical humanities has become a “mature discipline” (Crawford et al. 2010), this recent upsurge of interest and engagement with an increasingly diverse range of topics we think speaks to the youthful, exploratory vigour of a field which is better thought of as “beginning maturation” (Ahlzén 2007). We use the word “field” advisedly, for as well as being not (yet) mature, the medical humanities is also, and very self-consciously, *not* a discipline. Whether it is multidisciplinary (Chambers 2009), interdisciplinary (Evans and Macnaughton 2004), or postdisciplinary (Lewis 1998) is still and perhaps necessarily debated, but as Stephen Pattison has noted, “We will know that medical humanities as a vibrant, pluralistic, experimental, risky movement has died when,” among other things, it “excludes varieties of disciplinary perspective and performance and becomes an autonomous discipline in its own right.” (2003, 34).

One of the most widely discussed contributions to these debates about disciplinary purpose and identity has been a call by Paul Crawford and colleagues for a move from “medical” to “health” humanities. Central to their argument is the claim that the medical humanities have an overly narrow focus on “the medical” and marginalize the experiences of allied health professionals, nurses, carers and patients. Such a view is, we suggest, empirically and conceptually questionable. While it seems plausible to suggest that the clinical encounter does retain a privileged place in the medical humanities imaginary, the idea that the field has worked to exclude any voices but those of the doctor or medical student is clearly false. Some of the best work in the medical humanities has sought to examine not just the practice of healthcare in a diverse range of institutional and social contexts (Colls and Evans 2008), but also to consider ‘medicalization’ itself as a pervasive cultural force, and to question the historical and contemporary expansion of a ‘medical’ gaze (see for example, Coors 2003; Heath 2010). Furthermore, understanding the subjective experience of illness as something distinct from the biomedical attribution of disease is an enterprise uniting most, if not all, medical humanities scholars. The idea that the individual’s or patient’s perspective is somehow absent is therefore difficult to support. The argument, then, for a new discipline of ‘health humanities’ which is “more inclusive, outward-facing and applied” and would “engage with the contributions of those marginalized from the medical humanities” (Crawford et al. 2010, 4) is premised on a misleadingly narrow view of the field’s existing scope and depth. Moreover, the implication of a robust distinction between the two “disciplines” is also misleading; the health humanities, as described, promises an expanded programme of research and practice only in relation to a small fraction of the work that is currently pursued under the umbrella of medical humanities. The proposition, then, is not about a new perspective or broadening the theoretical or philosophical questions asked by the medical humanities, but simply about reaching out to include those “non-medical” health professions perceived to have been excluded. This not

only fails to recognise much of the work published and presented in medical humanities arenas (see for example Davis 2005; Flaming 2005; Nestel 1998), but more worryingly, completely bypasses a critical engagement with different understandings of what is meant by the key concepts of “the medical” and of “health”, a critical engagement that has been characteristic of research within the social sciences for at least two decades.

This kind of critical engagement is, we suggest, far more fundamental to any evolution of the medical humanities. Critical engagements with “the medical” which open out and interrogate the multiple ways in which “the medical,” medicine and health are encountered and experienced are not only important and desirable in their own right, as we will show, but would also facilitate recognition of the breadth and vibrancy of medical humanities research without the need to draw disciplinary lines around particular types of work. In order to advance such critical engagement, and in the context of this special issue, we will draw on the debates within one social science field, that of human geography, from the late 1990s and into the early 2000s. A “critical” geography specifically attends to the situated nature of health and health practices in both space and time, and as such challenges conventional treatments of context as either backdrop or determinant. So it is from “critical” geography, we suggest, that the medical humanities can draw their inspiration without jeopardizing the openness and heterogeneity of the field.

### **Critical distinctions: medical geography and geographies of health**

“Medical geography,” as a sub-discipline of human geography, has historically been dominated by epidemiological frameworks and biomedical models of health and illness. As such, much of medical geography prior to the past two decades sought to identify variations in the spatial prevalence of disease and to differentiate the contextual/environmental and compositional/individual determinants of ill health (for example, Cliff et al. 1981; Cliff and Haggett 1985; Learmonth 1988; Thomas 1992). However, in the ‘nineties, the field of human geography, along with other social sciences, embraced a cultural and critical turn which, within the sub-field of “medical geography,” led to a series of exchanges between those who wanted to “preserve” research on health, disease and illness as a conventionally spatial science and those interested in expanding the theoretical, empirical and political mode of inquiry (Andrews et al. 2012; Kearns and Collins 2010) New labels of “medical” geography and geographies of “health” initially served to distinguish different approaches, a distinction which both reflected and advanced contemporary movements within medical practice and public health policy. From its start, the World Health Organization enshrined in its constitution a vision of health as more than the absence of disease (WHO 1946). This vision was operationalized first through the Declaration of Alma Ata and its policy emphasis on primary health care, the prevention of disease and attention to wider determinants of ill-health (WHO 1978) and later through the Ottawa Charter and the call for a “new public health” directed to health promotion (WHO 1986). The distinction made between a clinically oriented medicine, or biomedicine, and a politically oriented social medicine, or public health, was picked up and elaborated within the social sciences through both theoretical and critical engagements.

Within geography, the distinction between “the medical” and “health” was expressed through three important areas of contention. The first of these concerned the object of study. Critics of a medical geography that was focussed on a largely

descriptive spatial epidemiology sought to challenge and extend the focus of the sub-discipline by adopting the WHO conception of health, seen not merely as the absence of disease, but as related to broader definitions of well-being, inequity and social justice (Kearns 1993; Kearns and Moon 2002; Moss and Dyck 1996; Smith 1973; Smith 1994; Smith et al. 2003). Researchers also directed attention to the processes and relations between places, health and health care, for example, through developing the concept of therapeutic spaces and landscapes (Conradson 2005; Gesler 1992, 2000; Smyth 2005; Tonnellier and Curtis 2005; Williams 2007) or by giving value to experiential and emotionally inflected understandings of such relations (Anderson and Smith 2001; Atkinson and Farias 1995; Davidson et al. 2005; Dyck 1992; 2003; Gesler and Kearns 2002; Milligan 2003; 2005). Moreover, from the 'nineties onwards, the social sciences in general took far greater interest in the body itself as the focus of enquiry, a move eagerly embraced by geographers who saw the theoretical possibilities in the body as site, or as poet Adrienne Rich put it, 'the geography closest in' (Rich 1986, 212; Simonsen 2000; Longhurst 1995; 1997). This new focus on the body by geographers brought a second point of contention around the place for critical theory. Rather than treating bodies as 'dots on a map', neither embodied, reflexive nor agentic, feminist and poststructuralist geographers demonstrated the need to question the social meanings attributed to particular forms of embodiment and, by engaging with texts such as Foucault's *Birth of the Clinic* (1994), to analyse the spatialities of power inherent in medical engagements with particular bodies (Foucault 1991; Longhurst 2000; Miller and Rose 2008; Parr 2002). Finally, debate focussed on new methodologies and epistemologies. How should geographers *do* this more critical work? Mapping incidences of disease, no matter how rigorous the statistical analysis, does not in itself further an understanding of the cultural specificity of embodiment, well-being, or the politics of health. What kind of knowledge should geographers pursue and with what imagined consequences and effects? Here, a divide emerged between those who positioned themselves as "policy-relevant" medical geographers through arguing that "real-world" and often quantitative data-sets were necessary to speak to and make an impact on policy (Dorling and Shaw 2002; Kearns and Moon 2002) and those who asserted that the more theoretical, emerging critical health geographies were important (Parr 2002) since "critical work which questions and contests the categories used in biomedical science has a clear and important role to play in medical geography's engagement with policy and debates around inequalities in health and health care – highlighting the processes by which some bodies are seen as more equal than others" (Evans 2006, 260).

These debates map on to structural and lingering issues in the medical humanities, particularly with regard to the definition and status of "the medical." Although it retains the name, the medical humanities, particularly in research terms, shares many of the concerns of the "new" medical, post-medical or health geography. These include rejecting biomedical reductionism without abandoning the materiality of the body; engaging philosophically with concepts of health and illness; exploring broader notions of health, well-being and human flourishing; valuing subjective perspectives on the experience of illness; engaging non-medical practitioners as research partners; recognizing alternative spaces of healthcare; and challenging dominant epistemological frameworks through new methodologies (Kearns and Collins 2010; Kearns and Moon 2002). However, and even more instructively for the medical humanities, these debates within the geographies of medicine and health have developed further to reconsider the distancing from "the medical" within a critical social theory, to blur

this once-cherished distinction and recover new encounters between “the medical,” “health” and critical theory within geography (Parr 2002).

### Critical engagements: medicine and health in contemporary biopolitics

In a review of the field at the turn of the Millennium, Parr (2002) defined two trends within “medical geography.” The first she argued was premised on “a stark retreat from things medical, resulting in “geographies of health” solely concerned with “healthy” spatialities which somehow exist beyond explicitly biomedical categorizations, treatments and practices” (241). As Kearns and Gesler argue, the vision here is one of “a more progressive medical geography – a medical geography released from the shadow of medicine and reinvented as geographies of health and healing” (1998, 3). However, Parr draws attention to a second approach which does not aim to “do away with’ the medical, but [continues] to engage with it, albeit in a more critical capacity than has been the case previously within the subdiscipline” (241). The key issue raised by medical/health geographers then, is not simply about the expansiveness of the field of enquiry, but of the field’s orientation to what might be meant by “the medical.” Although aiming to challenge the dominance of “the medical” in medical humanities, by arguing principally for an expansionist account, Crawford et al’s (2010) account of the health humanities leaves the power associated with “the medical” unchallenged, allows those claiming to speak from a “medical” position to continue to claim an authority which similarly remains unchallenged, and seems to preclude the possibility of grappling with the phenomena of “medicalization” or the expansion of a medical gaze (<http://www.healthhumanities.org/> or [http://en.wikipedia.org/wiki/Health\\_humanities](http://en.wikipedia.org/wiki/Health_humanities)).

Within geography, several strands of work have demonstrated engagements among critical theory, biomedical concerns and the relationalities of health, space and place. The central concern of critical theory with the ways in which power and politics interact with bodies, biology, health and life itself challenges us to consider how new knowledge is shaped, how it influences our understandings of ourselves and how such framings enable a seamless translation into response and responsibility. Geographers have examined this inseparable connection, variously captured by the terms biopower, biopolitics or biosociality (Foucault 1977; 1991; Rabinow and Rose 2006; Rose 2001), with particular emphasis on the expression of the complex interactions involved in biopolitics as it relates to medicine and health at particular times and in particular places. For example, McPhail (2009) discusses how concerns about obesity in early cold war Canada reflected broader political concerns about the “solidity” of the nation’s borders and of nuclear family life in the wake of increased immigration and the threat of war. In a similar vein, Craddock (1999) explores the co-production of race, place and pathology in relation to smallpox epidemics in 19th century San Francisco illustrating how a political anatomy of the Chinese body read disease and depravity into its fundamental structure and simultaneously stigmatized both China Town and Chinese bodies.

A renewed emphasis in biology on molecular life has been accompanied by a new social understanding of our biological selves, a “molecularization of life” that shifts our political engagements with our biological selves. Braun (2007) identified two distinct orientations within work on the matter of life itself, one informed by a Foucault’s notion of governmentality and one informed by the threats of infectious disease. The first of these has been dominant across a range of social science research drawing on Foucault to offer a critical engagement with much of contemporary health policy and medical practice. Such research argues that contemporary forms of governmentality characterise the individual as an autonomous agent holding responsibility for his or her own health and well-being. At the same time, choice is

directed and governed through a host of measurements and assessments of outcomes (Miller and Rose 2008). Researchers have challenged the ways in which bodies are governed through such calculative techniques and technologies in relation to the policy attention given to obesity (Evans and Colls 2009) and alcohol (Jayne et al. 2011); the ways in which different bodies are positioned as more, or less, capable of acting responsibly in contemporary public health (Colls and Evans 2008; Evans 2010; Evans et al. 2011) and the ways in which particular forms of bodily matter (such as fat) come to *matter* (Colls 2007).

There is a strand of inquiry driven by concerns of biosecurity which positions individual bodies as vulnerable to flows of molecular hazards that are neither visible, predictable nor initially framed as amenable to individual control. Braun's particular argument (2007) is that the conventional focus within either medical or health geographies means that social scientists and geographers in particular have paid insufficient critical attention to the ways that threats to biosecurity may reconfigure contemporary biopolitics or the ways such relations may interrelate with the concerns of governmentality. However, recent research has begun to redress a "governmentality" bias in critical engagements. Sparke and Anguelov (2012) explore how the framing of and responses to the pandemic in 2009 of H1N1 virus, popularly known as "swine-flu," reflected and reinforced existing multiple inequalities. These are seen in the positioning of blame for the outbreak onto poor countries and poor people, in the calculation and management of risk, in access to treatment both globally and within any one nation-state, and in the ways global processes of neoliberalisation help produce the emergence of new and virulent flu viruses. The authors unpack the ways in which global concerns of biosecurity are woven together with a contemporary emphasis on individualized responsibility of risk and response. In a similar vein, Mansfield (2012a, b, c) examines the framings of environmental contamination in fish products which can affect foetal neurodevelopment. Mansfield's critical engagement with a policy response that advises against consumption reveals a form of gendered and racial biopolitics. The importance of this work is that it draws together highly biomedical and biochemical concerns, concerns conventionally located under "the medical," with the interests of a critical theory, typically located under "health" through concerns with the biopolitics of health, life or well-being. Moreover, this welding of the medical, health and critical theory explicitly provokes new engagements with space and time in relation to material bodies and environment-body interactions (Guthman and Mansfield 2012).

### **Medical, health and the radical potential of the medical humanities**

What lessons might the medical humanities take from this exploration of "the medical" and "health" in the affiliated fields of the social sciences and in geography specifically? In part, the answer depends on how we understand the role for the medical humanities more widely, and here there are of course a range of viewpoints. Should medical humanities retain their focus on medical education, adopt the position of medicine's "supportive friend" (Brody 2011), become a disciplinarily "disruptive teenager" (Macnaughton 2011), or seek something else altogether? In particular, we ask, is there radical potential for the medical humanities? As our discussion of medical/health geography has made clear, our key argument is for a closer engagement with critical and cultural theory. To conclude this paper, we discuss (i) intersubjective and relational approaches to well-being, and (ii) activists' use of the arts and creative practice to disrupt medical definitions, categories and practices and to campaign for social justice, as two examples of the strength of such an engagement.

Recent work within the critical social sciences has argued for a re-configuration of the subject beyond a neoliberally-bounded model to one that recognizes intersubjectivity and

intercorporeality. This move extends the existing critique of “individualistic liberalism,” which asserts the rights of already constituted subjects by instead emphasizing the “relational constructedness of things” (subjectivities, bodies, spaces, etc) (Massey 2005, 10). In short, this is an approach to “the body” that focuses on “the connections that bind us together” (Lawson 2007, 4), and it reconceptualizes space and “the social” in terms of interrelations, multiplicity, heterogeneity and flux (Massey 2005). Within such work, therefore, “the body” is not understood as a bounded, singular body-subject but is instead involved in a “constant, ongoing process of connection with other human, non-human, past, present and future bodies” (Evans et al. 2011, 324). Health, then, is reconceptualized as something that is produced through the relations between bodies rather than as something that a body is or is not.

While the medical humanities has done a lot to challenge dominant medical perspectives, it seldom if ever ventures beyond a neoliberal, humanist notion of the individual body-subject and associated conceptualizations of responsibility, rights, and risk management to really explore alternative “collective” and “relational” approaches to “flourishing.” As well as learning from critical theory, here the medical humanities can also learn much from the practice of arts and health. By contrast to a medicalized arts therapy, which tends to focus on the internal dimensions of individuals’ trajectories of ill-health, the participatory ethos of arts and health engages with the social or collective dimensions and determinants of health to foster personal and community well-being, explicitly conceptualizing these as inextricably interwoven (Atkinson and Robson 2012; Atkinson and Rubidge 2013; White 2009). This is also a feature of arts and health practice that is addressed to specific types of communities, or experiences of ill-health, where, as Parr describes, “a distinctive theme is a sense of shared illness experience” (2006, 158). Agencies providing participatory arts and health activities constantly face the challenge of negotiating the demands of funders informed by the dominant model of a neoliberal subject whilst maintaining their own ethos of collective and relational care for well-being (Swan and Atkinson 2012). Without detracting from the importance of individual experience or silencing dissenting voices, such a collective approach questions the desirability of “personalized care” that separates the “ill” individual from the communities and spaces within which he or she lives. The argument for greater attention to collective, relational and situated understandings of differentiated experiences of health and ill-health is timely within the medical humanities as major political and policy changes are afoot within the contemporary provision of health care. For example, our understandings of personal narratives of ill-health experiences, something constituting a major area of research within the medical humanities, disclose as much about the politics of ill-health experiences as the immediate health care needs if interpreted as intersubjective and situated in their construction (Atkinson and Rubinelli 2012). Such engagements within the medical humanities disrupt the view of the individual as always and necessarily a bounded subject and challenges the spatio-temporalities in dominant concepts of recovery and therapy by recognizing that well-being is always in flux and allowing “space for differentiated self-development.”

Healing, well-being, happiness, wonder, beauty and empathy are important concepts in the medical humanities literature, but we would also argue that the medical humanities has a role to play in exploring the value and productivity of emotions seen as ‘negative’ and looking beyond the classics of the Western canon to engage with forms of creative practice that may unsettle and disrupt the ways in which particular bodies and subjects are defined as healthy or not. Again, there is no shortage of medical humanities work on illness narrative and the subjective experience of illness, but with little critique of the wider political climate within which such work emerges, it is dominated by positivity and praise of heroic survivorship (Bartels 2009; Ehrenreich 2009; King 2006) and by the failure to recognize its own cultural and historical specificity (Hooker and Noonan 2011). The medical humanities have also accorded negligible attention to the art, arguments and activities of activist movements. Mad

pride events, for example, feature cogent and carnivalesque critiques of what counts as “mental health”; fat activist groups such as ‘the Chubsters,’ based in the UK describing themselves as ‘a vicious girl gang’ and who aim to disrupt medicalized notions of fatness through performances which emphasize anger, rage and humour (<http://www.chubstergang.com/>). It is important to emphasize that the approach we are advocating is not simply about fitting ‘pride’ movements within a model of ‘recovery’ – the role of such arts-lead activism is not to help those whose bodies/minds do not fit or feel comfortable with their place in the world (although this is part of it); rather it is to challenge the ways in which such bodies are approached within medicine and health and in the wider culture, and to recognize anger as a productive force (Ahmed 2010, 108).

In conclusion, we are calling for the medical/health humanities to take seriously the challenges of critical and cultural theory, community-based arts-in-health, and the counter-cultural creative practices and strategies of activist movements. We are calling, in other words, for an evolution to a *critical* medical humanities which would enhance the intellectual as well as the “real-world” impact of our field’s interrogations of medicine, health and illness.

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## Scientific Contribution

### Medical humanities: stranger at the gate, or long-lost friend?

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**Abstract.** “Medical humanities” is a phrase whose currency is wider than its agreed meaning or denotation. What sort of study is it, and what is its relation to the study of philosophy of medicine? This paper briefly reviews the origins of the current flowering of interest and activity in studies that are collectively called “medical humanities”, and presents an account of its nature and central enquiries in which philosophical questions are unashamedly central. In the process this paper argues that the field of enquiry is well-conceived as being philosophical in character, and as having philosophy – albeit pursued over a larger canvas – at the core of its contributing humanities disciplines. The paper characterises humanities disciplines as having an important focus on human experience and subjectivity, of which the experiences and subjectivities at stake in health, medicine and illness form an important sub-set, the preoccupation of the medical humanities as a whole. Claims of interdisciplinarity (as distinct from multidisciplinary) are noted, but such claims need to be recognised for the high and stern ambition that they embody, and should not be made lightly.

**Key words:** humanities, interdisciplinarity, medical humanities, philosophy of medicine, subjectivity

In *The Curious Incident of the Dog in the Night-Time*, author Mark Haddon (2002) describes a fairly ordinary sequence of domestic unhappiness through the utterly extraordinary eyes of a logically clever, but emotionally severely disabled, teenager suffering from a form of Asperger's or other quasi-autistic disorder. The result of his condition is a quite unforgettable re-ordering of the world into bizarre yet internally consistent categories, including what is for the reader a heartbreaking systematic misperception of parental love as murderous threat; the book is a chronicle of how so disabled a child can somehow craft his own day-to-day survival. After reading this book I asked an experienced child psychiatrist whether he felt that the author had succeeded in capturing the “interior” of an autistic or Asperger child's experience. His answer was: “not quite”, but that even with its inaccuracies he remained very glad that the book had been written, because in his view it made available the intensity of the problems of Asperger's and autism to a wide audience, and would generate sympathy and understanding of the

condition. (I will from now on use the terms “autism” or “autistic” as an un-scientific shorthand to cover the range of Asperger's-like and other autistic conditions in general. The points I wish to make do not depend on the distinctions between these terms.)

The psychiatrist's answer – that the book had “not quite succeeded” – is an interesting one, for it implies the possibility of success. This in turn implies a number of moderately striking things, among them that, with sufficient professional experience, it is possible for the clinician to gain genuine insight into the interior of someone else's experience even in such notoriously inaccessible conditions as autism. That assumption is implicit in his being able to give a cautious approval of the book's partial accuracy – if I may use the term – i.e. partial accuracy with respect to a strange (and, in this particular case, damaged) form of self-experience and self-understanding. Of course this is an unusually difficult form of something that is somewhat difficult in even an *ordinary* case – namely, to get a sufficient degree of access to

someone else's experience, through what they write or say about themselves, for *us* to be able to talk about how successfully they have conveyed their experience, or how accurately they have represented it. The familiar obstacle is (depending on your position within the philosophy of mind) that since anyone's own experience is something that only he or she actually has, it can never be more than *inferred* by third-parties, that is, everyone other than that person.

However, the attempt to infer it – in the ordinary case – is obviously necessary a thousand times a day; and presumably it is no less necessary in trying to understand the perplexing case of autistic experiences. The psychiatrist's answer presumes this, too. He could hardly try to work clinically with autistic children and their parents if he had *no* ambition to understand something of the qualitative reality of autistic experiences, since without such understanding, the clinical role becomes reduced to something like advising the affected parents on the practicalities of crisis management.

The further implication of this verdict of partial accuracy is the possibility that the book could have succeeded in transmitting experience *among* third-parties: that is, an originating third-party such as a well-informed author could not only access such an obscure experience but also convey it accurately to other third-parties, namely ourselves as readers.

A somewhat distinct presumption in the psychiatrist's stance is the value of wider sympathy and understanding of the condition of autism. However intuitive such a presumption may appear, there is a question about where exactly that value lies. Would we be happy, for instance, if managerial decisions about funding and resources were openly based upon the extent to which the book-reading public sympathised with the plight of a particular group of patients and their carers? Surely not. Perhaps instead it lies in the likelihood that readers of the book will be more tolerant of the problems caused by autistic behaviour – and more supportive of the parents who routinely deal with those problems. But even this is problematic, in that whilst tolerance *per se* seems to be a good thing, we surely want it to be based upon a genuine and honest understanding, and not upon an inaccurate, picturesque, imagined or otherwise deficient representation. This seems to require, in the present case, that the book actually succeed in opening a genuine window into the autistic child's world. "Not quite" succeeding, in the psychiatrist's

words, seems to be an imperfect basis for greater tolerance.<sup>1</sup>

The reason I have opened with this example, and spent some time on it, is that it raises a number of questions with which I think the fledgling field of the medical humanities is concerned. Let me briefly review a list of the more obvious of these questions. First, how far is clinical medicine based upon scientific observation and intervention? What resources other than scientific observation and intervention are available to the clinician?<sup>2</sup> Is clinical medicine directly, or only indirectly, concerned with the experiential aspects of health and illness? In either case, how do we train doctors and other clinicians to address these experiential aspects (and hence do doctors need experience of life, as much as they need scientific knowledge, in their clinical practice)? How should we seek to understand and explore those problems of life and experience, including physical and psychological illnesses, that arise from the particular configurations of our bodily make-up? The suffering of any illness, not just the suffering of ingrained emotional deficits associated with some psychological disorders, is an intensely subjective matter. What kinds of knowledge and enquiry therefore are best suited to taking subjectivity seriously, and investigating it? Perhaps more radically, can there really be genuine knowledge of another person's subjectivity? And if there can, how is it to be achieved? Furthermore, how can it be usefully *transferred* – for instance, making an exploration of the autistic child's subjectivity a matter for a gain in the understanding of others?

Other epistemic questions as well are implicit in the psychiatrist's answer. What is the role of *values*, be they moral, social, aesthetic and so on, in our identification of the normal and the pathological? What kind of science-of-the-human is constituted by medicine in either its early modern form or its current, highly technologised form? Is it central or peripheral in the context of other sciences? How are we to consider a form of scientific *object of study* – the patient – that is also a thinking, experiencing *subject*? How should we understand such a science in a context that is increasingly dominated in an epistemic sense by, on the one hand, biophysical categories including those of molecular genetics, and on the other hand, statistics and the relationship between probabilities at a population level and the individual patient – who supplies, perhaps, the *only* context in which these questions are finally important? And so on.

All of these questions present, constitute, or point towards, problems and enquiries that are recognisable in the philosophy of medicine, and I acknowledge the need to clarify the relations between philosophy of medicine and the field of medical humanities. But the fact that these questions are indeed recognisable in itself suggests that from the standpoint of philosophy of medicine, medical humanities begins to look a little more like a long-lost friend than simply a stranger at the gate.<sup>3</sup>

To continue the enquiry, I will try to present an individual perspective upon the field's origins and its contemporary nature. This perspective involves the frequent occurrence of irreducibly philosophical questions; in this paper I can only notice them and not address them substantively.

## Origins

To begin with the field's origins, it is perhaps worth noting that the expression "medical humanities" is initially an American one, referring to primarily education concerns within the medical curriculum, and more particularly to bringing the study of humanities topics, principally literature and literary techniques, to the *teaching* of medicine; part of the aim was to develop clinicians' powers of listening and interpretation (Hunter et al., 1995). One difficulty the expression presents is that one always has to explain that "medicine" means other aspects of health care as well.

Another difficulty – and this implicitly brings us to the question of the field's current nature – is that some people regard medical humanities as of interest only within medical education, and indeed as essentially *being* a mode of medical education. So, to the extent that they are engaged at all in medical humanities, British medical schools have tended to maintain the original American approach of focusing on such things as literature, creative writing and film as vehicles for interpretation skills and self-expression alike. One development of this in the UK focuses on postgraduate and continuing education, using familiarity with the humanities and creative arts as a personal resource for hard-pressed clinicians facing the demands of professional life.<sup>4</sup> Another development emphasises the cathartic benefits to *patients* as well as carers, of writing creatively about their experiences (Bolton, 2001). These resources are no doubt all good things to have, but they do not in themselves plausibly constitute a field of study.

A further suggestion that has been made during the early evolution of medical humanities is that it is the attention we pay to (in the British sense) all the non-scientific (though not unscientific) aspects of medicine, or even simply all that concerns "the human" within medicine.<sup>5</sup> The trouble with this suggestion is that it is so dismayingly wide that it would be difficult to see how it could possibly be the name of a coherent activity or enquiry.

There is also a sense that medical humanities is a kind of *medical counter-culture*: a response to some forms of dissatisfaction felt by patients concerning how well their doctors listen to them, or dissatisfaction felt by doctors towards the somewhat dehumanising effects of large-scale, industrialised health care (Macnaughton, 2001). In this sense, such dissatisfactions (and they are not unreasonable) rather resemble some of the origins of medical *ethics* – that is, a kind of consumer voice of protest, *seeking* a critical counter-culture of this kind. This in turn invites a further resemblance to some of the early critical enthusiasm for medical ethics, before it met the twin dangers of being either turned into a respectable academic discipline or devoured by the law and legalism.

Perhaps this is a good point at which to review other parallels between medical ethics and medical humanities. "Medical ethics" is an ambiguous phrase with at least two denotations: on the one hand sets of practical and professional duties and their consequences (i.e. what actual, particular doctors ought to do in real situations, conveniently dubbed "normative medical ethics") and on the other hand a set of intellectual questions and enquiries which have been collected together as an academic field (i.e. how we might think about and understand what doctors in general ought to do in typical situations, sometimes called "critical medical ethics"). Now we might at first glance suppose that the phrase "medical humanities" is ambiguous in the same way.

I have discussed this problem at greater length elsewhere, and here I will merely summarise that discussion. The phrase is ambiguous between a form of enquiry and an approach to practice. The former denotes a specific branch, particularly aimed at medicine, of the broader area of enquiry known as "the humanities"; this critical and reflective undertaking corresponds to the critical form of medical ethics. (Such enquiry naturally includes questions in metaphysics and epistemology, insofar as these are natural components of any genuinely critically reflective examination – such as philosophical examination, whose importance we

shall recognise below – of medical practice and medical theory, which inevitably presuppose some metaphysical and epistemological positions on matters concerning, respectively, the nature of embodied human experience in health and illness and the sources of our knowledge of such experience and its bodily foundations.<sup>6</sup>) It contrasts with the advocacy of particular ways of actually doing medicine, that is, practising humanely and with due concern for the humanity of the patient; this exhortatory discourse corresponds to normative medical ethics. Unfortunately the problem for this latter interpretation of “medical humanities” is that it appears suspiciously like a truism of a rather pious kind.

It would certainly be a truism if humane practice were intrinsic to the concept of medical practice. However, this can be contested – as can the somewhat parallel presumption that ethical practice (of which humane practice might be thought to be a manifestation) is internal to medicine. In taking the relief of suffering as being an *internal* goal of medicine, Cassell (1991), for instance, seems committed to the idea that medicine in practice must be both ethical and humane *by definition*, a view whose consequence would be that if we fail to practise medicine humanely or ethically we fail to do medicine at all rather than just doing medicine badly, which seems on the face of it the more natural way of putting the matter.

If, prompted by caution, we disregard the normative interpretation of “medical humanities” as referring to particular (humane) ways of doing medicine then we are left with the still-valuable denotation of a critically reflective field of intellectual enquiry, and in this too, there is a useful parallel with medical ethics. I find persuasive the suggestion that medical ethics’ concerns can themselves be taken up amongst the “human” (*not* humane, be it noted) concerns of medicine. In this sense, medical humanities adopts part of the agenda of medical ethics but pursues it in a broader and perhaps more diffuse form.

Of course “ethics” is the specific name of only *one* area of values, and there are other areas that are at stake in modern medicine and healthcare – social values, political values, spiritual values, aesthetic values, epistemic values, perhaps sexual or gender values, even gustatory values. Despite their obvious relevance to clinical medicine (think of public health, palliative care, aesthetic and reconstructive surgery, the fashionable preference for population-level evidence and so on), some of these have received relatively little attention, and I

have a sense that this reflects a wider neglect of the philosophy of medicine – at least in the UK where, it seems to me, most philosophy of medicine is done in conjunction with medical ethics, perhaps actually as *part of* medical ethics. That is a legitimate place to do philosophy of medicine, of course, since critically undertaken value enquiry with regard to medicine is as fully a part of philosophy of medicine as is the pursuit of any of the other cardinal components of philosophical enquiry – epistemology, logic, metaphysics and so forth – directed at our understanding of medicine, whether undertaken in an analytic or an interpretative spirit.<sup>7</sup> Moreover from the philosopher’s viewpoint it is an enduring boon that medical ethics has provided this opportunity, since through its relatively high profile medical ethics makes some philosophical questions apparent, and even accessible, to a wider public. Medical ethics is, as one might put it, the most brightly illuminated shop window display of *any* form of philosophical enquiry.

Before we leave the question of the origins of medical humanities, it is worth including a cautionary note (one which may be somewhat familiar in medical ethics as well), namely that the very imprecision – so far – of what medical humanities comprises, can appear to offer a home for what one might call disciplinary refugees: that is, enquirers who for one reason or another are not comfortable within the traditional confines of their own discipline or practice, and have moved into the area of reflective enquiry into medicine, hoping to claim the academic equivalent of political asylum. The benefits of intellectual creativity that such a diversity of individuals in theory offers may be offset by the adverse impact of too many varying influences upon a field of enquiry that is not yet itself sufficiently mature to be entirely confident of its own general nature, still less its detailed identity and purposes.

Unfortunately amidst a clamour of voices, one has rarely the luxury of waiting for silence before adding one’s own voice. All I can therefore do in the remainder of this paper is offer a personal contribution to the discussion of the nature of medical humanities as a field of enquiry.

## Nature

In the personal conception of the nature of the field of medical humanities which now follows, I will try to begin *descriptively*, reporting on what I see when

I look at the field, whilst acknowledging that the report inevitably involves a somewhat editorial selection on my part and, as such, is liable to develop *prescriptively*, advocating a particular conception.

The simplest pattern that I can impose upon a varied field of activities claiming to constitute, or at least to affiliate to, medical humanities is to divide those activities essentially into three kinds. The first two kinds concern *substantive activities* within organised health-care, as well as academic or theoretical *reflections upon* those activities.

- First, there are those activities collectively known as “Arts in Health” including the therapeutic uses of creative arts activities such as writing and painting; and including also the use of creative arts and co-operative productions of public art as a way of helping to create and sustain healthy communities. An example of the former would be the encouragement of creative writing on the part of sufferers of chronic illness – or their carers – in an attempt to confront and give meaning to symptoms (Bolton, 2001). An example of the latter would be the use of stylised visual rituals, such as the lantern project in Wrekenton, near Durham in the North East of England, in which illuminated symbols of the heart at the core of a healthy community are produced collectively in community-based workshops and then paraded together in an annual and spectacular festival of lanterns (Robson and White, 2003). As mentioned, for me this area of medical humanities includes commentary, analysis and critical reflection upon arts-in-health activities.
- Second, there are those activities geared towards and embedded within Medical Education, including actual schemes of study for medical undergraduates and postgraduates, periodic study resources for Continuing Medical Education, and the general notion of offering personal resources, through art, literature and creative self-expression, for what I earlier referred to as “hard-pressed clinicians facing the demands of professional life”. Examples of modules devoted to the study of literature, film, fine arts, history and philosophy can be found in many medical schools, normally as options,<sup>8</sup> and as part of continuing medical education through, for instance, the Medical Royal Colleges in the UK.<sup>9</sup> Again this area should be taken to include academic commentary and analysis concerning such activities.
- The third area is more obviously an academic or theoretical undertaking *through and through* – namely, the task of attempting better to

*understand human nature* through the lens of a critical examination of technological medicine and its limitations. Examples of enquiries here could include the implications of molecular genetics for our concepts of free will; scrutiny of the role of technology in medicine in an age in which imaging the body’s interior is taken to have category-forming authority and explanatory power (Hofmann, 2001); or the two-way relationship between new surgical techniques and contemporary standards for so-called “ideal” bodies and faces.<sup>10</sup> This is not only the most clearly theoretical of the three broad areas of work; it is also the most irreducibly philosophical of the three. Whilst I do not want to suggest for a moment that only philosophers can undertake it, I do want to suggest that in undertaking it one is doing something that, whatever else it is, is usually also philosophical in spirit.

So, if we try to identify the nature of the medical humanities in terms of its characteristic preoccupations, then these three broad areas seem to me to describe it. But an equally important question concerns *who is* actually so preoccupied: Which *are* the contributing disciplines to the field? Well, almost by definition they are neither physical sciences nor, for the most part, social sciences. No doubt the division of human enquiry into discrete disciplines is a historical and conventional one that is in some respects unhelpful, but we are stuck with it and we might as well start from where we find ourselves. So, we are left with the humanities disciplines, whose conventional members include literature studies, history, philosophy, fine art, drama, critical theory, historiography, theology and religious studies, linguistics, music, law and so forth. The least generalising of the social sciences (the qualification is important as we shall shortly see) such as ethnography or that borderline humanities/sciences discipline, psychology, might also be included in an eclectic conception.

A putative list is all very well – although of course people will disagree over the inclusion of some of these, and over the exclusion of a larger number of disciplines not mentioned here (how about cultural anthropology or feminism studies?) – but we need to go on from this to ask, Do they have anything in common that makes them either characteristically *humanities* disciplines or specially able to contribute to medical humanities study? I will try to respond to this by suggesting that there are indeed two related characteristics of humanities disciplines that do make them especially useful for addressing the human side of medicine.

These are, first, a concern with experience – with recording and understanding and interpreting individual human experience (Evans, 2002b) and its qualitative dimensions, or, if you like, a concern with the world as it is humanly encountered, rather than as it might be detached and merely dispassionately observed, which is more plausibly the goal of the natural sciences.

The second characteristic of the humanities for me follows from this (at least in broadly Western culture where, currently, conventional humanities subjects as characterised above, and the medical humanities as a manifestation of them, are primarily to be found). This second characteristic is a concern to take subjectivity seriously – the individual point of view and its qualitative content, its unique antecedents and its idiosyncratic repertoire of meanings and connotations – as well as taking seriously its necessary reflection of, and embeddedness in, the many *interpersonal* contexts of society, including those of clinical medicine.

This second characteristic invites us to suppose that the specific observations of a given individual in context are as interesting – in the sense of providing grounding, meaning, implication and a guide to our future attitudes and actions in relevantly similar circumstances – as are the homogenised observations collected together under the natural sciences. It allows that for many purposes characteristic of clinical practice (such as the decision of whether or not to prescribe a marginally effective drug with unwanted side-effects), a single telling example of a vivid experience that is to some extent recognisable to us is, in principle, as powerful as population-derived evidence telling us which probabilities are compelling as guides to action (Sweeney, 1996).

The point is that both the objectivising gaze of science and what we may call the subjective-tolerant gaze of the humanities do indeed contribute to our reasoning as guides to future action. I should like to attempt a generalisation here – a generalisation that, if plausible, helps to rationalise the place of the humanities in our understanding of medicine, health and illness: perhaps the sciences provide constraints upon what is a *rational conception* of future action – they provide the basis for our beliefs. At the same time, perhaps the humanities provide models of *motives* for future action – they provide possible bases for our attitudes (what Stuart Hampshire (1989) called our conceptions of the good lives that are possible for us).

Having suggested the broad content of the field of medical humanities, and characterised the

humanities disciplines that engage in it, I would like to add something about the *modus operandi* that is at any rate claimed for Medical Humanities. This is its alleged interdisciplinarity. Most promotional references to medical humanities advertise this as a characteristic feature. However, I suggest that interdisciplinarity is a very ambitious goal, and that it is claimed on many more occasions than it is actually realised. This is arguably a further feature in respect of which medical ethics and medical humanities are somewhat alike.

First, however, what is at stake in attaining a proper conception of “interdisciplinarity”? Principally at stake is the way in which the various contributing disciplines are thought to relate to one another as they jointly engage medicine and health care. How do these actually *constitute* medical humanities as a field of enquiry?

The essential question here is whether the contributing disciplines remain as independent of one another as, inevitably, they must begin. For example, the question of the status of neurasthenia (in some respects, the late-19th-century counterpart of myalgic encephalopathy) as a genuine disease invites commentary from history of medicine (in terms of the emergence and refinement of an identifiable condition attracting medical attention), literature studies (in terms of the coalescing of references to the condition around certain prominent artistic or creative individuals at a particular historical period, and the value-assumptions that began to be tied to the condition) and philosophy (in terms of genesis and maturation of the concept “disease”). The question is whether these several enquiries are, or could be, or should be, undertaken in radical independence of each other; or, if not, the contrapuntal question is that of precisely how they should inform one another. Are they a mere sequence of set-piece investigations to be sampled piecemeal according to the interests of the external inquisitor, or are they the fused components of a more richly-layered and above all *emergent* enquiry, whose substance, concerns and specific questions would not be apparent to the contributing disciplines on their own?

This is of course a puzzle about what kinds of knowledge are possible when distinct disciplines collide, about whether their respective methods are mutually intelligible, about “how other disciplines see and name the objects in their world, and to what extent we can view that world with them: in effect, learning to see simultaneously through our own eyes and through theirs” (Evans, 2007).

No doubt true interdisciplinarity is sometimes achieved, but so far the more convincing examples appear to emanate from elsewhere than the medical humanities. A good example is arguably constituted by chemical process technology, in which those who, for commercial reasons, were interested in improving the mechanics of fluid flow and heat transfer in the production of polymer plastics, had initially no established field to draw upon at all (Evans and Macnaughton, 2004). Proceeding empirically, they engaged mechanical engineers to help them with pencil and paper calculations; the engineers in turn recruited methods from physics involving so *many* simultaneous calculations that non-linear mathematical modelling from computing science became integral to the emerging field.

A key feature of this process is that at each stage new *questions* emerged that could not have been asked, let alone answered, by the contributing disciplines in isolation. I think it is plausible to suggest that *emergent questions*, whose range of aspects cannot be found in any single contributing discipline, are one indication that genuine interdisciplinarity has been achieved. The full complexity of fluid mechanics was neither soluble by *nor apparent* to the paper-and-pencil generation of chemical and mechanical engineers who began the field; the relation between on the one hand real fluids traversing real locations and on the other hand mathematical representations of activity at notional and infinitesimally graded locations would at earlier stages have seemed arcane to both fluid mechanics and computer scientists.

It is I think more difficult to point to either emergent questions in particular or genuine interdisciplinarity as a more general attainment within medical humanities at the moment. The mutual implications, for our understanding of perception, between neurology and phenomenological philosophy become apparent and real only when these two forms of enquiries collide. More generally, patients' subjective experiences are foundational in their seeking medical care in the first place, yet the *forms* of experiences of the self occupy a surprising range; some forms are perhaps even made possible when disciplinary perspectives co-engage. Consider, for instance, Oliver Sacks' incorporation of the notions of music and musicality into his understanding of proprioception as a neurologist, an incorporation that informs his experience of his own bodily recovery and our appreciation of music's diagnostic and therapeutic possibilities (Sacks, 1986, pp. 108–110). As for interdisciplinarity

as such, one place where one might look for interdisciplinarity is where the methods of literary and philosophical analyses are combined – as has been fruitful in medical ethics and indeed ethics more generally. Examples might include the attempt to understand the processes of creative imagination in the evolution of scientific medicine, or the attempt to chart the complexities of paying attention to the character of the moral agent in expositions of virtue ethics. I am not here going to comment on the success or otherwise of any particular claim to interdisciplinarity. I merely want to insist on how difficult it is, at the same time as noticing how routinely and, I fear, *casually* it is claimed on behalf of Medical Humanities.

Notwithstanding this sceptical note, the foregoing (taken as a whole) suggests to me that we can say something about the characteristic projects of work likely to fall under the Medical Humanities. My suggestion is that at least such work as attempted any of the following four tasks – and it is straightaway apparent that they all have a philosophical flavour – could be thought of as constituting Medical Humanities work.<sup>11</sup> (That is to say, the attempt on these tasks provides a sufficient, although presumably not a necessary, condition for constituting Medical Humanities work.) The tasks are these:

1. To illuminate the practice of medicine (and, perhaps, medical theory) using ideas and insights distinctively associated with humanities or social science disciplines; especially doing so in a way that is not usually accessible through scientific descriptions and explanations.

Examples: any kind of value enquiry concerning medicine. This obviously includes medical ethics.

2. To illuminate what one might call “the human side of medicine” in a form that takes seriously the ways in which medicine, illness, suffering, disability, and (for that matter) health are *experienced*

Example: pathographies – the recording and interpretation of illness experiences; bringing creative and expressive arts to bear upon the experience of illness, in the therapeutic (and sometimes diagnostic) context

3. To attempt the understanding of one or more ‘subjectivities’ within the experience of medicine, or of health, illness, suffering or disability; and (from this) work that makes such understanding

*transferable* to our understanding of *other* subjectivities: such that we gain something which we can meaningfully relate to other insights gained on other occasions of comparable enquiry, allowing us to be systematic, albeit in a rudimentary way

Examples: the broad swathe of those enquiries in history of medicine, philosophy of medicine or medicine and literature where individual experiences are made available to others through description, analysis, representation, in the hope of learning something about ourselves – and about “the human condition”

4. To use some aspect of medicine (that is, health care, etc.) specifically to achieve some gain in our understanding of the human condition, or of embodied human nature

Example: philosophy of medicine generally, especially philosophical enquiries into embodiment and experience; or similar enquiries within medical anthropology and ethnography

What would be the point of the foregoing work? Why would we seek to undertake it? I put these questions somewhat rhetorically – since all of these kinds of work, especially the last area concerning gains in our understanding of embodied human nature, should commend themselves to all serious scholars and above all to philosophers. But rhetorical or not, we can I think see that work of this kind does help us to do a number of worthwhile things.

To begin with some fairly conventional objectives, the first three of these areas clearly help us – as commentators or as clinicians or, for that matter, as patients who necessarily contribute to the clinical consultation – to take human *values* seriously, including ethical values. They help clinicians and students alike to develop their own personal values. The second and third areas may help in developing clinicians’ interpretative sensitivity and their skills of listening and communication. Through the engagement with creative and expressive arts, they may also indirectly provide clinicians with personal resources for facing the demands of clinical life.

The fourth of these areas – fittingly enough for work that is essentially philosophical – serves I think more radical goals:

- asking how technological medicine’s picture of human nature/the human condition contributes

to our self-understanding, and whether other pictures are available (for instance, from the humanities);

- from this, asking whether technological medicine spurs humanities disciplines to extend (or revisit) their own research agendas;
- exploring disciplinarity, interdisciplinarity, and the varying nature of knowledge and evidence in medicine, sciences and humanities
- stimulating and encouraging a sense of wonder at embodied human nature.

I believe all of these goals are worth pursuing. To varying extents, each of them is reflected in current work in philosophy of medicine. I would describe this area of Medical Humanities as, in effect, pursuing philosophical questions in medicine over a larger, a more colourful and no doubt a more disordered landscape. If I may so put it, the “long-lost friend” has indeed been a stranger, but at others’ gates; it is returning now with tales of these colourful and disordered landscapes.

Finally, if the field is to develop credibly then, I would argue, its constitutive research enquiries must strive to be mutually coherent. Literary insights, historical investigations, philosophical reflections and linguistic analyses directed towards, say, culturally distinct experiences of nausea and their appropriate medical and psychological management (or towards the meaning of the epidemiology of psychological disorders, or towards the notion of “functional illnesses”, or towards the question of whether myalgic encephalopathy is genuinely comparable to late-19th-century neurasthenia, or towards radical deconstruction of the clinical consultation, and so on) should be seen to bear upon common objects in compatible terms. Unfortunately I do not think we can always claim that this happens as yet. There needs to evolve at some point a rudimentary structure, within the field of Medical Humanities, that minimally orientates the modes of attention of different disciplinary enquiries and focuses them together upon an object or concept that is recognisable to all the enquirers and has a shared meaning as well as, putatively, a *shared denotation*. Research in medical humanities needs to produce some sense of accumulated gains in understanding, and not just an unstructured “heap” of observations and remarks that are individually valuable but nonetheless essentially fragmentary.

I do not suggest that this is easy, but few worthwhile things are easy. Elsewhere I have suggested that in the biomedical age we might recast Blake’s powerful rendering of the human

constitution, famously the constitution of “impas-sion’d clay”, in terms of our being “meat with a point of view” – the combined biophysical and existential realities of our embodied state, in which our subjectivity is fused with our objective, external being. Understanding this fusing is among the most philosophical of the tasks to which, in my view, the Medical Humanities are properly addressed.

This suggests that those who, as I do, prefer the “long-lost friend” conception of Medical Humanities to the “stranger at the gates”, will recognise the centrality of philosophy among its contributory disciplines. Indeed I would go so far as to say that for those of its practitioners who are philosophers, the Medical Humanities amount to “Philosophy looking at the Humanities looking at Medicine”. Further, the philosopher sympathetic to this view will sense that philosophy of medicine is the queen of those humanities disciplines co-engaging our embodied human nature. This is my sense, too. However, philosophy is not the only such discipline, and its task in the medical humanities is perhaps to encourage, to inspire, to learn from, to respect and, when necessary, politely to marshal the others. Whether this is finally a responsible and sustainable view, rather than unwarranted disciplinary arrogance, is something we shall find out only when the field of Medical Humanities progresses towards maturity.

## Notes

1. *Perhaps* imperfectly grounded tolerance is better than nothing, if that is all we can get, but its wider consequences might involve more harm than good, if these include a more general decline in critical scrutiny of the bases of tolerance; we may end up tolerating things that we should *not* tolerate.
2. I am using the word “scientific” in its narrower UK sense. I mean by it the natural sciences, rather than the more general sense of organised knowledge implied by *Wissenschaft*, which extends to the humanities.
3. There are of course other viewpoints. Not all those engaged in clinical healthcare are so sympathetic to the programmes and projects of philosophy of medicine as to admit the value of medical humanities study through this particular door. I have elsewhere commended medical humanities to non-philosophical, expressly clinical, audiences; see for instance my ‘Roles for Literature in Medical Education’ (Evans, 2003); ‘Reflections on the Humanities in Medical Education’ (Evans, 2002b); or ‘Medicine, Philosophy and the Medical Humanities’ (Evans, 2002a).

4. The UK’s first Master’s in Medical Humanities, introduced in 1997 at University of Wales Swansea, appeals primarily to mid-career medical professionals. See Evans, M., in Kirklin and Richardson (2001).
5. Reported by Greaves (2001).
6. I am grateful to an anonymous referee for emphasising this.
7. The relation of philosophy of medicine to philosophy of science is an interesting one. Some enquiries within epistemology of medicine could readily be seen as an application of philosophy of science as could some enquiries within the logic of clinical reasoning and diagnosis. However, studies of the metaphysics of embodied experience will be more resistant to being captured in this way; indeed on Toulmin’s (1993) view the centre of gravity of traditional views of philosophy of science is liable to be itself shifted by taking seriously the epistemology of medicine’s objects.
8. See for instance Hampshire and Avery (2001).
9. The Royal College of General Practitioners’ regional Faculties support specific study events involving medical humanities, and the Royal College of Physicians of London has published two volumes of papers on medical humanities including Kirklin and Richardson (2001).
10. Holm (2000). In 2005 the UK Arts and Humanities Research Council also sponsored a workshop at Univ. Cambridge on the human face, as one of a series of workshops exploring medical humanities enquiries.
11. Drawn from Evans (2007).

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## Scientific Contribution

### Medical humanities – arts and humanistic science

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**Abstract.** The nature and scope of medical humanities are under debate. Some regard this field as consisting of those parts of the humanistic sciences that enhance our understanding of clinical practice and of medicine as historical phenomenon. In this article it is argued that aesthetic experience is as crucial to this project as are humanistic studies. To rightly understand what medicine is about we need to acknowledge the equal importance of two modes of understanding, intertwined and mutually reinforcing: the mode of aesthetic imagination and the mode of analytical reflection.

**Key words:** aesthetic experience, imagination, intertwining, understanding

#### Introduction

For several years, there has been an ongoing debate about the scope and the goals of medical humanities. This is often a reliable sign of beginning maturation in a newly established field of study. It is also a sign of health, as such a debate is urgently needed to provide a basis for continuous self-reflection during the further evolution of the field. It may be remembered that it took 10–15 years from the rise of medical ethics in the early 70s to the first substantial signs of a self-critical debate within that area in the mid-80s.

In this article I want to contribute to the exploration of the nature of medical humanities, departing from the assumption that the area involves two related but still different modes of understanding: aesthetic experience, involving emotions and imagination and empathetic identification – and cognitively oriented analysis, involving critical scrutiny, conceptual analysis and historical relativization. It will be argued that however intertwined these modes of understanding often may be, they are nevertheless different in nature and ideally work in a complementary way. It is when we ask ourselves what medicine is about, what its goals are and how they may be reached that these two complementary roads to understanding are needed. Given the all-embracing nature of medicine, penetrating our lives both literally and metaphorically, this is an understanding

that is in no way reserved for health care professionals. Medical humanities may have a particular responsibility in relation to these, but surely the scope of the project is wider than that.

#### Modes of understanding

First some remarks on terminology. There exists by no means a unanimous view on what the concept humanities ought to mean. I here take humanities to be concerned with the human realm, specifically with a view of human beings as intentional creatures searching for meaning, with their both shared and unique life worlds, reaching out for others, trapped in their history and biology but with some paradoxical margin of personal freedom. It is the task of the humanities to explore these conditions, and in doing this they basically employ hermeneutical approaches. The goal is understanding, rather than explanation (even if Dilthey's classical dichotomy is certainly not as clear-cut as it is sometimes assumed to be<sup>1</sup>). It is not unusual to identify humanities with what is otherwise often called the humanistic sciences, that is academic fields of study like history, philosophy, aesthetics, history of literature, history of art, anthropology etc. But the humanities, as I will here view them, involve not only the humanistic sciences but the arts as well (painting, sculpture, dance, novels, poetry, drama, film etc.), to the extent that

these present human beings as acting, choosing and responsible creatures.

What, then, are *the medical humanities*? I propose that medical humanities are those parts of the humanities that are of relevance to the study and practice of medicine. I want to put some stress on the second part of this statement. The goals of medical humanities are indeed both theoretical and practical. Theoretical in that they offer a basis for an analysis and a resulting understanding of what the phenomenon of medicine and health care is about. Practical in that this analysis of course is meant to have, and does already have, consequences for the way health care is practiced, from the very basic laboratory research through the clinical encounter to national health policies. In addition to this, medical humanities have a potential for influencing clinically relevant attitudes, through their capacity to work not only on intellectual capacities and rational reflection but also on emotions and intuitions. It is here we have what I believe to be the most promising and remarkable aspect of medical humanities – the breadth of its invitation and the potentially synergistic characters of the two modes of understanding that constitute their basis.

A comment may be needed on what is here meant by “mode of understanding”. The point made is the rather trivial fact that the attempt to reach understanding of a phenomenon may focus on different aspects and may hence be reached in different ways. We may, for example, say that we understand something when we know how it came about, or what its purpose is, or the human feelings and intentions involved in it, or the consequences of it, or how it is contextually related to other phenomena. All these aspects of understanding may more or less coexist and we may hence think that the more of them that are illuminated, the better we understand. Distinguishing between different modes of understanding would then mean acknowledging that different faculties of our mental repertoire are differently well suited to do this work for us. To understand a mathematical problem may involve certain capacities, to understand why the First World War broke out another combination and to understand a clinical situation a third. A point of departure for the following analysis will be that the richer our understanding is, the better the chances that we reach our goals – whether these be practical (ameliorating suffering) or theoretical (solving an equation).

A mode of understanding is hence a pattern of mental capacities activated in our attempts to come

to grips with a phenomenon, to understand it. Such capacities are usually combined emotional-cognitive. The mathematician can hardly avoid emotions when facing an intriguing problem to solve, and the artist painting a portrait will find cognitive reflection interacting with emotions. However, in general we may conclude that aesthetic experience usually more immediately and directly involves emotions, bringing in parts of our personality that we often keep outside of intellectual analysis. It is reasonable to assume that I get moved and perhaps even upset by seeing a drama of Chekhov, but far less emotionally involved by reading a philosophical essay on the notion of brain death (though this may of course occasionally be upsetting enough). Possibly, I go on to reflect on Chekhov’s drama when my feelings about it have sunk back and left more of curiosity and wish to verbalize and to bring cognitive reflection into my understanding. In this process of “distancing” myself from the immediate experience, of lifting from the particular to a more general level of understanding, one may experience that something is lost, some aesthetic quality that seems hard to capture into rational discourse. The aesthetic experience is not easily “verbalized”, as we all know, but nevertheless real and plausibly very influential on our way of looking at ourselves and the world.

### **The evolution of medical humanities**

Before presenting this argument in more detail, I want to make a short comment on the evolution of medical humanities as a field of study. The present situation of medical humanities naturally reflects its evolution and some of the challenges involved in the further development of the field ought to be understood in light of the impetus that set this project into motion. When the medical ethics boom lost some of its momentum, one of the remedies proposed was a shift of perspective, taking more areas of human study than moral philosophy into account when interpreting medicine. Barry Hoffmaster wrote, somewhat playfully, about ethnography “saving the life of ethics” (Hoffmaster, 1992). This is not to say that medical ethics, however interpreted, became obsolete, or that there were no medical humanities before the 80s and 90s. The point is that medical humanities were by many expected to offer a broader perspective and a widened frame of understanding – and with this the chance to address more aspects of the complex phenomenon of modern scientific medicine. It was

widely accepted that ethical questions in clinical practice are situated in contexts that may require that several perspectives are adopted in order to reach more fruitful results. It was also asserted that ethical deliberation may involve both feeling and intellectual analysis and that hence the humanities may offer a broader base for stimulating such ethical sensitivity.<sup>2</sup>

Hence, an increasing number of persons went looking for answers, or good questions, in history, philosophy, theology, anthropology, narratology and so forth. The result was a sometimes bewildering array of different perspectives. Moreover, not only were what I here want to call the humanistic sciences approached. Together with these, the fine arts increasingly came into focus. Literary texts – novels, short stories, drama, poetry – and the figurative arts were used to enlighten medical students or practicing clinicians. Not seldom it was said that reading novels or looking at paintings – preferably with motives borrowed from the world of diseases – would contribute to the development of the empathy of the clinicians or the doctors or nurses to be. The assumption was that health care workers, especially doctors, must have some sort of counterbalancing force to their scientific training, compensating for risks inherent in the medical gaze. An impersonal, cold and distanced physician, unable to go into a dialog with his patient and relying almost exclusively on technological devices was contrasted with an empathetic person-oriented doctor, who not only knew Beauchamp's and Childress's "four principles" but also had the kind of imaginative, yet critically reflective, attitude to her work that would revive the "art of medicine".

Hence, medical humanities in educational contexts came to be developed as some sort of additional and compensating activity on top of "the real thing", which was of course training in the biomedical sciences. As a result, and also reinforcing this "additional model", there was a general tendency to look at courses in humanities as preferably elective. The resistance against compulsory teaching of medical humanities often took the form of a rejection of the whole idea of having unmotivated students reading philosophical, historical or literary texts, with the assumption that this would rather make things worse. The fact that much of the teaching in the area of biomedicine is both boring and onerous to many students and other categories of health care professionals, but is done because it is seen as indispensable, was not really considered – or dismissed because the

sciences in some peculiar way are expected to be like that, while the humanities "must" be stimulating and creative. Neither was much said about the tacit signals that this unintended but obvious grading of curricular importance sent to students and professionals.

Medical humanities were of course never developed only for education and never only for health care professionals. There was research in what we now call medical humanities long before it was even named and long before it had come into medical schools. The scope of medical humanities is wider than professional development, however important this may be. It is the understanding of medicine in general that is at stake. Like any dominating socio-cultural force, medicine has to be scrutinized from different perspectives and we have good reasons to assume that society at large will benefit from this.<sup>3</sup> If, however, medical humanities as a resource for medical professionals are at the center of interest here, it is because there is still a need to illuminate and bring out more clearly what it is that medical humanities may contribute. If it can be shown that physicians and nurses and other persons involved in the treatment and the care of ill people benefit in different ways from the encounter with medical humanities in the sense here described, this may be of great value in the ongoing reconsideration of what constitutes professional competence in health care.

#### **Additional or integrated?**

The idea of humanities as a balancing field of study in relation to biomedicine may also be called *the compensatory model*. Perhaps, it is more meaningful to talk of compensation than of addition, since it highlights the historical fact that the humanities, as were medical ethics, were brought into the study of medicine as a result of an experienced *lack*. Of what? Probably of what is diffusely called "the human dimension" in medicine, of a visible person "behind" the disease, of an attention to the social and cultural aspects more or less strongly influencing medicine. The triumphs of scientific medicine had allegedly pushed the ill person into the background, in favor of a depersonalized search for biophysiological pathology.<sup>4</sup>

But is compensation enough? Will it do the expected work? If we add to the swelling biomedical curricula some "person oriented" human knowledge, some philosophical ethics, a few novels, call it medical humanities and then throw

this into the oven after the biomedical cake is almost baked – will that really affect the ailments of modern medicine? Will that help us reach the proud goals often mentioned in relation to medical humanities – to humanize medicine, to let biomedical progress coexist with a deep commitment for and recognition of the personal needs and predicaments of the ill person? David Greaves does not hesitate about his answer when he writes that “...medicine cannot be adequately understood within the more traditional framework of medicine as science counterbalanced by the arts. What we then need is an *integrated model* of medical humanities.” (Greaves, 2001) Such a model and such a resulting practice seem, however, to be rather far off. Taking a close look at the special issue of *Academic Medicine* from October 2003, where a rich variety of models are presented, it is hard to avoid the impression that medical humanities as educational programs at most places in the US and in Europe are predominantly exactly *compensatory*.<sup>5</sup> With a considerable simplification the standard model of the medical humanities program at medical schools involves some courses in literature reading, occasionally complemented by a course in creative writing, some philosophical seminars mostly in moral philosophy, courses on death and dying (synthesizing theological, anthropological, psychological and philosophical perspectives), not seldom also a chance to read some medical history (often under themes like “Plagues and peoples” and so forth), more seldom arts courses where visual presentations of illness are in focus. This is often good enough and certainly very ambitious – and, of course, in no way surprising, if we look at the official motivations for developing programs of this sort. That medical humanities would have anything important to say about, and as a result deeply influence, core issues like the disease concept, the diagnostic process, the use of medical technology and other “hard” issues in medicine is not so often acknowledged – or at least only marginally accepted. With a disease concept still heavily relying on biomedical sciences and with a mistaken idea still flourishing that this concept is basically value free, the doctor’s task of diagnosing and treating diseases will result in a medical education and a professional role that looks upon humanities as a sort of “luxury” added, if there is time for it, to the real thing and only externally related to clinical medicine – to compensate for some possible risks that are easily overcome in this way.

### The task of medicine

Why, again, may we conjecture that the humanities are at the very core of the understanding and practice of medicine? What would it mean to integrate humanities into medicine, rather than to add them as a compensation for marginal shortcomings of a still predominantly biomedical project? The answer to this will involve a view on what this practice is about, and this question will now be addressed.

Medicine is the activity that aims at the healing or the amelioration of suffering due to disease and at the prevention of such suffering.<sup>6</sup> Medicine is about bodies and it is about the persons that *are* these bodies. Human individuals suffer, bodies do not. The personal, biographical realm is in this sense prior to the abstracted world of the biomedically “constructed” body.<sup>7</sup> This is, of course, hardly new to anyone involved in this discussion. Actually, perhaps the most influential of all to propose this is Oliver Sacks (1984) who in his stories shows, rather than theoretically argues for, such a way of understanding what medicine is about.<sup>8</sup> Another convincing but perhaps not as influential example is John Berger writing about country doctor John Sassall in *A Fortunate Man* (Berger, 1967).

Philosopher Drew Leder has succinctly captured the point of departure for a medicine that takes human beings as biological and cultural creatures into full account:

Just as the lived body is an intertwining of intentionality and materiality, subject and object, so we would arrive at a medicine of the intertwining. That is, our notions of disease and treatment would always involve a chiasmatic blending of biological and existential terms, whereas these terms are not seen as ultimately opposed, but mutually implicatory and involved in intricate ‘logics’ of exchange. (Leder, 1992)

Stephen Toulmin says basically the same thing, though in other words, in an essay on “clinical judgment and historical reconstruction”:

However, even the generalized principles of the medical art could be learned and exercised only as applied to and embodied in the condition of particular human beings. (...) the proper application of general medical knowledge to individual human beings demands an accurate appreciation of their particular needs and conditions; so that the task of medicine – however “scientific” it may become – remains fully *ethical*. (Toulmin, 1993)

This view of medicine leads me to the following conclusions: The practice of medicine integrates – intertwines, amalgamates – knowledge and experience of the human condition in the broadest possible sense, from understanding cellular systems to approaching unique and sometimes strange life-worlds of ill persons, as well as understanding the socio-cultural forces influencing health and disease. The goal of medicine is to restore health, which means alleviating suffering that is due to disease. This may be accomplished in basically three ways, closely related and almost always intertwined but analytically separable: (1) by applying biomedical knowledge in order to explain pathophysiological processes in the body, manipulating these processes in the wanted direction and relying on results from biostatistical methods to evaluate treatment outcomes; (2) through the attempt to approach a degree of common understanding between physician and patient, necessary both for diagnosis and for treatment decisions and also for the ill person's sense of recognition; in Gadamer's words, the partial fusion of meaning horizons in the clinical encounter (Svenaeus, 1999); (3) by the ongoing critical reflection on the theory and practice of medicine, in order for the conduct of professional medicine not to transmute into smugness and conceit. Key words are for (1) *explanation* of disease through scientific theory and *scientifically based control* of pathological processes and treatment outcomes, for (2) *understanding* of the illness experience through imaginative dialog, and for (3) *conceptual, ethical and historical scrutiny* in order to place the practice of medicine in a larger socio-historical context and rightly evaluating it as such.

The importance of *not* thinking about these three aspects of medical work as fully discrete and separable can hardly be overstated. They are meant to be seen as ideal types, in Max Weber's sense (Poggi, 2006). In practice they intertwine just as Leder and Toulmin write. When, for example, the physician faces the patient with a minor stroke she must of course understand as much as possible about the normal and pathological physiology of cerebral vessels and tissue, as well as about ways of diagnosing, treating and preventing new incidents of the same sort. She must, *at the same time*, be able to approach the experience of just this ill person, what he experiences, what he hopes for and fears, what he is prepared to stand and not stand, which his basic motivating forces in life are. But this would not do if she were not prepared and capable of lifting herself, to some extent and at occasions, out of these perspectives, reflect on

other possible ways of understanding and conceptualizing what is happening, if she were not able to relate this unique case to a broader cultural and historical context, letting her cherished assumptions at least marginally and occasionally meet other modes of understanding.

It is with the two latter tasks that medical humanities are involved. It is not difficult, I think, to see that there might be a tension here. Approaching a person's illness experience, taking some steps towards a shared life world, involves a degree of identification, although very conditional. This seems to be a significantly different challenge from the distancing that the critical analysis involves, however closely intertwined these modes of understanding may sometimes be. Imagination and empathetic openness and involvement are capacities that would be of value in the former task. If the physician constantly keeps relativizing and critically examining the words of his patient, he would lose the crucial personal contact and seem distant and indifferent. If, on the other hand, he does not keep a critical eye on his engagement with the patient, if he lacks both the will and tools to analyze crucial elements of the encounter from a somewhat distanced position, his good intention may be transformed from being beneficial to being dangerous and harmful for his patient. May we perhaps look upon this as a sort of wavering movement, a process of amalgamation, where imaginative participation, involving emotional and aesthetic aspects, intimately interacts with distanced analysis, involving applying abstract concepts and logical deliberation (of course as crucial in the successful accomplishment of diagnosis and therapy). It is when these two modes of understanding coexist and are brought to interact with profound biomedical experience and skill that the full human potential of scientific medical knowledge is actualized.

### **The role of the arts**

Philosophy and history may facilitate conceptual analysis and stringency of thought and provide inspiring perspectives on medical reality. But are the arts – poetry, novels, paintings, drama, film – really of any value to clinical medicine? Are they not rather a sort of pleasant “turning-away-from” reality? Do the arts really give us knowledge of the world; do they really say anything about the essence of clinical work? David Greaves has suggested that medical arts, as he formulates it,

are basically ornamental to the practice of medicine, while medical humanities proper (and I take it that he here means philosophy, history and other humanistic sciences) are at the core of medical practice and hence crucial to the integrated view of medical humanities (Greaves, p. 22). Greaves does not deny that the arts<sup>9</sup> may be beneficial to practitioners but fears that these will go on working with an unchallenged idea of medicine as exclusively biomedical in its nature. I disagree with his position – if I understand it rightly. Acquaintance with the arts in forms appropriate for increasing medical understanding will, I contend, in the long run lead those involved in clinical medicine to question the simplified model of medicine – medicine as exclusively the application of biomedical knowledge – that Greaves so strongly laments. I would even go as far as to say that medical humanities without medical arts may be sterile and unable to influence more deeply our attitudes, just as philosophy without literature loses something of its potential to change our views of the world. This position is the result of my association of aesthetic experience with emotions, and with combined emotive-cognitive reflection – that is with aspects of our personalities that are crucial for our moral position, our apprehension of complex contexts and of ambiguous and paradoxical aspects of reality.

In contrast to Greaves I regard arts in medicine, used as roads to a more nuanced and complex understanding of human conditions and to what illness is, to be at the very core of the project of developing medical humanities. As such, the arts stand in a complicated but fruitful tension to the humanistic sciences. Most of what we do in clinical practice involves – or ought to involve – the two modes of understanding that characterize these areas of knowledge, blended into an intriguing mixture of conceptual analysis, historical relativization, literary imagination, visual perception, ethical reflection, narrative understanding, emotional participation, intellectual distancing...

The question must once again be raised concerning the nature of the two modes of understanding described above. Art is often associated with empathy and imagination. Now, to this one may object that imaginative empathy is far from the only attitude that may characterize our encounter with a work of art. Some novels, for example, rather seem to constantly sabotage the reader's attempts to read for identification. Dependent upon the kind of work and upon the attitude of the person varying degrees of distanced

reflection may accompany the primarily identificatory reading or looking. We may, thus, distinguish between prereflective and reflective elements in the experience of art. On the whole, the prereflective experience is more emotionally dominated while intellectual analysis has a greater chance to get into the reflective phase of art experience. Somewhat simplified, we may conjecture that art evokes emotions that we then, to a greater or lesser degree, reflect on, problematize, scrutinize. Many works of art seem to sabotage a non-reflective approach, like the dramas of Brecht with their capacity for *Verfremdung* – that is, sabotaging attempts to identify with the events and persons of the drama. If this element in, for example, a novel becomes too predominant it will lose its capacity to move the reader, to evoke those emotions that so stimulate and encourage reflection.<sup>10</sup> Or, similarly, if the reader adopts an attitude, a way of reading, that is “hyperactive”, he will risk escaping this rewarding interplay of prereflective identification and reflective analysis.<sup>11</sup>

Of course there are considerable aesthetic elements involved also in the sciences, both humanistic and natural. A degree of empathetic imagination is often part of scientific work.<sup>12</sup> However, the encounter with works of art in most cases predominantly involves identification and imagination, usually directed towards particulars, and only in a second phase reflection on those images and emotions; whereas humanistic sciences primarily involves conceptual abstraction, distanced reflection – admittedly often emotionally textured – and usually also a more universal ambition. My partition is hence by no means clear-cut and the borders between aesthetic imagination and scientific reflection may be less sharp than often assumed, but I insist that it is still valid as an over-all characterization.

### The reading experience

The imaginative immediacy and the strongly emotive texture of the experience of a work of art may hence be transformed into a more or less distanced analysis when we reflect upon, for example, a literary text – especially if this is done in a more or less systematic way. If students of medicine read Lars Gustafsson's (1990) *The Death of a Beekeeper* and then discuss it in groups, perhaps under supervision, the two modes of understanding that characterize medical humanities will potentially unite: imaginative involvement with the

beekeeper's predicament and his problematic life history, his more and more intractable pain, his actions and their consequences in terms of close relations to persons – together with theory-inspired analysis of his motivating forces in psychological and existential terms, of the ethical standard of his important choices in life and his responsibilities to himself and others, of historical factors influencing his social position and hence also his repertoire of choices. This would probably in most cases not be sufficiently reached through the reading experience as such, neither through exclusively historical analysis or philosophical reflection. It is when two modes of understanding unite – the mode of prereflective aesthetic participation during the act of reading and the mode of hermeneutically inspired, distanced intellectual analysis in the following analysis – that a work of art offers its richest contributions to clinical medicine.

Why not “real life” then, why art? Is not the interplay with persons around us, the stories encountered when meeting and listening to living individuals, a road to human understanding far superior to fictive stories? One would easily guess so and of course there is much good to be said for a broad life experience and a keen attention to the stories around us. But returning to Gustafsson's book, the experience of reading about the beekeeper is prone to be richer in complexity and in detail and also in a sense easier to get adequately moved by exactly because it is fictive. Imagine meeting this man at a party. What would he say? What would we learn of him? Or encountering him on a train and having a long conversation with him? What would we learn? Would dislike prevent us from seeing him? Or would, on the contrary, strong positive emotions also prevent a more nuanced understanding? And would the kind of associative reflection on his life, his chances, his dilemmas that the novel inspires really occur?

Martha Nussbaum has perhaps more eloquently than any other philosopher pledged for an alliance between moral philosophy and literature, that is: between critical scrutiny and aesthetic experience. In several of her books she develops the thoughts presented here in much more detail. Her experiences from teaching law students in Chicago led to her to write the book *Poetic Justice*. Among several passages worth quoting at length we find this:

Another way of putting this is that good literature is disturbing in a way that history and social science writing frequently are not. Because it summons powerful emotions, it disconcerts and puzzles. It inspires distrust of conventional pieties

and exacts a frequently painful confrontation with one's own thoughts and intentions. One may be told many things about people in one's own society and yet keep that knowledge at a distance. Literary works that promote identification and emotional reaction cut through those self-protective stratagems, requiring us to see and to respond to many things that may be difficult to confront – and they make this process palatable by giving us pleasure in the very act of confrontation. (Nussbaum, 1995, pp. 5–6)

If Nussbaum is right, and I believe she is, we need to focus on the process of moving on from this emotional confrontation that meeting good literature (or a painting) may give us, and that of course from the beginning involves some cognitive activity, to a personal reflective involvement that opens up possibilities for a widened experience, for moral growth and for a more nuanced knowledge of the world. We need of course also to face a number of intriguing, but certainly not unsolvable, questions about which works of art and which areas of humanistic study ought to be included in medical humanities.

### Concluding remarks

What then, with the integrated view of medical humanities? With such a view and practice of medical humanities, in theory and in practice, it is acknowledged that disease and illness are two aspects of the same coin and that applying the one without the other in our understanding of medicine is meaningless and will prevent medicine from reaching its goals. Integrated medical humanities are then not brought in when the hard sciences have already done most of the work; they are with us all the time as the Siamese twin of biomedical sciences. Integrated medical humanities are ideally taught in close connection to the teaching of biomedicine. The medical intern instructing the students in the art of doing a sternal puncture will, when medical humanities are thus integrated, find it just as natural and inevitable to direct their attention to the anatomy of sternum and underlying structures, to the histology of healthy and diseased bone marrow and potential pathological findings – as to the experiences of the ill person undergoing such a procedure, to ethical aspects of consent to medical interventions, to the history of blood analysis and treatment, to stories of persons living with and dying from hematological diseases.

This is how integrated medical humanities will work. Integration will mean that medical humanities take as their task to contribute to an intertwining of the experiential aspect of “not being well”, often called illness, with the scientifically constructed disease concept, expressed through the language and concepts of biomedical science. This intertwining of the epistemology of science and that of personal biography will not take place if the two modes of understanding described above as central to medical humanities are not accepted as crucial to all clinical work, as well as to the understanding of medicine as a cultural and historical project.

### Notes

1. Dilthey proposed the goal of science to be the explanation of natural phenomena by ways of universal causal forces, such as natural laws. The humanistic sciences, on the other hand, were involved in the understanding of human actions by means of intentions and motivations. This has led certain observers to infer that the sciences are not aiming at understanding – a suggestion that seems blatantly mistaken, as understanding is crucial to all scientific work.
2. The influence of Aristotle was clearly seen in this context, presented for example by Martha Nussbaum in her influential *Love's Knowledge* in 1992.
3. And medicine has been lucky, in this sense, to have been the subject of intelligent and provocative critique, contributing to a thoroughgoing debate about its nature and goals. Excellent examples are Ivan Illich's (1976) *Medical Nemesis*, Susan Sontag's (1979) *Illness as Metaphor* and, lately, James LeFanu's (1999) *The Rise and Fall of Medicine*.
4. This theme is recurrent in medical humanities literature since Paul Ramsey's (1970) *The Patient as a Person*.
5. *Academic Medicine*, October 2003: “The Humanities and Medicine: Reports of 41 U.S., Canadian and International Programs”.
6. We have recently seen a vast and often illuminating literature on this subject. Among the contributions presenting thoughts most worthwhile to pursue are Eric Cassell (1991) and Fredrik Svenaeus (1999).
7. We are reminded for example by Martyn Evans (2001) about the degree of abstraction from our ordinary experience of a lived body involved in the medically perceived and treated body.
8. I consider his *A Leg to Stand On* to be the outstanding example of his capacity to capture the reality of falling ill.
9. I do not here talk of medical arts in their *therapeutic* use – that is, literature, drama, poetry, visual art as therapy for ill persons. It is better not to include these in what we regard as medical humanities, but rather in the field of medical therapeutics.
10. For an extensive discussion of the role of emotions when understanding the world through works of art, see Katarina Elam's *Emotions as a Mode of Understanding*, particularly part III (Elam, 2001).
11. Kevin Vanhoozer distinguishes four basic reader attitudes: “reactive”, with a reader in both cognitive and emotional clinch with the text; “hyperactive”, where the reader escapes the pre-reflective stage of reception to get stuck in a quagmire of analytic interpretation; “inactive”, with an inactive, indifferent reader not responding to the text; and finally the most hopeful attitude, “proactive”, where the reader gives justice to the combined emotional-cognitive content of the text, acting responsibly in relation to the fictional content and “gives the text the best possible chance”. See Vanhoozer (1998, pp. 395–398).
12. The idea of an emotion-free science, distanced and unengaged, may in many instances be misguided, even in the so-called hard sciences. See for example Evelyn Fox Keller's book (1983) about Barbara McClintock.

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## Scientific Contribution

### Medical humanities and philosophy: Is the universe expanding or contracting?

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**Abstract.** The question of whether the universe is expanding or contracting serves as a model for current questions facing the medical humanities. The medical humanities might aptly be described as a metamedical multiverse encompassing many separate universes of discourse, the most prominent of which is probably bioethics. Bioethics, however, is increasingly developing into a new interdisciplinary discipline, and threatens to engulf the other medical humanities, robbing them of their own distinctive contributions to metamedicine. The philosophy of medicine considered as a distinct field of study has suffered as a result. Indeed, consensus on whether the philosophy of medicine even constitutes a legitimate field of study is lacking. This paper presents an argument for the importance of a broad conception of the philosophy of medicine and the central role it should play in organizing and interpreting the various fields of study that make up the metamedical multiverse.

**Key words:** academic disciplines, bioethics, medical humanities, models, philosophy of medicine

#### Introduction

Cosmologists debate the question of whether the universe is expanding or contracting. They have puzzled about an unresolved consequence of the big bang theory known as the flatness problem. At issue is how much matter there is in the universe. If the amount of matter is small enough, the universe will go on expanding forever. On the other hand, if there is a critical amount of matter, gravity will eventually stop the expansion and cause the universe to condense toward a “big crunch,” possibly followed by a re-expansion. In the 1980s, Alan Guth developed his “inflation theory,” which sees the origin of the universe in a tremendously rapid period of expansion in a tremendously short period of time, and there are now several versions of inflation theory. The one developed by Andrei Linde, known as the “bubble theory,” proposes the possibility that other universes, presently unknown, might also have inflated, thus making our universe only one “bubble” in a much vaster “multiverse.” While these “parallel universes” exist simultaneously, the finite nature of the speed of light makes it impossible for us to see into any of these other universes. Even in the midst of this explosion of theories, however, the question of

whether our universe will continue to expand forever or collapse in a “big crunch” remains unanswered because we have no way to predict how much energy the universe contains (Siegfried, 2002, pp. 127–182).

I want to suggest that even though there are obvious limitations to the analogy, this image of a multiverse is an illuminating one for the present state of the medical humanities. “Medical humanities” is a term that is usually taken as a collective for various disciplines that study the human aspects of medicine, as opposed to the technical aspects. It includes such things as philosophy, theology, history, literature, and art, insofar as they are concerned with understanding medicine and medical practice. “Medical humanities” is also sometimes understood in a broader sense to include law, sociology, anthropology, and psychology. Work in the medical humanities seems to be expanding at present, but it is not at all certain whether this expansion will go on indefinitely or whether the enterprise will shrink or even collapse in upon itself. We just do not know how much energy there is in this academic world, and the data from which we might draw such conclusions at times seems as complex as the data from which cosmologists draw their speculation about the universe.

The medical humanities constitute a kind of academic multiverse, although it is a multiverse composed of the academic universes that are the traditional academic disciplines, and hence they interact more than the universes of Linde's bubble theory. What makes these universes cohere as a multiverse is that they share an appreciation of medicine as a human endeavor that reaches beyond its technical and scientific aspects. Their subject might aptly be called "metamedicine," which was the wonderfully descriptive and alliterative original title for the journal *Theoretical Medicine*, lately expanded to *Theoretical Medicine and Bioethics*. This titular evolution is, perhaps, a good indication that the "metamedical multiverse" is indeed expanding.

If we take the medical humanities to be a metamedical multiverse composed of the universes of philosophy, history, literature, etc. insofar as they concern themselves with medicine, there arises the question of how these various universes influence each other. I want to explore some models that describe these influences, and argue that the philosophy of medicine has a central role. Philosophy has always been the discipline that seeks the assumptions behind all human endeavors and the very essence of those endeavors; philosophy attempts to give an integrated account of these endeavors. Thus, philosophy of medicine seems the most likely candidate to serve as an integrating force in metamedicine. But we must also take note of a great gravitational force – some might say a black hole – that sometimes seems to be sucking many other metamedical studies, and even entire universes, into itself: bioethics. I will be particularly interested in the relationship of bioethics and the philosophy of medicine and the question of whether bioethics will ultimately doom philosophy of medicine to be lost in space.

### Medical humanities

The most common understanding of medical humanities takes the field as an attempt to "humanize" scientific medical practice. David Greaves (2001, pp. 15–19), however, finds fault with most approaches to medical humanities because they maintain the traditional separation between medicine as an art and medicine as a science and side with the arts aspect to humanize the science aspect. Greaves (p. 22) distinguishes between medical arts, which attempt to humanize the physician, and medical humanities, which

attempt to humanize medicine. He calls for a new conception of medical humanities that is humanistic in that it brings a "philosophical outlook" to both the science and the art of medicine. Greaves understands "philosophical" not in the restricted sense of philosophy as a field of study, but rather as an attitude of critical reflection. Medical humanities, then, promotes a humanistic perspective that attempts to unite the art and science of medicine.

This is a laudable goal, but what remains at issue is whether it is possible to conceive of medical humanities as a field unified enough to accomplish such a goal. Furthermore, we might well ask whether it is even desirable to conceive of medical humanities as an interdisciplinary field itself, and thus more than a metamedical multiverse of distinct academic universes reflecting on medicine. I have doubts about such conceptions, which will become more evident with some discussion of the notion of interdisciplinary fields and, in particular, bioethics.

### *Interdisciplinary and multidisciplinary fields of study*

It is my contention that medical humanities do not constitute a field of study. Rather, "medical humanities" is a name given to the multiverse consisting of many academic universes that reflect on medicine, in both its theoretical and practical aspects. The medical humanities bring well-established disciplines such as philosophy, literature and history to a critical reflection on medicine.

This is not to say that the various fields that constitute the medical humanities are pure academic disciplines. For instance, the history of medicine is quite well established as a field of study, but it includes a disparate group of members, including both historians and physicians. The question of whether philosophy of medicine constitutes a distinct field has raised considerable controversy not only because it includes practitioners from both medicine and philosophy, but also because there is disagreement about exactly what subject matter constitutes the field.

Although medical humanities all attempt to lend a humanistic perspective to medicine, they do so in diverse ways. One doing a philosophical study of the logic of medical diagnosis, for example, approaches the task in a way that is very different from one studying a short story about a doctor puzzling about making a diagnosis that has important implications for a patient. Both shed light on the process of diagnosis, but the light comes from

quite different directions and is refracted in quite different directions.

That the medical humanities comprise many distinct academic disciplines and fields should not be seen as a liability, for this is precisely what makes the medical humanities such a rich human endeavor. It does, however, contribute to analytical complexity and controversy about how the parts relate to the whole.

When members of various disciplines meet to address topics of mutual interest, one might well ask how they see what they are doing. In *The Birth of Bioethics*, Albert Jonsen (1998, pp. 24–26) discusses the origin of the now superseded Society for Health and Human Values. The society was focused not only on ethical issues in medicine, but on the medical humanities, which included art, philosophy, history and literature. At the time it held its first annual meeting in 1970, it served as a meeting place for some “otherwise lonely figures,” those few people who came from the disciplines of theology, philosophy, literature and art, and were now teaching in medical schools.

That society always struck me as multidisciplinary. That is, people from the various academic disciplines and the various health care professions came together to talk about their common interest – how to keep a human focus on an increasingly technological practice of medicine. Some people may have called themselves bioethicists because bioethics is what they did for most of the day, but they still identified in a more fundamental sense with their training as theologians, philosophers, physicians, nurses, etc. That sense of multidisciplinary cooperation is increasingly being supplanted by interdisciplinarity. Renée Fox and Judith Swazey (2005, p. 367) call bioethics “a multidisciplinary field with interdisciplinary aspirations.” The distinction I am making here, which may not be exactly the same as that of Fox and Swazey, is this: a multidisciplinary endeavor is one in which people from several disciplines come together to talk about a topic of common interest. An interdisciplinary endeavor is one in which the endeavor itself is seen as growing from one comprising several distinct disciplines into a new “interdisciplinary discipline.” In other words, multidisciplinary is the meeting of people from different disciplines, who all retain their own sense of working in their own disciplines, while interdisciplinarity requires that each person be versed in several disciplines.

Evans and Macnaughton (2004, pp. 1–2) define a discipline as “a self-conscious field of sustained,

systematic inquiry with its own distinguishable subject matter, questions, and methods.” Interdisciplinarity, then, is the engagement of disciplines with subject matter that “somehow both straddles the disciplines and falls between them.” They suggest that the most important characteristic of interdisciplinarity is *emergence*. That is, particular problems and their solutions become evident, or emerge, only in the interaction of different disciplines, not within the disciplines by themselves. Furthermore, the participants that begin in different disciplines begin to share each other’s metaphors.

My contention is that medical humanities is losing its multidisciplinary focus and moving more and more toward becoming interdisciplinary. This is coming about, I believe, because of the increasing acceptance of bioethics as a new discipline itself, an “interdisciplinary discipline.” Bioethics, with its self-contained theoretical debates about such new ethical theories as “principlism,” matters of informed consent arising from legal cases, and incorporation of principles such as double effect from moral theology, has provided a new *lingua franca* for medical humanities. Bioethics engulfs other disciplines, especially the philosophy of medicine, into itself. To see how this model has come to be so prominent, it will be helpful first to look at the development of bioethics as a new discipline.

### Bioethics

Most observers trace the origins of bioethics back to about 1970. Of course, reflection on the ethics of medicine goes back at least to the time of Hippocrates, some quite specific ethical thought developed around medical issues in the Middle Ages, and medical ethics was developed systematically in the early nineteenth century, but present-day bioethics is seen to be different. Albert Jonsen (1998, pp. 3–33) finds the “birth of bioethics” rooted in the rapid changes in medicine following World War II. This prompted several conferences during the 1960s to reflect on the moral dimensions of these changes, followed by the establishment of two centers, the Hastings Center, outside of New York, and the Kennedy Institute of Ethics at Georgetown University in Washington. These centers provided a permanent home for discussions about the burgeoning questions of bioethics. A third organization, the previously mentioned Society for Health and Human Values, bolstered the development

of bioethics as a discipline by instituting a series of annual meetings of interested persons.

Warren Reich (1994, 1995) has argued that the word “bioethics” came into being independently at about the same time in two places, but with slightly different understandings. At the University of Wisconsin, Van Rensselaer Potter used the word to focus on a discipline that would study evolutionary and cultural adaptation in the context of the new biology in order to enrich human lives and prolong the survival of the human species. This conception of bioethics would embrace environmental concerns as well as medical ones. It was, in this sense, a holistic view. Potter regarded bioethics to be involved in “the search for wisdom,” that is, for knowledge about what would enable good judgment about what was valuable for survival.

At Georgetown, on the other hand, André Hellegers was using the word to designate an academic discipline that would also focus on the interaction of science and ethics, but more narrowly on the realm of health care. The Georgetown model would seek to “resolve moral problems in three areas: (1) the rights and duties of patients and health professionals; (2) the rights and duties of research subjects and researchers; and (3) the formulation of public policy guidelines for clinical care and biomedical research” (Reich, 1995, p. 20). Reich (1995, p. 30) concludes that the word “bioethics” was what gave rise to the field of bioethics in part because “the word itself symbolized and stimulated an unprecedented interaction of biological, medical, technological, ethical, and social problems and methods of thinking.”

Albert Jonsen (1998, pp. 327–342) argues that any discipline is characterized by the presence of a central theory, or sometimes alternative theories, principles, and a methodology to order, analyze, and evaluate the discipline’s content. Bioethics has this to the extent that it has been formed into a body of knowledge that can be taught, and while it does have some elements of emerging theory, it is still not a discipline with any universally agreed upon methodology. As Jonsen (1998, pp. 342–344) says, bioethics is a “*mélange* of disciplines,” including philosophy, theology, law, social sciences, and now more and more the arts and literature.

But Jonsen (1998, p. 346) has a further insight that is illuminating: he says that bioethics might well be considered a “demi-discipline.” That is, only half of bioethics is like ordinary academic disciplines. The other half is a public discourse involving people of all sorts and professionals of all

sorts arguing about bioethics, teaching it, and struggling to make practical decisions about how to deal with suffering. Bioethics, then, is a discipline unlike other purely academic disciplines, and more like a professional endeavor. From its earliest days, bioethics was shaped by the realization that its focus would be to help physicians to make hard decisions. It would have to move out of the ivory tower of academe and become as much a profession as an academic discipline. More than thirty years ago, Daniel Callahan (1973, p. 73) concluded his discussion of bioethics as a discipline: “The discipline of bioethics should be so designed, and its practitioners so trained, that it will directly – at whatever cost to disciplinary elegance – serve those physicians and biologists whose positions demand that they make the practical decisions.”

Bioethics, then, has grown past its academic origins, if, indeed, its origins were academic. It has become, as Carl Elliott (2005, p. 380) puts it, “a self-contained, semiprofessional entity whose place in the bureaucratic structures that house it has become distinct – both from the traditional academic disciplines from which it emerged and from the clinical disciplines that it has sometimes aspired to resemble.” As a result, it has become possible to work as a bioethicist without necessarily working as a professor, physician, or anything else. The bioethicist has come to garner “a certain amount of deference within the institution,” dispensing ethical advice that many people working in the hospital feel they cannot ignore.

Judith Andre (1997, pp. 161–165), a philosopher by training but now engaged in bioethics, reflects upon bioethics precisely as a practice. By “practice,” Andre means something like Alasdair MacIntyre’s notion, developed in his book, *After Virtue*. As a practice or near-practice, Andre argues, bioethics should be evaluated not only for its scholarship, but more broadly for its practical impact. Does bioethics make the world a better place for the sick, and indeed for all of us? Andre argues that bioethics is not a subfield of philosophy because bioethics does not simply supply philosophical insights to health care. To be a practitioner of bioethics demands that one master a body of scholarly knowledge specific to bioethics, but also that one develop “interpersonal and institutional skills” that are necessary to communicate with people from a range of disciplines and walks of life. Andre’s description is an apt one for what has become known as clinical bioethics. Indeed, interpersonal skills are probably more important than scholarly knowledge when it comes to

negotiating conflicts between family members. But Andre's comments only serve to confirm Jonsen's characterization of bioethics as a demi-discipline.

The term "bioethics" may have been born in the United States, but the practices of bioethics are engaged in throughout the world. Culture does, of course, shape discourse. Henk ten Have (2000, pp. 28–31) has noted that while some southern European countries have maintained a stronger emphasis on traditional medical ethics as "medical deontology," i.e., codes of conduct that are mixtures of ordinary moral rules, professional codes of conduct and rules of etiquette, northwestern European countries and the United States have emphasized problems in the doctor-patient relationship and moral issues created by the health care system, as well as public policy issues resulting from biomedical advances and research. Academic culture also shapes bioethical discourse. The different philosophical methodologies in the Anglo-American academy and in Continental Europe have also shaped the discourse differently, with Americans talking largely about justice, for example, while many in Europe focus on the notion of solidarity.

This diversity raises the important question of how different discourses and disciplines shape the universe of bioethics, and some scholars have been at work trying to analyze the situation. Edmund Pellegrino (1997, pp. 11–19) has described five models of how the disciplines that contribute to bioethics relate to one another. In the *traditional model*, ethics is taken as a philosophical discipline and bioethics is seen as a branch of philosophy. He sees this as closest to the "Georgetown model," as described by Warren Reich. The problem with this model, as Pellegrino points out, is that it is too narrowly conceived and risks missing the insights that the various other humanities can contribute to bioethics.

The *antiphilosophical model*, by contrast, reflects the antipathy of many both within philosophy and outside it to philosophical ethics. It tries to banish philosophy from bioethics altogether and replace it with one of the other disciplines. Pellegrino rightly worries that ethics without a philosophical basis will be reduced to "a species of moral gnosticism or intuitionism," or worse, "moral nihilism and relativism."

The *process model* is a procedural enterprise that "evades the conceptual issues." It emphasizes only the ways in which people go about trying to resolve moral issues. Thus it rejects identification of bioethics with any discipline and instead sees bioethics as a method for deliberation and

decision-making. The process of collaborative deliberation is clearly necessary for bioethics, and Pellegrino recognizes this. But as he rightly points out, this is not enough. The purpose of moral reflection is "right and good conduct," and this will not necessarily come from process alone. The process itself must be subjected to critical analysis. Philosophy is the obvious discipline from which to conduct this critical analysis, but historical, psychological, and even scientific analysis may also play roles.

The *eclectic-syncretic model* corresponds in many ways to Potter's "Wisconsin model" of bioethics. Eclecticism recognizes merit in many different disciplines and moral viewpoints and selects from each what it sees as useful. Syncretism then tries to resolve the differences and fuse what it has chosen into a new system. This is, as we have seen, one of the hallmarks of interdisciplinarity. The general problem with this model, as Pellegrino recognizes, is that it robs each discipline of its specific contribution to the bioethical discourse. Ethics interacts with biology, with literature, with the law, with the social sciences, and with other disciplines to create the interdisciplinary bioethics. One prominent incarnation of the eclectic-syncretic model in today's medical humanities is the interaction of literature and ethics. Literature has much to contribute to our understanding of the human condition and of good and evil. It is especially important in its ability to evoke in us emotional responses to ethical demands. However, Pellegrino is right in pointing out that the rich moral content of literature does not confer any epistemological status on literature. As he says, "fictive characters are fictions." Literature can inspire us to be good; but literature can also inspire us to be bad. On its own literature cannot give the type of moral sanction and "complete account" of the moral life that is the very essence of moral philosophy.<sup>1</sup>

Finally, the *ecumenical model* allows philosophical ethics to retain its traditional identity, but also allows dialogue with literature, anthropology, history and evolutionary biology, all of which retain their own distinctive identities. All of these disciplines study the moral life, but each does so from a different perspective. These differences are precisely what make the bioethical dialogue so rich. The non-philosophical disciplines aptly describe the complexity, the context and the psycho-social aspects of moral behavior. Any ethical analysis must take these factors into account. But it is philosophy that has the power to examine "those conceptual elements and principles that transcend

detail.” Thus, the ecumenical model makes bioethics closest to ethics traditionally considered, but enriches it by drawing in a broader range of human experience and reflection.

I think that Pellegrino’s ecumenical model for bioethics is moving in the right direction. The medical humanities enrich bioethics greatly in the ecumenical model, yet philosophy retains a central position among the medical humanities, because it is the discipline that is rightly concerned with critical analysis of the moral claims and methodologies of other related disciplines. I would like to move even more, however, toward a model in which the philosophy of medicine has a central place in the metamedical multiverse. Thus, although the philosophy of medicine can be seen as a universe of discourse itself, it would also be the organizing force for the entire metamedical multiverse, including the universes beyond bioethics.

### Philosophy of medicine

Henk ten Have (1997, pp. 105–106) has argued that the era in which bioethics was born and blossomed is also characterized by the virtual invisibility of the philosophy of medicine as a theoretical and practical endeavor. He attributes this invisibility to three interrelated phenomena. The first is the “ethicalization” of the philosophy of medicine. Instead of examining the range of philosophical issues raised by medicine, focus is increasingly put on ethical issues by people who “have renamed themselves ‘bioethicists.’” The second is the “technicalization” of ethics. That is, bioethics is now seen as an autonomous discipline aimed at solving practical problems; it is no longer adequately characterized as moral philosophy. The third phenomenon is the anti-realism that is fostered by the stress of privatization, relativism and proceduralism. This is characteristic not only of bioethics, but more generally of post-modernism and in particular the social constructivism that is so prominent in science and technology studies. This is all in general agreement with the way I have characterized bioethics. I also concur with ten Have’s (2000, p. 31) call for a “broader philosophical framework” for bioethics in order to connect the “internal morality” of medicine with the “external morality” of the social, cultural and religious traditions in which medicine is practiced.

Ten Have (1997, pp. 111–113) finds the origins of the philosophy of medicine in the nineteenth century and coming from a reinterpretation not

only of medicine but also of philosophy. This was the time of the emergence of an organized medical profession, which could claim authority because of its scientific basis. But at the same time, philosophy also began looking to science for methodological and theoretical models for philosophical study itself. Thus, by the end of the 19th century, philosophers gave up the quest of constructing grand idealistic systems to explain medical reality. Instead, they shifted their attention to philosophical interpretation of the practices of medicine. Philosophy of medicine changed from a discipline offering alternative and competing theories of medicine, to a meta-discipline. Philosophy of medicine did not lose its connection with philosophy in general, however. The prominent Polish school of philosophy of medicine, for example, identified itself as Polish analytical philosophy and was particularly interested in clarification of language, logic, and epistemology. The Polish philosophers concerned themselves with analyzing very particular problems in great detail rather than constructing grand philosophical systems (ten Have, 1997, pp. 113–116).

Looking at the conceptual structures of philosophy of medicine over the past 100 years, ten Have (1997, pp. 116–119) identifies three major traditions. The *epistemological tradition* grew out of the characterization of medicine as a natural science and its increasing specialization. The theory and practice of medicine became radically separated, and the need for synthesis became a fundamental epistemological problem for the philosophy of medicine. Two epistemological strategies developed. One focused on organizing knowledge by focusing on rigorous methodology. The other focused not on methodologies that could produce objectivity and precision, but rather on appreciating the subjectivity of the knowing subject. The latter recognized that medicine was concerned more with acting than with knowing. The *anthropological tradition* predominated in Germany and the Netherlands from about 1930 until 1960. It emphasized the subjectivity not only of the knowing and acting physician, but also of the patient. Medicine is unique because it attends to the patient as a person. The *ethical tradition* has predominated since the 1960s.

All three of these perspectives should be included in contemporary philosophy of medicine. As ten Have (1997, pp. 119–120) recognizes, medical practice is embedded in society and culture, and so the essential nature of medical practice cannot be understood by the study of medical

science in isolation. This, ten Have claims, has two effects. First, it has changed the relationship between medicine and philosophy. Because medical practice is so directed by social influences and cultural values, it is no longer the province purely of physicians doing meta-reflection on their own practices. Second, medical practice cannot be understood without understanding the cultural values in which it exists. The question for philosophy of medicine is not simply one of what we know, but of what we want to do with our knowledge. For this, the epistemological, anthropological, and ethical traditions in the philosophy of medicine are all necessary.

How these perspectives are organized in the philosophy of medicine has become a matter of academic debate, however. This debate relates directly to the question of what is included in the philosophy of medicine universe – and whether it is expanding to be more inclusive, or contracting to be more exclusive.

#### *The narrow view*

Edmund Pellegrino represents a notable instance of a narrow view of the philosophy of medicine. He and philosopher David Thomasma proposed three ways in which philosophy and medicine interact (Pellegrino and Thomasma 1981, pp. 28–30). (1) Philosophy *and* medicine has to do with “mutual considerations by medicine and philosophy of problems common to both.” For example, the mind-body problem set up by Descartes is an important problem for philosophers of mind, metaphysicians and epistemologists, but it is also an important concern for philosophers of medicine, who might have very different views of the problem itself stemming from particular concerns of medicine or medical ethics. In this model, philosophy and medicine address a common topic, but they remain independent disciplines in particular interests and methodologies. (2) Philosophy *in* medicine refers to the “application of the traditional tools of philosophy – critical reflection, dialectical reasoning, uncovering of value and purpose, or asking first-order questions – to some medically defined problem.”<sup>2</sup> In other words, this model sees the contributions that the discipline of philosophy has made to critical thinking, framing questions, and other basic work of philosophy itself, and simply applies these methods to issues in medicine. (3) Philosophy *of* medicine is concerned specifically with the meaning of clinical medicine. Philosophy of medicine examines the conceptual

foundations and ideologies of the clinical encounter of doctor and patient; thus, it really tries to provide a foundation for medical ethics. In a later paper, Pellegrino added a fourth category – medical philosophy – which is more literary than philosophical. This includes the informal or literary reflections of physicians on their clinical experience (Pellegrino, 1986, 1998). Essays of William Osler or short stories of William Carlos Williams would count as medical philosophy.

Philosophy of medicine, for Pellegrino, then, is restricted to the third model. The first model might take purely epistemological questions in medical research to be outside philosophy of medicine. On this account, such questions are more properly questions of philosophy of science or epistemology. These may have great importance for the practice of medicine, but they are not properly philosophy of medicine unless they directly contribute to the clinical encounter of doctor and patient. The second model is of interest only in the recognition that philosophy has provided methods for clear thinking; their application in medicine is important, but no more important than clear thinking in any facet of human life. The fourth model, medical philosophy, is more akin to the medical humanities in general. Philosophy of medicine proper, for Pellegrino (1998, p. 327), is concerned only with what is “peculiar to the human encounter with health, illness, disease, death, and the desire for prevention and healing.” Philosophical concepts are studied only insofar as they relate to the human encounter with somatic or psychological well-being and dysfunction.

Arthur Caplan also sees philosophy of medicine in a narrow sense, albeit a very different one. In actually arguing that the philosophy of medicine does not exist, Caplan (1992) presents a narrow view. Referring to an early work of Edmund Pellegrino, Caplan distinguished philosophy *and* medicine from philosophy *in* medicine. The former includes medical ethics, bioethics, health policy, and medical aesthetics. An example of the latter is the study of professional codes by those in bioethics. But philosophy *of* medicine, for Caplan (1992, p. 69) is “the study of epistemological, metaphysical and methodological dimensions of medicine; therapeutic and experimental; diagnostic, therapeutic, and palliative.” Caplan states that this is a stipulative definition. We can, of course, organize our pursuit of knowledge in any way we see fit, but the question is why we should accept this particular stipulation. Caplan’s understanding of philosophy of medicine at first appears to be quite broad, but it really is not,

for its primary intent is apparently to exclude much of what others consider important to the philosophy of medicine. It is curious that it is limited to epistemological, metaphysical and methodological dimensions. Why should the philosophy of medicine not include aesthetic and ethical dimensions, when aesthetics and ethics are clearly part of the philosophical universe? Caplan seems to want to limit the philosophy of medicine to just those sorts of questions that the philosophy of science addresses. In fact, even in the argument against the existence of the philosophy of medicine, Caplan (1992, pp. 69–70) slips in this statement: “In short, the philosophy of medicine is a sub-discipline of the philosophy of science. Thus, its primary focus is epistemological not ethical, legal, aesthetic or historical.”

A reasonable concern that both Caplan and Pellegrino have is in trying to limit the field so that it is not unnecessarily broad. While Pellegrino would narrow the focus to the clinical encounter, Caplan would narrow the focus to medical science. This latter strategy, however, narrows the focus too much. Certainly, part of the philosophy of medicine must concentrate on the issues that Caplan mentions. However, understanding aesthetics is as important to an analysis of plastic surgery as understanding epistemology is to an analysis of pathology and laboratory medicine. Both of these specialties are part of medicine. So, if Caplan’s claim that epistemology should be a part of philosophy of medicine is correct, then aesthetics should also be a part of philosophy of medicine.

#### *The broad view*

A broader view of the philosophy of medicine is the one outlined by Schaffner and Engelhardt (1998). I take this broad view to be closer to what those who see themselves engaged in the philosophy of medicine are actually doing. On this account, philosophy of medicine is defined as “encompassing those issues in epistemology, axiology, logic, methodology and metaphysics generated by or related to medicine.” The broadest conception includes medical ethics, although the authors recognize that this has become such a large topic that they do not specifically include it in their article. Elements of the philosophy of medicine that they do discuss include models of medicine, such as the narrow biomedical model or the broader biopsychosocial model of George Engel. Concepts of health and disease have been a “defining problem” for contemporary (and classical) philosophy of medicine. Whether these concepts

are value-laden or not has been a source of ongoing debate. In addition, recent advances in molecular genetics challenge older views of normality and pathology. Investigations into the logic of diagnosis, prognosis and evaluation of therapies began in the 1950s and were extensively developed in the ensuing decades. Artificial intelligence programs led to computer-assisted diagnosis, and this became a source of rich philosophical discussion. Philosophical discussion has also focused on causation of disease and evaluation of therapies.

In fact, even those who hold a narrower view of the philosophy of medicine would endorse the importance of all the matters included in the broad view of the philosophy of medicine. Pellegrino’s own work has touched on causality, logic and the mind-body relationship. These issues are taken to be important only insofar as they lay a foundation for medical practice and medical ethics, however. On the other hand, the broad view takes all these matters, including medical ethics itself, as part of the philosophy of medicine. Philosophy of medicine does contribute importantly to medical practice, but it goes beyond this in trying to understand theory as well.

#### **Situating the discipline**

As is the case with trying to understand the structure of the physical universe, the way one sees, or does not see, the philosophy of medicine in the metamedical multiverse depends to a great extent on how one interprets the data. Of course, how one interprets the data also is influenced by the way one sees the situation with regard to philosophy of medicine. The question how the philosophy of medicine is related to other fields was advanced by Arthur Caplan’s paper (1992) arguing that the philosophy of medicine does not exist as a field. Even though there has been no diminution, and indeed a significant expansion, of scholarship in what appears to be philosophy of medicine in the nearly 15 years since Caplan’s paper was published, the philosophy of medicine still struggles for recognition in the immense shadow being thrown by bioethics. In fact, Caplan has always recognized the importance of the philosophy of medicine, and part of the momentum that drove his paper was the recognition that the philosophy of medicine is sorely needed not only by bioethics, but also by the philosophy of science and by medicine itself.

Vic Velanovich (1994) argued that, even twelve years ago, philosophy of medicine had all the

characteristics of a developing field, even according to Caplan's criteria. The most problematic area, then and now, is the integration of the field into some "cognate areas of inquiry." Velanovich admitted that this was the most underdeveloped area, but drew on John Dewey to argue that the logical forms that govern a field of inquiry are developed as the inquiry itself proceeds (Velanovich, 1994, pp. 78–79). Thus, he admitted that Caplan's assessment of the state of the field may have been right at the time, but that the proper connections may emerge.

Twelve years later, philosophy of medicine activities are as robust as ever, yet as a field, it still seems to wander, not part of philosophy and not part of medicine, yet studied with great interest by members of both disciplines. Indeed, Caplan (2006) has recently argued that bioethics is an insufficient remedy for what ails contemporary medicine. He maintains that medicine needs to know what its methods are for dealing with bias and fraud so that it can resist the pressures put on it by "politics, money, ambition and greed." This is fundamentally an epistemological problem, and Caplan laments the fact that few physicians have any sophisticated knowledge of the philosophy of science or the philosophy of medicine. Philosophy of medicine may still not be a field, but Caplan obviously believes it is essential, at least in the narrow sense that he conceives it.

A related problem in defining philosophy of medicine as a field is figuring out exactly who is doing it. In a response to Caplan, Henrik Wulff (1992, pp. 79–81) distinguished several groups involved in matters pertaining to the philosophy of medicine. There are professional philosophers who have become interested in medical matters, physicians whose main interest has turned to philosophy, professional philosophers who have become very well versed in medicine, medical professionals who are also trained in philosophy, and medical professionals who devote themselves to medical practice. It is this last category, Wulff argues, that plays an important role in formulating problems for the philosophy of medicine. Wulff (1992, pp. 83–85) argues that Caplan fails to see the existence of the philosophy of medicine because he is looking at it from the perspective of a professional philosopher. This seems right, for philosophy has been reluctant to add the philosophy of medicine to its recognized list of sub-fields. However, Wulff (1992, p. 85) claims that philosophy of medicine is a "philosophical activity" that is "closely linked to the main trends of contemporary medical thinking."

Because it "serves the same goal as the rest of medicine, philosophy of medicine should be seen as an "emerging (or reemerging) medical discipline." The trouble here is that the practice of medicine, a practical pursuit, is quite different from the practice of metamedicine, by definition a reflective pursuit. It seems much less likely that the medical profession will recognize the philosophy of medicine as a sub-discipline than philosophers will, for philosophy of medicine is much more like philosophy than medicine. To conclude, I would like to suggest a model of metamedicine that holds a broad view of the philosophy of medicine at its center.

### Mapping the metamedical multiverse

Philosophy was traditionally regarded as the "queen of the sciences," standing in a unique place to establish foundations of knowledge and ultimate truths. Although those goals may no longer seem realistic, and although professional philosophy itself has sometimes wandered far from them, philosophy still occupies a central position inasmuch as it seeks the assumptions behind and essence of all human endeavors and seeks to integrate them. In this sense, philosophy of medicine might serve as the central metamedical discipline, reflecting upon and integrating the various disciplines that reflect on the science and art of medicine.

Van Leeuwen and Kimsma (1997, p. 100) rightly point out that medicine is both more than a science and less than a science. It is more than a science because it does not restrict itself to formulation of theories that hold under carefully circumscribed conditions; it is less than a science because it is confronted by the need to act even in the face of an uncertainty that is characteristic of medicine. Physicians bring to bear several different kinds of skills and knowledge on real problems, thus instituting a "medical discursive account of the patient's situation" (Van Leeuwen and Kimsma, 1997, p. 102). I believe that they are right in saying that philosophy, and especially European philosophy, provides crucial insights necessary to understand medical practice. If anything, providing such crucial insights is what makes philosophy of medicine distinctive, and in a sense, confirms Pellegrino's insistence that the clinical encounter is at the heart of the philosophy of medicine.

Specialization is obviously necessary, in metamedicine as well as in medicine, for understanding all

the aspects of such a complex practice is beyond any one individual or discipline. Indeed, Robert Neville (1974) argues that this ideal is impossible because the disciplines inhabit what he calls “different worlds.” Each discipline selects elements as either relevant or irrelevant to the model of that particular discipline; the discipline then takes its own explanatory system to apply to the world as a whole and not just part of it. This allows the scientist, for example, to see science as the only discipline worthy of explaining the way the world is, with all other disciplines merely offering subjective opinions not worthy of being called knowledge. Nonetheless, Neville (1974, pp. 63–64) suggests that philosophy, which aims to cultivate the “richest possible experience” of the world, might serve the role of integration of knowledge by translating what those in the various disciplines are saying into an “integrating cosmology.” Of course, these cosmologies would be only hypothetical, but they could be judged according to such values as comprehensiveness, ability to specify the terms of the various disciplines, applicability to the whole of experience, and internal consistency and coherence. This approach would be committed not so much to finding truth, but rather to providing a common language for various matters, theoretical and practical, arising from all the disciplines.

Thus, I would like to suggest an alternative model for our metamedical multiverse. The model that sees the medical humanities as a broad family containing the various disciplines is what, at first glance, seems obvious. Within the medical humanities, the various disciplines such as bioethics, philosophy, art, literature, and history of medicine, all inform one another to some extent, but remain worlds of their own, hence retaining their individual identities as disciplines. An alternative model, the bioethics model, tries to incorporate all the various disciplines within it to create a new interdisciplinary discipline called bioethics. The model I am suggesting is one inspired by Cardinal John Henry Newman. Newman (1996, p. 45) argues that all knowledge forms one whole that can be separated only by abstraction. All disciplines have a bearing on one another. For Newman, it belongs to philosophy as the “science of sciences” to comprehend “the bearings of one science on another, and the use of each to each, and the location and limitation and adjustment and due appreciation of them all, one with another.” In a sense, it is philosophy in this sense (although not necessarily in the sense of professional philosophy as it is practiced today) that is the genuinely interdisciplinary field.

This model, somewhat analogous to Pellegrino’s ecumenical model of bioethics, sees the philosophy

of medicine as the core discipline, but not in the sense that bioethics tries to ingest all other disciplines. Rather, philosophy of medicine becomes the common language for all the medical humanities. I believe that taking philosophy of medicine, rather than bioethics, as central will benefit all the medical humanities by providing a broader foundation for analysis of this very complex realm of activity. Making the metaphysical, epistemological and aesthetic aspects of ethical decisions more prominent would provide for a much richer ethical discourse than is currently being fostered by the professionalization of bioethics. Bioethics as a practical endeavor is undoubtedly important, but it could be more.

This necessarily demands that philosophy of medicine be considered very broadly. It cannot just be a subset of the philosophy of science that looks at epistemological, metaphysical and methodological facets of medicine, as suggested by Caplan. Certainly these elements will be part of this broad philosophy of medicine, but they will not constitute the whole of it. Philosophy itself is a broad field – so broad, some might say, that it has ceased being one field. Nonetheless, I am suggesting a return to the roots of philosophy. That view is the one that gave rise to awarding the degree of doctor of philosophy to people who have studied in all sorts of fields, the humanities and the sciences. Thus, philosophy of medicine would offer reflection not only on the traditional philosophical problems inherent in medicine, but also on all of the medical sciences and humanities, and medical practice as well. I am suggesting neither a philosophical imperialism, nor that only professional philosophers will be capable of doing philosophy of medicine. I am only suggesting that philosophical thought about all the medical humanities and sciences offers the best hope at integrating a very broad field of scholarship and enabling at least some communication in a metamedical multiverse that is now characterized either by separate bubble universes that have much trouble seeing into other universes, or worse, by one big bioethical bubble.

## Notes

1. This is not to say that bioethics must give a complete account of the moral life. Giving such an account is, however, just what moral philosophy tries to do. Martha Nussbaum (1990, pp. 138–143) has argued that traditional moral philosophy, or ethical theory, lacks the power to express all moral truths, and that literature is important in conveying some of these truths.

She thus distinguishes between ethical theory and moral philosophy, the latter being a more inclusive term, which would include both traditional ethical theory and literature (Nussbaum, 1990, p. 169, n. 2). I do not doubt the power of literature to convey truths in a way that abstract ethical theory cannot. However, it remains a fundamentally philosophical task to judge that what is being conveyed in the literature is indeed a moral truth.

- It might seem that philosophical reflection on medicine constitutes “second order” reflection. But apparently the point is that in the philosophy *in* medicine model, first order philosophical questions are applied to medicine; it is only in the process of applying the first order questions that the reflection becomes “second order.”

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## **Part II**

### **Philosophy of Technology:**

#### **Basic Concepts and Implications for Medicine**

# What Is Technology? Defining or Characterizing Technology

## Why Bother with Definitions?

Many students, in my experience, especially in the natural sciences, are impatient with disputes about definitions. They are often called “merely semantic” and may seem hairsplitting. Indeed, they are semantic, in that they deal with meaning, but they are hardly trivial. Many apparently substantive disagreements really stem from the disputants having two different definitions of what is being discussed, say religion, but not being aware of it. Often people think that definitions are purely arbitrary; it means that effort need not be wasted on choosing among opposing or alternative definitions. This is itself based on one view of definition, but it is not the only one. We shall learn something about philosophy by seeing the different sorts of definitions that people have used and their connection to differing philosophical views.

Looking at the alternative definitions of technology shows something about the alternative kinds of definition and also about the characterization of technology. Even if one doesn’t find a final definition on which everyone can agree, an investigation of the definition of technology shows us the range of things that can count as technology and some of the borderline cases where people differ on whether something should be counted as technology or not. Even an unsuccessful search for a best definition helps us to explore the layout of the area we are investigating.

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As mentioned above, the major theorists of technology of the first two-thirds of the twentieth century believed that a universal, essential definition of technology could be given. A number of recent theorists, such as Don Ihde, Andrew Feenberg, and others, believe, in contrast, that there is not an essence or single defining characteristic of technology, and that searching for an essential definition is unproductive.

### Guidelines for Definitions

Some general guidelines for definition are the following:

- 1 A definition should not be too broad or narrow. (That is, the definition should not include things we would not designate by the word we are defining, and the definition should not be so restricted as to exclude things that should fall under the term defined.)
- 2 A definition should not be circular. (For instance, we shouldn't define "technology" as "anything technological" and then define "technological" as "anything pertaining to technology.")
- 3 A definition should not use figurative language or metaphors.
- 4 A definition should not be solely negative but should be in positive terms. (A purely negative definition in most cases would not sufficiently limit the range of application of the term. A definition by contrast has to assume that the hearer knows the contrasting or opposite term.)

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An example of defining technology in a too narrow manner is the common contemporary tendency to mean by “technology” solely computers and cell phones, leaving out all of machine technology, let alone other technology. A case of defining technology in a manner that may be too broad is B. F. Skinner’s inclusion of all human activity in technology. Skinner understands human activity as being conditioned and self-conditioning. For Skinner conditioning is considered to be behavioral technology. A related move is the general inclusion of “psychological technology” as part of the motivational apparatus of technological activities, such as chanting in hunter-gatherer societies, or various political beliefs in industrial societies (propagated by propaganda, understood as a kind of technology by Ellul), thereby erasing the distinction between technology and culture by including *all* of culture within technology (see below on Jarvie).

### Definitions of Technology

Three definitions or characterizations of technology are: (a) technology as hardware; (b) technology as rules; and (c) technology as system.

#### Technology as hardware

Probably the most obvious definition of technology is as tools and machines. Generally the imagery used to illustrate a brochure or flier on technology is that of things such as rockets, power plants, computers, and factories. The understanding of technology as tools or machines is concrete and easily graspable. It lies behind much discussion of technology even when not made explicit. (Lewis Mumford (1895–1990) made a distinction between tools and machines in which the user directly manipulates tools, while machines are more independent of the skill of the user.)

One problem for the definition of technology as tools or machines is cases where technology is claimed not to use either tools or machines. One such non-hardware technology is the behavioral technology of the psychologist B. F. Skinner (1904–90). If one considers verbal or interpersonal manipulation or direction of the behavior of another as technology then it appears we have technology without tools. Mumford claims that the earliest “machine” in human history was the organization of large numbers of people for manual labor in moving earth for dams or irrigation projects in the earliest civilizations, such as Egypt, ancient Sumer in Iraq, or ancient China. Mumford calls

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this mass organized labor “the megamachine” (Mumford, 1966). Jacques Ellul considers patterns of rule-following behavior or “technique” to be the essence of technology. Thus, propaganda and sex manuals will be technology involving rules, and can, but need not always, involve use of tools or hardware.

### Technology as rules

Ellul’s “technique” mentioned above is a prime example of another definition of technology. This treats technology as rules rather than tools. “Software” versus “hardware” would be another way to characterize the difference in emphasis. Technology involves patterns of means–end relationships. The psychological technology of Skinner, the tool-less megamachine of Mumford, or the “techniques” of Ellul are not problems for this approach to technology. The sociologist Max Weber (1864–1920), with his emphasis on “rationalization,” resembles Ellul on this, characterizing the rise of the West in terms of rule-governed systems, whether in science, law, or bureaucracy. Physical tools or machinery are not what is central; instead it is the means–end patterns systematically developed.

### Technology as system

It is not clear that hardware outside of human context of use and understanding really functions as technology. Here are some examples:

- 1 An airplane (perhaps crashed or abandoned) sitting deserted in the rain forest will not function as technology. It might be treated as a religious object by members of a “cargo cult” in the Pacific. The cargo cults arose when US planes during the Second World War dropped huge amounts of goods on Pacific islands and cults awaited the return of the big “birds.”
- 2 The Shah of Iran during the 1960s attempted to forcibly modernize the country. He used the oil wealth to import high technology such as jet planes and computers, but lacked sufficient numbers of operators and service personnel. It has been claimed that airplanes and mainframe computers sat outside, accumulating sand and dust or rusting, as housing for storage and the operating and repair staffs for them were not made available. The machinery did not *function* as technology.
- 3 Technological hardware not functioning as technology is not solely the province of indigenous societies or developing nations, but can also be

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present in a milieu of high tech, urban sophisticates. Non-Western technology was displayed in an exhibit of “Primitive [*sic*] and Modern Art” at the Museum of Modern Art as purely aesthetic or artistic phenomena. Indigenous implements and twentieth-century Western abstract art objects were exhibited side by side to emphasize similarity of shape and design. The labels of the primitive implements often did not explain their use, only their place and date. (The use of these devices for cooking, navigation, and other purposes was not explained in the captions.) In some cases neither the museum visitors nor even the curators knew the technological function of the objects. Therefore, although the artifacts were simultaneously both technology and art for their original users, they were not technology, but solely art, for the curators and viewers of the museum exhibit.

These examples suggest that for an artifact or piece of hardware to be technology, it needs to be set in the context of people who use it, maintain it, and repair it. This gives rise to the notion of a **technological system** that includes hardware as well as the human skills and organization that are needed to operate and maintain it (see consensus definition below).

### Technology as Applied Science

Much of *contemporary* technology is applied science. However, to *define* technology simply as **applied science** is misleading both historically and systematically. If one understands science in the sense of the combination of controlled experiment with mathematical laws of nature, then science is only some four hundred years old. Even the ancient Greeks who had mathematical descriptions of nature and observation did not have controlled experiment. The medieval Chinese had highly developed technology (see chapter 10) and a rich fund of observation and theory about nature, but had neither the notion of laws of nature nor controlled experiment. Technology in some form or other goes back to the stone tools of the earliest humans millions of years ago. Clearly, with this understanding of science and technology, through most of human history, technology was not applied science. Part of the issue is how broadly one defines science. If one means by science simply trial and error (as some pragmatists and generalizers of Popper’s notion of conjecture and refutation have claimed; Campbell, 1974), then prehistoric technology could be treated as applied science. However, now the notion of science has

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been tremendously broadened to include virtually all human learning, indeed all animal learning, if one holds a trial and error theory of learning. Perhaps this is an example of a definition of science that is too broad.

Even after the rise of early modern experimental science and the notion of scientific laws in the seventeenth century, and the development of the technology that contributed to the industrial revolution, most technological development did not arise from the direct application of the science of Galileo (1564–1642) and Newton (1642–1727). The inventors of the seventeenth and eighteenth centuries usually did not know the theories of mathematical physics of their day, but were tinkerers and practical people who found solutions to practical problems without using the science of their day. Even as late as Thomas Edison (1847–1931) we find a tremendously productive inventor in the field of electricity who did not know the electromagnetic theory of James Clerk Maxwell (1831–79) and his followers, but who produced far more inventions than those scientists who did know the most advanced electrical field theories. Edison initially even disparaged the need for a physicist as part of his First World War team, thinking one needed a physicist only to do complicated numerical computations, but that a physicist would have nothing much to contribute to technology. By this time Edison's view of the role of theory was getting somewhat dated.

Even in the contemporary situation, in which scientific training is essential for most technological invention, the notion of technology as applied science, if taken in too simple and straightforward a way, is misleading. Modern technology is pursued primarily by those with a scientific background and within the framework of modern science, but many of the specific inventions are products of chance or of trial and error, not a direct application of scientific theory to achieve a pre-assumed goal. Many chemical discoveries have been results of accidents. Safety glass was discovered when a chemical solution was spilled on a piece of glass laboratory apparatus, the glass was accidentally dropped, and it did not break. Penicillin was discovered when a bacterial culture was accidentally contaminated by a mold. Paper chromatography was discovered when a scientist accidentally spilled some chemical on a filter paper, and the chemical separated into two components as it seeped up the paper. The Post-it was discovered when a technologist, Art Fry, using little bookmarks in his hymnal, remembered a temporary glue that a colleague, Spencer Silver, had developed back in 1968 that was too weak to permanently stick two pieces of paper together. In 1977–9 3M began to market the invention, and by 1980 it was sold throughout the USA. Charles Goodyear's development of vulcanization of rubber

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involved numerous trials and experiments, but one crucial event involved him accidentally leaving his treated “gum elastic” on a hot stove, and noticing that it charred like leather. He then experimented to find a lesser, but optimum, heat of exposure (Goodyear, 1855). Louis Pasteur (1822–95) famously said that chance favors the prepared mind. The development of these accidental discoveries made much use of the scientific knowledge of the people who made them. But the discoveries were hardly the straightforward application of scientific theory to a preset problem.

For these reasons, although technology involves knowledge, particularly know-how, a definition of technology that characterizes it simply as applied science is too narrow.

### Systems Definition as a Consensus Definition of Technology

A number of writers have formulated a somewhat complex definition of technology to incorporate the notion of a technological system. The economist John Kenneth Galbraith (1908–2004) defined technology as “the systematic application of scientific or other knowledge to practical tasks” (Galbraith, 1967, chapter 2). Galbraith describes this as incorporating social organizations and value systems. Others have extended this definition to mention the organizational aspect of technology, characterizing technology as “any systematized practical knowledge, based on experimentation and/or scientific theory, which enhances the capacity of society to produce goods and services, and which is embodied in productive skills, organization and machinery” (Gendron, 1977, p. 23), or “the application of scientific or other knowledge to practical tasks by ordered systems that involve people and organizations, living things, and machines” (Pacey, 1983, p. 6). We can combine these definitions into “the application of scientific or other knowledge to practical tasks by ordered systems that involve people and organizations, productive skills, living things, and machines.”

This consensus definition is sometimes characterized as the “**technological systems**” approach to technology. The technological system is the complex of hardware (possibly plants and animals), knowledge, inventors, operators, repair people, consumers, marketers, advertisers, government administrators, and others involved in a technology. The technological systems approach is more comprehensive than either the tools/hardware or the rules/software approach, as it encompasses both (Kline, 1985).

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The tool approach to technology tends to make technology appear **neutral**. It is neither good nor bad. It can be used, misused, or refused. The hammer can be used to drive a nail or smash a skull. The tool user is outside of the tool (as in the case of carpenters' tools) and controls it. The systems approach to technology makes technology encompass the humans, whether consumers, workers, or others. The individual is not outside the system, but inside the system. When one includes advertising, propaganda, government administration, and all the rest, it is easier to see how the technological system can control the individual, rather than the other way round, as in the case of simple tools.

The notion (known as autonomous technology) that technology is out of human control and has a life of its own (see chapter 7) makes much more sense with technological systems than it does with tools. Technological systems that include advertising, propaganda, and government enforcement can persuade, seduce, or force users to accept them.

As noted above, not all students of technology wish to develop a definition or general characterization of technology. Some, particularly among the "postmodern" devotees of science and technology studies, claim not only that there is no "essence" of technology of the sort that mid-twentieth-century thinkers such as Martin Heidegger, Jacques Ellul and others claimed or sought, but that no general definition of technology is possible.

Despite the validity of the doubts of postmodern students of technology studies concerning an essence of technology, the "consensus definition" delineated above will help to keep the reader roughly focused on the kinds of things under discussion. For instance, the recent advocates of "actor-network theory" (see chapter 12) developed an approach to technology that has many affinities to the consensus definition in the technological systems approach. Advocates of the technological systems approach have recently begun to ally with or even fuse with the social construction of technology approach. Understanding technology as a network fits well with the European sociology of actor-network theory (see box 12.2). Thomas P. Hughes, the person who is perhaps the leading American historian of technological systems, has moved toward the social construction view, and combined it with his own approach (Bijker et al., 1987; Hughes, 2004).

# PHILOSOPHY OF MEDICAL TECHNOLOGY

Sven Ove Hansson

## 1 INTRODUCTION

It has often been remarked that one of the foremost characteristics of modern medicine is its extensive use of technology. Medicine has always used technology, but since the late 19<sup>th</sup> century its reliance on technology has expanded dramatically. One of the many consequences of this is a change the location of the physician's activities. The use of special equipment made it necessary to move consultations from home visits to hospitals and physician's offices. As an example of this, the number of hospitals in the US increased from 200 to 4000 from 1873 to 1910 [Davis, 1981, p. 8].

Not surprisingly, various uses of technology figure prominently in discussions on medical ethics. However, few attempts have been made to give a comprehensive philosophical perspective on medical technology, and in the philosophy of technology medical applications are in fact marginal [Vos and Willems, 2000, p. 2].

Medicine and technology have much in common. Contrary to the natural sciences, neither of them is aimed at obtaining knowledge for its own sake. Both have an emphasis on *techne* rather than *episteme*, i.e. their goal is to find means of achieving practical results, to change the world rather than just to understand it [Hansson, 2007a; 2007b]. Medicine and technology also have a large and rapidly growing intersection, namely the use of technological methods to achieve the goals of healthcare. However, “[e]ven the most mechanical elements of medicine... are rarely, if ever, described as technology by its practitioners. Physicians are reluctant to see themselves as technicians or applied scientists” [Davis, 1981, p. 3].

The use of ever more complicated technology in hospitals has increased the role of engineers in healthcare. Engineers are responsible for the operation of essential diagnostic, therapeutic and palliative equipment. Due to the need for their expertise, some technological and engineering personnel are moving closer to the patient and assume more clinical roles in multidisciplinary healthcare teams [Deber and Leatt, 1986; Fielder, 1991; Wood, 2002]. Unfortunately, their role is often insufficiently understood by the public and by members of the more well-established healthcare professions. “Unlike other health professionals who have a firmly established role within the hospital system, clinical engineers often assume

new and greater responsibilities without the needed authority or institutional support” [Saha and Saha, 1997, p. 189].

By investigating philosophical issues in medical technology, we can obtain a better understanding of clinical and biomedical engineering that are important branches of modern technology. Such studies will also help us to achieve a better understanding of the nature of medicine itself.

There are five major categories of medical or healthcare-related technology:

- *Diagnostic technology* identifies diseases and other conditions for treatment or palliation.
- *Therapeutic technology* is used in the treatment of diseases.
- *Enhancing technology* improves human functioning beyond what is needed to cure diseases.
- *Enabling technology* alleviates the impact of disease or a disability. This includes personalized equipment such as eyeglasses and artificial limbs but also universal technologies such as entrances that are accessible via wheelchair.
- *Preventive technology* reduces the risk or severity of accidents, toxic exposures, and other social and environmental mechanisms that give rise to disease or injury. This includes a wide variety of technologies, from sewage treatment plants to airbags.

Diagnostic, therapeutic, and enhancing technologies are integrated in healthcare. Enabling technology includes both technology that is part of healthcare, such as prosthetic technology, and technology that has little connection with healthcare. Preventive technology is usually not closely connected with healthcare, but in many cases, such as automobile safety, it makes extensive use of medical knowledge.

This chapter contains sections on diagnostic technology (Section 2), therapeutic technology (Section 3), enhancing technology (Section 4), and enabling technology (Section 5). Preventive technology is not treated here, but some aspects of it are discussed in *Risk and Safety in Technology* in part V of this handbook. The final Section 6 of this chapter is devoted to some issues that concern medical technology in general, namely how technology shifts responsibilities, what effects it has on the quality of care and human contact, and whether it gives rise to unsound and perhaps unnatural dependence on artificial devices.

## 2 DIAGNOSTIC TECHNOLOGY

Up to the 19<sup>th</sup> century, diagnosis was primarily an oral and visual process, unaided by instruments (the main exception being uroscopy). Physical diagnosis, often including measurements, was developed to a high degree of precision in the early 19<sup>th</sup> century [Davis, 1981, p. 183]. Around 1840 clinical laboratories were

introduced, offering an increasingly sophisticated repertoire of biochemical tests [Büttner, 2002]. In the 1880s and 1890s clinical photography rose to importance as a means of documentation. After Röntgen's discovery of X-rays in 1895 photography was overshadowed by X-ray diagnosis that had a deep impact on most clinical disciplines [Kröner, 2005]. Today, medical diagnosis is based on a combination of anamnesis (information obtained by interviewing the patient), physical examination of the patient, laboratory examination primarily of blood but also of other tissues and excretions, and imaging techniques including classical X-ray images, tomography and ultrasonography.

In recent years some types of diagnostic technology that were previously in the hands of physicians have been made available to the patients themselves. Asthmatics can use a peak flow meter to regulate their medication, and insulin-dependent diabetics can measure their blood-sugar levels and adapt the dosage. In particular the latter practice has had large impacts on therapy. With frequent measurements of blood sugar, blood sugar regulation has been made tighter, i.e. lower values can be kept without risking hypoglycaemia. This reduces long-term risks of blindness, neuropathy and atherosclerosis. It also makes it possible for diabetics to lead a less regular life, since they can adjust dosage to food intake and physical activity [Willems, 2000; Mol, 2000].

Technologically mediated progress in medical diagnosis gives rise to several important philosophical questions: How does increased diagnostic precision influence our concepts of disease? Is diagnostic precision motivated even when it does not lead to better therapy, or can it even have negative side effects? Can excesses in medical diagnosis give rise to social discrimination? The recent introduction of genetic technology in the clinical laboratory gives rise to further issues, in particular: Should we avoid collecting genetic information that may tell the patient more about herself than what she wants to know?

### 2.1 *An excess of diagnoses?*

Diagnosis is essential for treatment. Some of the most important contributions of technology to medicine have been diagnostic procedures that made it possible to offer patients more specific therapies and to commence therapy at an earlier stage of the disease. In some cases, the recognition of previously unknown preclinical signs of disease have made it possible to begin therapy before the patient suffers from the disease. Important examples of this are the use of mass radiography to discover early stages of tuberculosis and the use of sphygmomanometry to diagnose hypertension.

Not surprisingly, there are also cases when improved diagnosis has not been matched by corresponding developments in therapy so that, at least for a period of time, diagnosis has no effect on the patient's health. It has often been questioned whether diagnosis can have any value when it does not lead to a therapeutic intervention. In this discussion it is important to distinguish between two cases. The first case is *diagnostic information about a manifest disease*. Consider for

instance a patient with a back pain, who is referred to an X-ray exam. A possible outcome of the exam is the discovery of physiological changes in the spine that are not accessible to specific treatment and do not change the advice that the physician had already given the patient. Is such a diagnosis useless or perhaps even of negative value?

Experience from this particular diagnosis points in the opposite direction. Patients with back pain often want confirmation that their disease is real, and therefore appreciate knowledge about the physiological nature of the disease [Rhodes *et al.*, 1999]. Generally speaking, patients often want to know what disease they have. Furthermore, an exact diagnosis is in most cases required before the physician knows that it is useless to search for other, perhaps treatable, causes of the symptoms. Therefore, although not all diagnoses of manifest disease lead to improved treatment, careful diagnostication is usually an unavoidable component of responsible medical management of the patient's complaints.

The other, more problematic, case is that of a *diagnosis without a manifest disease*. Alvan Feinstein introduced the term *lanthanic disease* for diseases that can be detected by technological means, but are not experienced in any way by the patient [Feinstein, 1967; Hofmann, 2003]. Since the 19<sup>th</sup> century, life insurance companies have been a driving force behind the development of such diagnoses. They need methods to prognosticate a prospective customer's expected remaining length of life. Two technologies were shown in the early twentieth century to be efficient for this purpose, namely measurement of the person's blood pressure and her vital capacity (the maximal volume of exhaled air after a maximal inhalation). Physical standards based on sphygmomanometry and spirometry were used as health indicators in insurance medicine in the early twentieth century, but these diagnoses were not then matched by therapies [Davis, 1981, p. 185].

A modern example of a possibly problematic lanthanic diagnosis is osteoporosis at an early stage (also called osteopenia), as diagnosed through low bone mineral density (BMD, bone mass). This is an X-ray diagnosis (dual energy X-ray absorptiometry, DXA); the patient has no symptoms other than a somewhat increased risk of fractures. A study of women who received this diagnosis revealed that for many of them the bone scan had influenced their social lives. They perceived their bodies as fragile and therefore chose not to participate in a number of social activities. It is a widespread misconception that a person who suffers from osteoporosis should avoid physical activity in order to avoid fractures. In actual fact, the contrary is the case: physical activity is an important means of preventing an aggravation of osteoporosis [Magnus *et al.*, 1996; Dalsgaard Reventlow *et al.*, 2006]. Hence in this case, information about a technology-mediated diagnosis can be counterproductive in terms of medical prognosis. However, it is important to observe that this is not a necessary consequence of the use of this technology. Its effect will be positive if the physician who informs the patient of the diagnosis also manages to encourage her to increase instead of decreasing her physical activity, and to take other measures that contribute to halting the development of the disease, such as to stop smoking and reduce the intake of soft drinks.

## 2.2 *Diagnosis as a source of social discrimination*

New diagnoses often have impact on our concepts of disease and health, and they can also influence the way in which we conceive our bodies [Vos and Willems, 2000]. Hence, the exact measurement of physiological functions has led to new concepts of normality and abnormality, such as the notion of hypertension [Davis, 1981, p. 5]. New diagnoses can also be used to classify persons in new ways. Such classifications can have negative social effects for the persons to whom they are applied; in particular they can be used to discriminate against the persons so classified.

Discrimination means that certain persons receive a worse treatment, or less of some advantage, than others, without sufficient justification to select them for such inferior treatment. The most discussed types of discrimination are those that affect women, ethnic, religious, and sexual minorities, and people with certain handicaps and medical conditions. In some cases a diagnosis alone, i.e. a diagnosis without an accompanying actual condition, can have a discriminating effect [Hansson, 2005].

The clearest evidence of such discrimination can be found in the insurance sector. Insurance companies have a right to collect medical information about their customers. They also have economic incentives to use such information to the customers' disadvantage. Hence, patients with hereditary hemochromatosis have found themselves excluded from insurance although they complied with therapeutic phlebotomy and therefore had no increased risk of disease or death. (Some relatives of patients with this diagnosis have avoided such discriminatory treatment by not having themselves tested but instead donating blood as often as phlebotomy is recommended for patients with the disease [Barash, 2000]). Afro-Americans who are carriers of the sickle-cell trait have been discriminated against by life insurers, although their condition does not give rise to an increased risk of death [Bowman, 2000].

It should be emphasized, however, that the extent to which insurance companies have incentives to discriminate customers with certain diagnoses depends on the politically chosen construction of the insurance system. Hence, the American insurance industry uses such information to reject applications for health insurance policies and to refuse payment for the treatment of illnesses [Alper and Beckwith, 1988; Anderlik and Rothstein, 2001]. The prevalence of this practice depends on the fragmentary nature of American health insurance [Wolf, 1995]. Most European countries have more developed health insurance programmes that cover everyone and have the same premium for all persons on the same income level. In such systems there is no incentive for health insurers to collect prognostic medical information about their customers. On the other hand, the system for life insurance seems to be more or less the same in all countries, and gives rise to such an incentive.

Another situation where discrimination can be based on a diagnosis is the recruitment of personnel. Employers can require medical information about prospective employees. A well-known example concerns the sickle cell gene. The U.S. Air

Force barred Afro-Americans with the sickle-cell trait from becoming pilots due to an erroneous belief that they were prone to illness at high altitudes [Dolgin, 2001]. In later years worries have been expressed that genetic information can be used by employers to discover predispositions to certain diseases, recessive genes for inherited diseases, or (hypothetically) various psychological characteristics [Brady, 1995; Silvers and Stein, 2002; Persson and Hansson, 2003]. However, it should be emphasized that the use of diagnostic technology for such purposes is within social control. Several countries have passed laws that regulate what information an employer may acquire about a prospective employee.

One of the best-known examples of maltreatment based on a mere diagnosis is the social discrimination of recessive carriers of the sickle-cell gene in the Greek village Orchemenos. Since the gene was unusually common in this village, all inhabitants were offered testing. The purpose was to make it possible for carriers of the gene to avoid marrying other carriers. However, this strategy failed, and instead testing led to stigmatization of the carriers. Non-carriers chose to only marry other non-carriers, and carriers were left to marrying each other [Moore, 2000]. Another example is the Ashkenazi Jews. This group has a long history of volunteering for genetic research, and therefore a disproportionate number of genetic alterations have been shown among them. This has given rise to a widespread though mistaken view that they are more prone to genetic disorders than others, and they have on occasions been discriminated for that reason [Dolgin, 2001].

### *2.3 Genetic diagnoses*

In recent debates about discrimination it has usually been taken for granted that genetic information is more sensitive than most non-genetic information. The use of genetic information is also much less accepted. While it seems to be fairly accepted that a person who has a manifest illness with a bad prognosis is denied a life insurance, rejections based on genetic tests have been vehemently protested against. The view that genetic information requires more protection to ensure privacy than most other forms of medical information has been called genetic exceptionalism [Green and Botkin, 2003].

Genetic exceptionalism is an example of a general tendency that is also seen in many social and ethical debates on biotechnology: The application of technology to a genetic material is conceived as particularly sensitive and is sometimes seen as ethically problematic in itself.

More concretely, three major differences between genetic and non-genetic information have been invoked to defend genetic exceptionalism. First, genetic information is said to give more precise information about the likelihood of future disease than what is obtainable from non-genetic tests. Secondly, genetic tests provide information not only about the tested individual but to some extent also about her relatives. Thirdly, genetic information is said to reveal fundamental and immutable characteristics of the individual [Alper and Beckwith, 1988].

As one example of the first argument (the predictive power of genetic tests), Roche and Annas [2001] claim that DNA-sequence data differs from other types of medical data in providing information not only about a patient's current health status but also about her future health risks. According to these authors, genetic information is in this sense analogous to a coded "future diary". This, however, is a severely misleading statement. Although information about single-gene diseases may have a high predictive power, most health-related genetic information refers to diseases with a complex etiology involving several genes and several environmental factors. In such, more typical cases the predictive power of genetic tests is far from impressive. There are also several examples of non-genetic diagnostic technologies with a high degree of predictive power. Two practically important examples are sphygmomanometry and tests for fecal occult blood. They both have great value in detecting diseases (hypertension respectively colon cancer) in their early stages before the patient is aware of it.

Concerning the second argument, it is certainly true that family members can be affected by results from genetic tests. However, the same applies to non-genetic tests for infectious diseases (not least sexual partners in the case of sexually transmitted diseases). An interesting comparison can be made between Huntington's disease and HIV in this respect. Huntington's disease is a rare genetic neurological disease that usually does not give rise to noticeable symptoms until the patient is in her thirties or forties. Having the abnormal Huntington gene is similar to being HIV-positive in at least two important respects: One may remain healthy for a number of years before the onset of the disease. Furthermore, both conditions are frequently transmitted to offspring [Gin, 1997].

Finally, concerning the third argument, genetic information is believed to reveal who the person "really is". This view of personhood has been called "genetic essentialism" [Alper and Beckwith, 1988]. According to that view, genetic information is more intimately related to a person's true nature than other sorts of information about the person. As Launis [2000] has argued convincingly, genetic essentialism is based on the highly controversial metaphysical presumption that there is such a thing as a person's core nature, or essential identity. Furthermore, the available empirical evidence shows that we are constituted by a combination of genetics and environment, not by genetics alone.

However, it is possible that the technological availability of genetic information will lead to more emphasis on genetic, inherited aspects not only of health but also of human personality. In this way, technologically mediated knowledge might have impact on how we view each other as persons: It might lead to a focus on inherited, unchangeable traits rather than on the social influence on personality.

On the other hand, other technologies are also developing that may have an opposite effect. Proteomics, and information about the expression rather than the presence of a gene, may become more predictive than genetic sequencing. Biochemical tests can be developed that reveal environmental influences on the person. The development of future diagnostic technologies will in all probability provide us with tools that reveal both the genetic and the environmental influences

on our bodies and our personalities. It is not possible to predict in what way these developments will influence our views on human beings, but the philosophical impact may be substantial.

### 3 THERAPEUTIC TECHNOLOGY

Therapy, the remediation or treatment of a health problem, is of course at the centre of medicine (although the prevention of disease or accidents is no less important). Therapy has always involved technological procedures; fairly advanced surgery such as trepanation was performed in Neolithic times.

#### *3.1 Therapeutic knowledge and knowledge of side-effects*

Today it is taken for granted, at least in academic medicine, that therapy should be based on scientific knowledge. However, the connection between therapy and science is much more recent than that between therapy and technology. In Hippocratic medicine that dominated medicine for more than two millennia, the most common therapies were bloodletting, purging, and emetics, all of which were positively harmful to the patients. Although medicine has been taught in universities since the late thirteenth century, its practice was based on Hippocratic teachings. Important advances in understanding of human biology were made, such as Harvey's discovery of the circulation of blood, but they led to no therapeutic advances [Wootton, 2006]. It was not until the nineteenth century that professors of medicine strove to make their discipline one of the sciences. Two major approaches were taken to achieve this. One was to make medical therapy essentially a branch of the natural sciences. By studies in the laboratory, diseased organs and tissues could be classified and causes of disease could be revealed. Claude Bernard was a leading proponent of this approach to the scientification of medicine. The other approach was treatment experiments, i.e. what we today call clinical trials. In the nineteenth century the first pioneers of clinical research began to evaluate the effectiveness of therapeutic methods through statistical comparisons of groups of patients who had received different treatments [Booth, 1993; Wilkinson, 1993]. Originally, the two approaches to scientific medicine were seen as competitors. Today it is generally recognized that laboratory research is as necessary to develop new therapies as is clinical research to validate, evaluate, and calibrate them.

Hence, the crucial source of therapeutic knowledge is the clinical trial. In a clinical trial, groups of patients with the same disease receive different treatment, and statistical analysis is performed to determine both the therapeutic effects and the side effects in the different groups. In this way, the therapy with the best balance between therapeutic chances and (risks) of side effects can be identified. The ethical defensibility of clinical trials is far from self-evident. The consensus view is that a clinical trial is only acceptable if there is genuine uncertainty about which of the tested treatments is best, and informed consent has been obtained from all the subjects [Hansson, 2006].

Although clinical trials were proposed in the early nineteenth century, they were rare until after World War II. Today, a large part of the published medical research is reports from clinical trials. Since the 1990s, the use of information from clinical trials for clinical decision-making has been facilitated by the development of systematic procedures for evaluating clinical research (evidence-based medicine, EBM) [Evidence-Based Medicine Working Group, 1992].

The vast majority of clinical trials concerns pharmacological treatment. A major reason for this is that new drugs are not allowed unless they have been shown in clinical trials to be therapeutically useful in comparison to previously available therapy. Government control of medical devices is less extensive than for pharmaceutical products. In particular, there is no general system for premarketing testing similar to that for drugs [Altenstetter, 2003]. As a consequence of this, much less clinical research is performed on the therapeutic use of technical devices than on the therapeutic use of drugs.

Not surprisingly, mechanical and other technological devices can fail in unforeseen ways, just like drugs. There is a long historical list of such failures. The majority of these did not give rise to severe injuries. But there have also been cases when technological failures had fatal outcomes. One of the best-known cases is the Bjork-Shiley heart valve, in which case regulators and industry seem to have been too slow in taking actions to prevent continued implantation of a defective product. The decision to withdraw the product came unnecessarily late according to critics. The decision was not made by the regulators but voluntarily by the company [Fielder, 1991].

It is important to relate the producer's responsibility for the functioning of a device to the actual clinical settings in which it will be used. One critic complained that "most medical device designers appear to have envisioned the controlled, delicate, and precise choreography of a surgical team, not the frantic activity of the emergency room or a 'code-blue' call. Consequently, many devices are not as rugged and easy to use as they could be" (Houston, quoted in [Saha *et al.*, 1985]).

However, this situation may change. One observer of the system described the current situation as follows: "The long-lasting honeymoon between the industry and European healthcare regulators seems to have ended. For healthcare payers and purchasers the case is clear: medical technology is a cost-driving force. Thus, medical devices and the medical device industry have come under increasing scrutiny and regulation" [Altenstetter, 2003]. A possible outcome of such increased scrutiny could be that more clinical trials are undertaken in order to determine the functionality of therapeutic technology.

### 3.2 *Therapy vs letting die*

Discussions on death have a central role in medical ethics, and they have often been connected to critique of technology. Some critics see the "modern" death in a technologically equipped hospital as "unnatural", whereas they regard "natural" death without modern medical technology as more dignified. This is a highly ro-

manticized view. "Natural" death is often an extremely painful process, whereas modern technology can to some extent relieve the dying person of pain and distress [Barnard and Sandelowski, 2001].

Many critics also underestimate the quality of life that is obtainable with life-sustaining technology. Hence, it is often believed that a life with a ventilator could not be worth living. In actual fact, long-time use of a ventilator is perfectly compatible with a good quality of life [Bach and Barnett, 1994].

However, even after the exaggerations have been removed, difficult ethical problems remain in the use of medical technology on severely ill patients. Just as there are occasions when permanent use of a ventilator can help a patient to a meaningful life, there are also occasions when the use of a ventilator will keep alive the body of a person whose brain does not function any more. The issue of futility, and what technological means are justified in the treatment of a severely ill person, is mainly a medical issue. The crucial criteria are the patient's condition and prognosis, in particular her level of consciousness, and her own preferences as far as they can be known. However, there are also some technological aspects to this question.

One such issue is the distinction between act and omission, and correspondingly between causing someone's death actively and causing it by refraining from doing something (e.g. refraining from a therapeutic action that is considered to be futile). This distinction has crucial role in the debate on euthanasia, but it is nevertheless far from clear [Hansson, 2008]. Hence, a physician who withdraws a respirator from a terminal patient with no hope of recovery is often seen as (passively) permitting death to occur through natural causes. In contrast, a well-meaning friend or relative who disconnects the respirator would run much greater risk of being accused of killing the patient. It seems as if the distinction between killing and letting die depends on social conventions and role norms [Winkler, 1988].

The withdrawal of nutrition from a terminally ill patient seems to be particularly problematic. It is an important part of medical and nursing tradition that patients should be given basic care and comfort even when the progress of the disease cannot be prevented or delayed. This includes the provision of food and fluid. Therefore, some maintain that the terminally ill should be provided with nutrition and water, even if this has to be done by technological means rather than by feeding them and giving them to drink. Others are unwilling to extend the requirement to provide nutrition and hydration to cases when this can only be done with a nasogastric tube or intravenously [Winkler, 1988, p. 165].

The continued use of new advanced devices on terminally ill persons has sometimes been questioned. This applies in particular to left ventricular assist devices (LVAD) and total artificial hearts (TAH). Although originally intended as bridging devices, LVADs have been used as destination therapy with good results. Total artificial hearts are at the time of writing still essentially an experimental therapy. Consider a case when an LVAD has been implanted as a bridging device, but circumstances have changed so that transplantation is no longer an option. It could then be claimed that since the device is no longer medically indicated,

it can be turned off or removed. However, both of these actions are expected to hasten the death of the patient [Bramstedt and Wanger, 2001]. Switching off the device under such circumstances would be contrary to generally accepted ethical principles. The same problem arises, perhaps in more drastic form, for total artificial hearts. Katrina Bramstedt has claimed that “the fact that a TAH (or any other implant or assist device) is functioning without flaw is of no relevance to the futility discourse. What is relevant to these discussions is whether the ‘perfectly’ functioning device is serving the goals of medicine and the best interests of the patient. Just as with a ventilator, a TAH can be functioning ‘perfectly’, yet be ethically inappropriate.” Furthermore, she says that “[a]s with implantable defibrillators, inactivation of a TAH is a simple procedure not involving surgery, and this inactivation should not be seen as ethically separate from the withdrawal of other life support measures such as dialysis or ventilation” [Bramstedt, 2003]. A contrary view was expressed by Robert Veatch [2003], who claims that Bramstedt “appears to be endorsing unilateral actions by physicians that will directly cause the death of their patients and do so against the will of the patient or surrogate. That should be called ‘murder’.” According to Veatch, “[t]hrowing a switch that stops a TAH is more like injecting a drug that paralyzes the heart muscle or like excising the SA node. Either of these would be considered direct, active killing. How can it be that turning off the heart is any different?” Whereas other authors have emphasized the similarity between turning off an artificial heart and discontinuing other life-prolonging treatment [Miles *et al.*, 1988], Veatch emphasizes the difference. It could be argued in favour of his view that a patient who has received an artificial heart will regard it as her own, and thus not as a device that somebody else has a right to stop.

Future technological developments may provide us with other types of life-sustaining devices that give rise to essentially the same type of questions as the artificial heart. This would apply, for instance, to an artificial lung or kidney. A somewhat different type of end-of-life issue would arise from a brain implant that is not necessary for life but necessary to support consciousness. If the quality of the achieved consciousness deteriorates, arguments could be made in favour of turning off such an implant. This would, however, be a highly problematic standpoint for same reason that turning off a life-sustaining artificial organ is problematic.

### 3.3 *Subcultures that resist therapy*

Medical technology has effects not only on individuals but also on social groups and on society as a whole. Radical improvements in treatment will change the situation of disabled subcommunities in our societies. Perhaps surprisingly, therapeutic improvements are not always received positively in these subcommunities. The “fat is beautiful” movement denies that obesity is a disease requiring treatment and medical attention. Segments of the dwarf community have reacted against the introduction of therapies against their condition, seeing this as a threat to the future existence of their way of life and their organizations [Berreby, 1996].

By far the strongest such counter-reaction is the criticism from the Deaf World of cochlear implant surgery in prelingually deaf children [Crouch, 1997; Lane and Bahan, 1998].

The criticism of cochlear implantation is associated with a positive view of deafness. The Danish Deaf Association has stated that “deaf children are not sick or weak children, but normal Danish children, who just happen to use another language” (quoted in [Nunes, 2001]). Members of the Deaf World reject the idea that they have an impairment or disability. Instead, they view themselves as a minority culture with its own language, customs, attitudes, knowledge, and values. The use of cochlear implants will lead to a drastic decline in the population of this minority culture. Deaf activists have often referred to the ethical principle that minority cultures should be preserved. They claim that large-scale implantation of children conflicts with the right of the Deaf language and cultural minority to exist and flourish. The term “genocide” has sometimes been used to describe that prospect [Lane and Bahan, 1998].

This claim has given rise to an interesting discussion about the definition of a minority culture and whether cultures have intrinsic value [Levy, 2002]. Critics have pointed out the problematic nature of arguments that give precedence to the preservation of a culture over the interests of individual children. Some have noted that it is difficult to draw the line if cochlear implants are disallowed for this reason. If cochlear implants are unethical, then how should we judge the rubella vaccine [Balkany, 1996]?

From the viewpoint of mainstream medical ethics the interests of a subculture that needs to recruit new members could hardly prevail over the physician’s responsibility towards the individual patient. Nevertheless, there are important lessons to be drawn from this debate. In particular, it shows that the ethical discussion on medical technology must take into account the social and cultural notions of disease.

## 4 ENHANCEMENT TECHNOLOGY

Technological devices such as implants can be constructed not only to cure disease and restore human functioning to normal levels, but also to improve human functioning to levels above the normal. The philosophy of medical technology therefore has to deal with issues of normality and disease and with the admissibility of human enhancement. If it becomes possible to improve a healthy person’s physical strength or her memory to levels above her natural endowment, to what extent is it advisable to do so?

### *4.1 Enhancement and the limits of normality*

Much of the recent debate on enhancement has referred to genetic enhancement, which only few writers defend [Resnik, 2000]. In this area, the enhancement discussion is anticipatory since no enhancing genetic technology is currently available.

However, there are at least two branches of medicine that already deal with enhancement in everyday clinical decisions, namely cosmetic surgery and neuropharmacology. Many types of cosmetic surgery, including breast implants, have been criticized for not complying with the aims of medicine, since they do not treat a disease or malfunction [Jacobson, 1998; Miller *et al.*, 2000]. Several drugs developed to treat diseases of the nervous system also have the ability to improve normal functioning. Hence, drugs developed for the treatment of narcolepsy are already in use in armed forces as wakefulness drugs. Drugs against depression are used for mood elevation by persons with no psychiatric diagnosis, and drugs against erectile dysfunction are used for pleasure [Wolpe, 2000]. Drugs developed to prevent cognitive deterioration in Alzheimer's disease seem to be capable of improving cognitive functioning in the healthy.

In addition to enhancement of capabilities that we already have, it is also possible to develop entirely new functions for the human body. Currently, microchip devices are implanted in animals for identification purposes. It is technically possible to implant similar devices into humans. One use of such chips would be to let airplane passengers travel without a ticket or identity document; instead they would be scanned. A more sophisticated read-write chip could carry a person's medical history or her criminal record. An implanted radio transmitter can be used to track a person [Ramesh, 1997]. A related prospect is that of implanting a device in the body that continuously monitors levels of substances in the bloodstream, and adjusts drug release accordingly [Wood *et al.*, 2003].

Some authors are against virtually all forms of enhancement since it transcends the traditional task of medicine that is to treat and prevent diseases, not to improve humanity generally. "[T]he goals of medicine concern not all human suffering, but only that suffering connected with a malady" [Miller *et al.*, 2000]. There are at least two problems with this standpoint. First, the distinction between disease and health or normality is not as clear as it may first seem. Disease is not a biologically well-defined concept but one that depends largely on social values. Some conditions previously regarded as diseases are now regarded as normal states of the mind or body. Other conditions that were previously regarded as variations within normality are now regarded as diseases. Homosexuality is an example of the former, attention-deficit hyperactivity disorder (ADHD) an example of the latter.

Secondly, it is easy to show with examples that our intuitions about whether treatment should be offered for a condition are strongly influenced by other factors than whether or not that condition is classifiable as a disease. One well-known example is the treatment of short stature. Both public and private insurers have chosen to pay for growth hormone treatment only if the child has some diagnosable growth hormone deficiency, not otherwise regardless of how short it is projected to be [Verweij and Kortmann, 1997]. As was noted by Norman Daniels [2000], this criterion for treatment is difficult to defend from an ethical point of view. If one person is short "just" because of her genotype and another due to some identified dysfunction, this does not mean that the first person suffers less or needs treatment less. Clearly, neither of them is short through a choice or fault of her own.

(In practice, however, we have been saved from ethical predicaments of growth hormone therapy by studies showing that this treatment does not affect the final, adult height of children who have a normal endogenous production of the hormone [Murray, 2002].)

Presbyopia is a normal feature of aging, and should therefore not be regarded as a disease. Nevertheless, we do not hesitate to treat this condition (mostly with eyeglasses). Hopefully, no one would try to prevent ophthalmologists from treating this or other age-related conditions of the eye. Now suppose that a remedy becomes available for age-related cognitive decline. It is a good guess that — perhaps after some initial hesitation — our attitude to such a treatment would be the same as to presbyopia. (Or would anyone say: “Just let grandmother become confused. It is not a disease, so although there is a treatment she should not take it. Treatments are only for diseases.”)

We already endorse improvements of the immune system (vaccinations). Other ways to improve the body’s resistance against disease would probably find acceptance relatively easily. There are also situations in which improved cognitive function would be seen by most of us as an advantage, such as improved driving ability and improved ability of surgeons to operate [Whitehouse *et al.*, 1997].

It is also interesting to compare our views on improvements of the teeth and of the skin. In the middle of the 19<sup>th</sup> century it was normal for nearly all an adult’s teeth to display signs of decay. At that time, the type of dental work that is now routine would have been seen as remarkable and perhaps even as ethically doubtful. Today, it is about as difficult to provide old people with skin that looks youthful as it was then to make their teeth look youthful. How will we react if future developments make wrinkled skin as avoidable as discoloured tooth stubs are today?

These examples show that the disease/normality limit does not tell us what treatments are acceptable. However, there may still be other arguments against enhancement, arguments that do not depend on the distinction between disease and normality. One obvious such argument is that enhancements may have serious side effects. Hence, we can expect genetic enhancement to have unknown negative effects [Goering, 2000]. In one experiment, mice that were genetically engineered to improve their performance on learning tasks turned out to have greater sensitivity to pain [Wei *et al.*, 2001]. Perhaps a method to improve memory will have psychological side effects since it prevents us from forgetting things we cannot bear to think about. “Who needs to remember the hours waiting in the Department of Motor Vehicles staring at the ceiling tiles, or to recall the transient amnesia following a personal trauma” [Wolpe, 2000]? Other side effects may follow from other types of enhancement. However, although this type of argument can be used against many methods of enhancement, it is not a decisive argument against enhancement as such.

At the bottom line, the enhancement issue concerns what kinds of human beings there should be. Should future people be stronger and more intelligent than we are? A common, often religiously motivated view is that human nature has been given

to us and should not be changed. Others see considerable scope for improvement of the human race. In one of the few scholarly papers devoted to the issue, James Hudson maintains that to the extent that we can influence the innate natures of future people, we should make them intelligent and probably without a sexual drive or “*any drive... other than a drive to rational thought and action in general*” [Hudson, 2000]. Needless to say, this is a controversial standpoint.

The issue what kind(s) of persons there should be is among the most difficult ones to deal with rationally in moral philosophy. The very basis for the discussion is insecure. What criteria should we use? Should we judge future persons by our own criteria, or by the criteria that we predict (and partly determine) them to have? (Population ethics that deals with how many persons there should be has similar difficulties.) Possibly, the best way to tackle issues of enhancement is to deal with them incrementally, judging each individual case on the basis of our current values without even trying to take future values into account. However, such incrementalism needs to be informed by a discussion about possible long-term developments. The following words of warning are worth taking into account:

Whereas one can make the case that future generations should have the right to decide by themselves about their fate, it should be prevented that we enter a slippery slope towards ever greater manipulation of the human body, without medical necessity, and do so without having fully considered the consequences. [Altmann, 2001]

#### 4.2 *Making man-machines*

Microprobes implanted into nervous tissue can create interfaces for communication between a patient’s nervous system and devices that replace or supplement a malfunctioning organ. Currently the most important of these neural interface implants are cochlear implants (see above, Section 3.3). Brain implants are also used for bladder control and for blocking tremors for instance in Parkinson’s disease. There are several other promising applications, including the control of epileptic seizures [Pereira *et al.*, 2007]. Experiments have been performed with chips implanted in the brain or a peripheral nerve in order to control a wheelchair or other compensatory technology, or a prosthetic device such as a prosthetic hand [Warwick *et al.*, 2003; 2007]. Research is being conducted on prosthetic vision for the blind, based on essentially the same principles as cochlear implants, namely that stimuli from technological sensors are relayed to the nervous system via a nerve-implant interface. Two major alternatives are being investigated for the placement of this interface, namely retinal chips and chips implanted in the visual cortex of the brain. Prosthetic vision is currently primarily developed in animal models, but preliminary testing on human volunteers has taken place [Bertschinger *et al.*, 2008; <http://www.bostonretinalimplant.org>].

If efficient implantable brain chips become available, then they can be used for various forms of enhancement. It has been speculated that military applications

can come first, with the purpose of producing soldiers with enhanced abilities [Maguire and McGee, 1999; Altmann, 2001]. Some computer visionaries dream of a future in which many or all humans have implantable computer chips that connect them to sensors, assist their memory, and provide them with a variety of capacities. The “cyborgs”, cybernetic organisms, of science fiction that are mixtures of man and machine would then become reality [Behling, 2005]. Some authors have hailed this as a positive development, since cyborgs can become better than men [Haraway, 1991].

It has also been argued that such neural implants could in the future be used to scan, upload and transfer (the contents) of a mind. Computer-brain connections will then allow electronic communications with other similarly connected individuals in a way that may require that we radically reassess the boundaries between self and society. However, this is even more speculative than the idea of a cyborg. We do not know whether or not complex sensory impressions, feelings and thoughts, can be communicated in either direction through an implant [White, 1999].

## 5 ENABLING TECHNOLOGY

The extent to which persons with impaired bodily functions are forced to live their lives differently than other people depends not only on therapeutic technology but also to a large part on a variety of other technologies, from wheelchairs to computer interfaces, from hearing aids to garage doors. Since the 1970s, handicap activists have urged us to see handicap less as a medical problem than as a consequence of social exclusion that is often mediated by technology. This standpoint was well expressed by Alison Davis:

[I]f I lived in a society where being in a wheelchair was no more remarkable than wearing glasses and if the community was completely accepting and accessible, my disability would be an inconvenience and not much more than that. It is society which handicaps me, far more seriously and completely than the fact that I have spina bifida. (Quoted in [Newell, 1999, p. 172].)

It is important to observe the difference between a medical condition (such as being blind) and a social condition that it contributes to (such as being unable to read the newspaper). This can be expressed with the distinction between disability and handicap. Disability is an impairment of a bodily or mental function. Handicap is the presence of obstacles that persons with disabilities are subject to in society. Hence disability is inherent in the person, whereas handicap is a relation between a person and her environment [Amundson, 1992].

Technology with capacity to reduce the negative impact of having a disease or disability can be called *enabling technology* [Hansson, 2007c]. Leaving aside therapeutic technology that we have already treated, enabling technology can be divided into three categories: compensatory, assistive, and universal technology.

### 5.1 *Compensatory and assistive technology*

*Compensatory technology* is technology that replaces (fully or in part) a lost biological function by a new function of a general nature. Hence, whereas therapeutic technology reduces handicap by reducing disability, compensatory technology reduces handicap by providing new abilities that compensate for the disability. Some examples of compensatory technology are eyeglasses, hearing aids, speech synthesis systems, walking sticks, crutches, wheelchairs, orthotic appliances, ventilators, and equipment for total parental nutrition. Rehabilitation medicine that aims at replacing lost functions by new compensating ones makes much use of compensatory technology.

*Assistive technology* makes it possible for the individual to perform a task or activity despite an (uncompensated) disability or lack of function. Assistive technology provides abilities of a more specialized nature than what compensatory technology does. Typical examples are knives that require less strength than standard kitchen knives, plates and dishes that do not slide on the table, appliances for dressing, toileting, and bathing, remote controls for doors, windows, and light switches, textphones and videophones for the speech and hearing impaired, reading machines for the blind, etc. Adaptive interfaces of software products have become an increasingly important form of assistive technology, both for private life and on workplaces. However, the adaptation of software has often lagged behind other technologies. As one example of this, many colleges and universities have ensured that handicapped persons have access to their buildings, but have failed to give them full access to their electronic information [Grodzinsky, 2000]. Household robots that assist disabled and elderly persons in a variety of daily activities are an important new development [Erlen, 2003].

Compensatory technology provides the person with general-purpose functions that can be used also in unforeseen situations, whereas assistive technology only provides solutions for more limited tasks. Therefore compensatory technology is more enabling than assistive technology. Hence, having a prosthesis that replaces a lost arm in a number of different tasks appears to be preferable to having a series of assistive appliances with which each of these tasks can be performed with only one arm.

### 5.2 *Universal technology*

Universal technology is technology that is intended for general use, not only for persons with a specific disease or disability. Without being restricted to persons with a disability, technology can be adjusted so that it includes them among its potential users. The difference between assistive and (adjusted) universal technology is often social rather than (in a restricted sense of the word) technological. Hence, a ramp that is used to enter a building both walking and in wheelchairs is universal technology; a wheelchair ramp at the back of the building intended only for those who cannot use the stairs at the front is assistive technology.

In the development of new technologies, accessibility for disabled persons is seldom treated more than at best as a side issue. Therefore, improvement or deterioration in terms of accessibility is often an unintended side effect of developments that have been driven by other aims. It is not easy to determine if the general trends in technological development are in general positive or negative for accessibility. There seem to be contradictory trends. One positive trend is mechanization that gradually decreases the need for physical strength in most occupations. Another positive trend is digitalization, that makes information more easily convertible to formats that are accessible to blind and deaf people [Cornes, 1993; Coombs 2003]. Mobile phones have also turned out to be more important for many handicapped people than for persons without a major handicap. A negative trend is increasing intellectual requirements, particularly on workplaces, that seem to be a consequence of many new technologies. This often makes life more difficult for mentally disabled persons. Hence, tentatively it seems as if ongoing technological developments make life easier for physically disabled persons but more difficult for those who are mentally disabled.

Appropriately adapted universal technology has the advantage over compensatory and assistive technology that it makes it possible for disadvantaged people to interact with the technological environment in the same way as others. As one example of this, if a machine — such as an elevator — has both visual and auditory signals, then both blind and deaf people can use it in the same way as people who see and hear. Similarly, if a heavy door is operated from a panel that is accessible from a wheelchair, then both walking and wheelchair-bound persons can open it in the same way. Therefore, universal technology is, as a general principle, superior to compensatory or assistive technology. It is therefore a plausible ethical standpoint that if a problem cannot be solved with therapeutic technology, then it should if possible be solved with universal technology, even if alternative solutions with compensatory or assistive technology are available.

However, contrary to therapeutic and compensatory technology, universal technology is usually not subject to decisions in the healthcare sector but rather in other sectors of society. This is in all probability a major reason why universal technology has often lagged behind therapeutic and compensatory technology.

## 6 GENERAL EFFECTS OF TECHNOLOGY IN MEDICINE

Technology has often been talked about very sweepingly in discussions on healthcare. In this chapter we instead focused on the impact on specific technologies and technological practices. However, there are some issues that do not relate to particular technologies but rather to the more general use of technology in healthcare. We will treat three major such issues: how technology shifts responsibilities, what effects it has on the quality of care and human contact, and whether it gives rise to unsound and perhaps unnatural dependence on artificial devices.

## 6.1 *Shifting responsibilities*

There are several ways in which current technological developments move responsibility for healthcare away from its traditional locus, i.e. physicians and nurses. The responsibility of companies that deliver medical equipment increases with the complexity of the equipment. In hospitals, bioengineers and clinical engineers take over some of the responsibilities of physicians, such as the calibration of advanced treatments. A quite different trend is the transfer of complex and sometimes life-critical equipment from the hospital to the patient's home, which confers more responsibility on patients and their relatives. Finally, as complex decisions are "delegated" to machines, some responsibilities become more diffuse, and bound to machines rather than to humans. Here, we will look more closely at the two last-mentioned of these trends, beginning with the shift of responsibility to patients and their relatives.

More and more patients receive treatments in their homes such as ventilator therapy and artificial nutrition through infusion pumps. These are treatments that were previously only administered in hospitals [Arras, 1994]. The increase in homecare is partly a response to patients' preferences, partly a response to economic pressures. "The combination of psychological benefits with cost containment makes home care seem an irresistible option" [Lantos and Kohrmann, 1992] (cf. [Kun, 2001]). Communications technology has an important role as facilitator of this development. Telemedicine allows for monitoring and diagnostics at home by the means of medical sensors connected to a personal computer. Temperature measurement, oximetry, electrocardiography, blood pressure measurement, and auscultation are among the diagnostic procedures that can be performed from a distance [Dansky *et al.*, 1999; Stanberry, 2000; Elger and Burr, 2000].

The administration of advanced diagnostic and therapeutic technology in homes has many advantages. When things go well in homecare, patients receive "the best of both worlds" [Arras, 1994], advanced medical treatment in the privacy of their own homes. Telemedicine in home care can be a way to ensure that access to healthcare is not limited by geographical location and ability to travel [Bauer, 2000; Elger and Burr, 2000].

However, technological homecare is not without its problems. For an increasing number of families, it has erased the boundaries between hospital and home, between intensive care unit and living room [Arras, 1994]. Sometimes parents and other relatives take over tasks that nurses perform only after taking special courses [Kirk, 2001]. Advanced technological home care with life-sustaining machines can place excessive burdens on family members, typically women, who live with a constant fear of failure. One of the most important ethical issues in home care is what tasks and responsibilities can and should be taken over by laypersons. "As home healthcare broadens to include traditionally hospital-based therapies, it is unclear whether traditional hospital norms, which place ultimate responsibility for decisions on professionals, or traditional home care norms, which place responsibility on parents, should apply" [Lantos and Kohrmann, 1992].

This can have negative social consequences. Homecare can make familiar domestic settings alien, and may confuse family roles. In comparison, hospitals can often allow patients greater autonomy, and therefore better preserve family relationships. Sometimes patients have a greater sense of privacy in hospitals than in homecare [Ruddick, 1994]. A patient's dependence on a spouse or a parent can be problematic for the relationship [Kohrmann, 1994]. Studies have shown stress and psychological problems in families who care for ventilator-dependent children at home [Lantos and Kohrmann, 1992; Arras and Neveloff Dubler, 1994; Kirk, 2001].

The other major shift in responsibilities emanates from a general tendency to automatize more and more advanced functions. Decisions are "taken over by machines" so that no human is directly responsible for them at the point in time at which they are made. Another way to express this is that decisions are pre-determined in decision support systems.

Healthcare is often seen as one of the most promising areas for the introduction of computerized decision support. It has been shown in several cases that decision support systems can help the clinician in important ways, for instance by decreasing the risk of kidney failure, and providing more rapid treatment of critical laboratory abnormalities [Bates, 1997]. If a decision support system is connected to electronic patient records, it can include mechanisms for following up and for automated learning. Like other applications of artificial intelligence, an advanced clinical decision support system will therefore have capabilities in addition to those explicitly programmed into it.

We may very well be approaching systems in which computers perform what we usually see as the tasks of physicians: making diagnoses, performing therapies, and communicating with patients [Gell, 2002]. A system has already been tried out in which diabetes patients used a touch-tone telephone to obtain self-management instructions and dosage decision support from a computer. The result was encouraging; an improvement was shown in their diabetes management [Albisser, 2001]. Nevertheless, important questions can be raised about the implications of such systems. If the advice was wrong, how important is it whether the patient communicated with a machine or with a human being? How can responsibilities be assigned when decisions are taken over by machines [Klieglis *et al.*, 1986; Hucklenbroich 1986]? Furthermore, what will the effects be on the physician-patient and nurse-patient relationships if much of the therapeutic-technical support comes from a machine whereas the psychological part of the support presumably stays with the physicians and nurses?

## 6.2 *Technology, care and human contact*

One of the most important effects of enabling technologies is to facilitate human communication. Hearing aids, textphones, appliances for reading and writing, speech reading programs, and various technologies for physical mobility are all examples of this. However, technology can also be used to replace human contacts or reduce the need for them. A phone call from a nurse can replace a personal

visit. A central electronic monitoring system can supersede assistant nurses at the bedside, and a nasogastric tube can be used instead of spoon-feeding.

In public debates, medical technology has often been accused of causing the dehumanization and depersonalization of healthcare and the objectification of patients. However, there is no inbuilt conflict between care and technology; technology can be used both in ways that improve care and in ways that make it less humane [Haber, 1986; Barnard and Margarete Sandelowski, 2001; Widdershoven, 2002]. In a balanced discussion on technology in healthcare it has to be realized both (1) that technology is not in itself dehumanizing and (2) that technology cannot replace genuine human contact and care.

For a practical example, we can consider the proposal to use virtual environments for training stroke patients. Virtual technology can be used to expose these patients to a wider range of sensory stimuli, over much longer periods, than what is otherwise possible in a hospital setting. This can yield benefits in terms of time and cost of therapy to stroke patients, who typically spend only 30-60 min per day in formal therapy. Thus, virtual reality “increases the possibility of stimulation and interaction with the world without increasing demands on staff time” [Wilson *et al.*, 1997]. However, potentially this technology can also be used to reduce individual, staff-to-patient contact. This is then a negative effect of the way in which the technology is used, not of the technology itself.

Recently, attempts to replace human contact with technology have in fact been made through the therapeutic use of companion robots. These products have been developed in Japan, where there is less resistance to robots with human features than in most other parts of the world. Elderly patients are invited to interact with robots such as the robot baby seal Paro that reacts when one speaks to it or pets its fur, and the “healing partner” Yumel that looks like a baby boy, has a vocabulary of 1200 phrases, and sings lullabies. Patients tend to appreciate these robots, cuddle with them and talk to them. Some patients with age-related dementia do not realize that they are interacting with a machine [Sullins, 2005]. Replacing human contact in this way is obviously problematic from an ethical point of view. It is questionable whether it is compatible with human dignity to provide demented patients with technological devices that they wrongly believe to be living beings. However, on the other hand, removing these robots without replacing them with true human contacts is not necessarily an improvement.

### 6.3 *The technological imperative*

Resistance to technological medicine has a long history. Around the year 1900 there was a “neohippocratic” movement among doctors who saw scientific medicine as a threat to the old art of medicine. One of the most prominent members of this movement was Ernst Schweninger, Bismarck’s personal physician [Koch, 1985].

A much stronger such movement developed in the 1960s and 1970s as a counter-reaction to the rapidly growing use of mechanical and electronic equipment in healthcare. In 1968 economist Victor Fuchs introduced the term “technological

imperative”, by which he meant the tendency to give the best care that is technically possible, even if its costs are high [Fuchs, 1968; Barger-Lux and Robert P. Heaney, 1986]. Much of the criticism of medical technology was couched in the term “medicalization”. This term was used (and possibly invented) in 1961 by T. Szasz who originally used it to describe the incorporation into psychiatry of problems that should not be dealt with as psychiatric or otherwise medical [Nye, 2003]. The term was adapted by Ivan Illich (1926-2002), the foremost critic of technological medicine in this period. Illich, who has been incorrectly credited with inventing the term [Barnet, 2003, pp. 276 and 286], was an ardent critic of scientific medicine and in particular its use of technology [Illich, 1975]. In later years, the form of anti-medical movement that he represented has been significantly weakened.

Critics of medical technology have done great service to society by pointing out various problems in the use of this technology. However, much of their criticism is weakened by an (explicit or implicit) technological determinism: a belief that medical technology of necessity must have certain negative traits, such as being dehumanizing and standing in the way of good care. On the other hand, blind belief in the progress of medical technology can be equally dangerous.

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## Scientific Contribution

# On the value-ladenness of technology in medicine

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**Abstract.** The objective of this article is to analyse the value-ladenness of technology in the context of medicine. To address this issue several characteristics of technology are investigated: i) its interventive capacity, ii) its expansiveness and iii) its influence on the concept of disease, iv) its generalising character, v) its independence of the subjective experience of the patient. By this analysis I hope to unveil the double face of technology: Technology has a Janus-face in modern medicine, and the opposite of its factual face is evaluative.

**Key words:** ethics, technology, value-ladenness, values

### Introduction

In order to address the issue of the value-ladenness of technology in the context of medicine, it is urgent to make clear what “value free” means.<sup>1</sup> “Value-free” apparently does not mean that something is free of being associated with values. There seems to be a general agreement that technology is related to issues of value. Technology has widely enhanced the possibilities of acting and producing which poses the question of how we *ought* to realise these possibilities (Schrader-Frechette & Westra 1997). Rephrased we might say that what *is* urges questions of *ought*. In this respect technology is part of the general question of what *the good life* is and clearly is associated to issues of value. Understanding value-ladenness as anything that poses value issues certainly answers the question of whether technology is “value-laden”. It also replies to the question of how this influences medicine: by giving rise to a variety of ethical challenges technology makes medicine “value-laden”.

However, this understanding of value-ladenness does not add to our theoretical knowledge of medicine.<sup>2</sup> Even proponents of “value-free” technology will agree that technology is associated with issues of value. In particular they argue that the values associated with technology are values of society at large (Bijker 1990; Hollander 1997; Tatum 1997), certain social classes (Rothman 1997) or particular interest groups (Vos 1991; Payer 1992; Moss 1991; Blume 1992).

Therefore in this study “value-free” will mean that values are aspects external to technology as such.

Correspondingly, the claim that “technology is value-laden” will denote that values are related to technology qua technology. Technology does not only generate issues of value, but it is related to values as such. In other words, if technology is value-laden, it is not only a matter of what *is*, but also what *ought* to be, not only of what *could be done*, but what *ought* to be done.

Hence, the objective of this study is to analyse the value-ladenness of technology in the context of medicine. How then, can technology be conceived of as value-laden? There appears to be two major approaches to answer this question. The most common way to analyse the value-ladenness of technology is by an overall theoretical approach. There are several positions conceiving of technology as value-laden. It has been argued that technology represents an imperative enforcing humans to act in certain ways. Technology, under cover of being a mean, directs human ends and values. This position has been labelled *technological determinism* and its main issue is to investigate this *technological imperative* (Ellul, 1964; Winner, 1977; Smith and Marx, 1994).

From a phenomenological position it is claimed that technology is part of human understanding of being (Heidegger, 1953; Idhe, 1990). Man and his world are shaped by technology, which is of value not only as means for certain ends, but as a basic part of our being.<sup>3</sup>

An alternative approach to this theoretical analysis of value-ladenness of technology is to analyse technology’s value-ladenness from a practical point of view: How do we recognise values of technology in medical practice? Instead of subscribing to any of the

mentioned monistic perspectives on technology and value, I will try to analyse how values are related to technology on a practical and detailed level. In other words, I will investigate whether the monistic theories of technology are adequate for analysing the issues of value. In particular, I will analyse a collection of well known examples to illustrate the wide range of value-ladenness related to medical technology. The examples will demonstrate how difficult it is to comprise technology's value-ladenness within a monistic theory. As a framework for this analysis I will investigate some key characteristics of technology in medicine. Technology is characterised as being:

- i) *Interventive*: Through technology medicine has changed from assisting the healing capacity of nature to controlling and manipulating bodily healing itself.
- ii) *Expansive*: Due to its interventive capacity technology has greatly expanded the field of medicine and increased its specialisation.
- iii) *Defining disease*: By providing the basic phenomena to be studied and manipulated in medicine, technology strongly influences the concept of disease, and hence medical action. It defines what is diagnosed and what is treated.
- iv) *Generalising*: It represents a general method for diagnosis, palliation and treatment. Its ability to generate reproducible results has made medicine a science.
- v) *Liberating*: Technology has made medical knowledge independent from the subjective experience of the patient.

Hence, the objective is to investigate these characteristics in order to analyse the value-ladenness of technology in the context of medicine. In particular, it will be argued that technology does not only generate (external) issues of value, but it represents issues of values as such. Technology is value-laden on a constitutive level, which becomes particularly clear in medicine.

### 1. Interventive medicine

Hence, one of the main characteristics of technology in medicine is that it is interventive (*interveniere*). It has come to control and manipulate the organs, functions and processes of the human body. Conditions that earlier were fatal are today treated and cured. This interventive capacity of technology has greatly expanded the field of medicine, and it has changed medicine in several ways.

Firstly, whereas medicine earlier mainly was explanatory, it has now become manipulative. The

function of humoral pathology was mainly to explain the observed phenomena. Practical measurement of and intervention with the processes of nature were of little interest (Hippocrates: *On ancient medicine*). The role of medicine was to explain and foresee the processes of nature. Today its function is to intervene in the observed processes. Practice comes before theory: Interventive methods are applied if they prove effective, independent of whether their mechanisms are known.

Secondly, the interventive capacity has altered the content of medicine. The explanatory entities of assistive medicine have been replaced by the manipulative entities of technological medicine. Physiology, biochemistry and molecular biology have become basic subjects in medicine because they identify entities that can be manipulated. The interest, for example in the chemical substances of the human body, is due to the possibility of manipulating them. Hence, the interventive capacity of technological medicine has changed the subject matter of medical knowledge.

Thirdly, technological medicine has strongly influenced the classification of diseases. What is possible to manipulate and treat has been defined as a disease. The influence of technological medicine on the concept of disease will be dealt with later. Suffice it here to note that its interventiveness has influenced medical taxonomy. It influences what is and what is not subject to medical attention.

Fourthly, technology's interventive capacity has changed the status of medicine. Through the extended potential of action it represents power. The medical profession has gained power by the interventive and manipulative capacity of technology.

Altogether, the interventiveness of technology has altered medicine in a profound way, and this is an issue of value in several aspects.

#### *Evaluative aspects of interventive medicine*

This is not the place to enter into a discussion of the vast number of examples of evaluative challenges inherent in the *interventive capacity* of medicine. Only some issues will be investigated to illustrate the spectrum of fundamental evaluative issues: Firstly, technology challenges the concept of the patient. Secondly, it urges medicine to define its goals, and thirdly, to set limits to its activity. Additionally, there is an extended responsibility inherent in the extended potential of technological medicine.

The interventive capacity challenges the concept of the patient. It gives rise to the question: Who is the subject of the treatment – who is the patient? Technological medicine involves other subjects than

the traditional one-to-one patient-physician relationship. Transplant technology forces the physician to pay attention to the donor. Foetal surgery forces health care professionals to balance the concerns for the mother with the concerns for the child. In vitro fertilisation poses similar challenges. Perfusion of a brain-dead mother until her foetus is viable or of an anencephalic child until its vital organs can be transplanted into another baby represent similar types of evaluations. Xenotransplantation and cloning are other examples. These cases illustrate how technology challenges traditional values in medicine: the personal physician-patient relationship.

Moreover, the interventive capacity of technology challenges the goals of medicine (Kass, 1975; Hanson and Callahan, 1999). The case of life-sustaining treatment is a widely applied example. The possibilities for keeping comatose patients alive with respirators forced us to answer the question of *why*: What is the end of such treatment? Is it survival and extension of life, or is it the welfare of the patient? Inherent in issues of foetal surgery, human enhancement and genetic engineering there reside questions concerning the purpose of interventive treatment. The same questions are posed in cases where technological medicine is applied in excess, is futile, or is detrimental.<sup>4</sup> If the interventive capacities of technological medicine influence the actions and ends of medicine, they are issues of value. They do not only tell us what is, but also question what ought to be.<sup>5</sup>

Determination of the goals for interventive medicine touches upon an additional evaluative question: *Whose* goals? Does the interventive treatment serve the patient, the relatives, the professionals or society? The case of *hypoplastic left heart syndrome* might illustrate this (Bove and Lloyd, 1996; Hagemo et al., 1997; Kern et al., 1997). Here it is not obvious whether the complex, painful and risky treatment with low efficacy and effectiveness serves the benefits of the child, the parents, the skills of the professional or society. The difficulty of defining the goals of interventive medicine therefore relates to the concept of *who* is the subject in medical treatment. Hence, the interventiveness of technological medicine challenges patient autonomy.

Related to this urge for defining the goals of medicine due to technological interventiveness is a requirement to set limits to its activity. Where are the limits to what medicine should do? When the possibilities of treatment are substantially extended it becomes important to know when to abstain from or when to terminate treatment. Inherent in technology's interventiveness there is an issue of its limits, which is clearly displayed in medicine.

Additionally, the comprehensive capacity of interventive medicine is associated with an extended

responsibility. The thalidomide case illustrates how the increase in interventive capacity of medicine also increases the seriousness of its consequences if applied erroneously. An increase in the possibility of doing good also enhances the potential of doing wrong. The extensive possibilities related to technological medicine lead to extended responsibilities.<sup>6</sup>

So, as a result of the interventive capacity of technological medicine, the concept of *patient* in medicine is challenged. Due to the increased interventive capacity the goals and limits of medicine have to be redefined, and physicians face an enhanced responsibility. Altogether, what is possible in technological medicine is related to the questions of what *ought* to be done. *Can* implies the question of *ought*. Hence, inherent in the interventive capacity of technology in medicine we encounter issues of value. Inherent in factual issues of *how* to do things, there is an evaluative question of *if* and *what* to do. The new possibilities force us to cope.

## 2. The technological expansion of medical knowledge

Related to the expanded possibility to intervene, there is an expanded possibility to know. Due to the interventive capacity and the widespread application of technology, the *Corpus Medicorum* has become more extensive and specialised than ever.

This has given rise to a set of demanding questions: Is the new knowledge *good or bad*? Furthermore, *how* is this comprehensive knowledge to be applied? For example, is it right to clone humans, or to make hybrid pigs for xenotransplantation? How shall we ration technological medicine? It has been argued that the evaluative aspects of this expansion of medical knowledge have been ignored (Jonas, 1985; Gadamer, 1993) and, as a consequence, that medicine does more harm than good (Illich, 1975; Lewis, 1977; Stewart-Brown and Farmer, 1997; Sharpe and Faden, 1998; Fischer and Welch 1999). Is it true that we have grown to become technological giants, while we are still to be considered as ethical embryos? Science and technology does not appear to liberate medicine from ethical issues, on the contrary: "It is paradoxical, perhaps, that to apply the creations of our newest scientific disciplines, physicians must reexamine the moral principles by which they act, and turn to ethics, one of our oldest humanistic disciplines" (Reiser, 1977, p. 55).

It is beyond the scope of this study even to sketch the features of this technologically determined expansion of medical knowledge. Only the case of predictive testing will be employed to exemplify the expansion of medical knowledge and its evaluative challenges.

### *Predictive testing – a case study*

Particular to predictive testing is that it can be used to detect cases of disease where the patient has no subjective experience of being ill. Such *asymptomatic diseases*<sup>7</sup> seem to be rich in evaluative consequences. The aims of treatment are altered from removing causes and symptoms of experienced illness to treating unperceived disease. This represents a fundamental epistemological and evaluative change in medicine. Epistemologically, medical knowledge seems to be independent of the patient's subjective experience. This will be discussed in detail later. Evaluatively, the initiative of care and cure is shifted from the patient seeking help to the health care provider offering assistance.<sup>8</sup> Hence, medicine seems to have liberated itself from the initial initiative of the patient.

It has transgressed its traditional ethical basis where a person seeks help because of pain, discomfort, weakness, or ailment. Furthermore, medicine's independence of the patient's illness gives health care unrestricted power to prescribe treatment. Misuse of such power is not difficult to imagine, and how to manage this power is obviously an evaluative challenge. Predictive diagnostics, therefore, represent a change in the ethical status of the patient.

Additionally, some cases of *asymptomatic diseases* would never have become apparent to the patient if they had not been detected by a predictive test. The patient would never have developed symptoms during his or her lifetime. (Black and Welch, 1993; Stewart-Brown and Farmer, 1997; Kevnanagh and Broom, 1998). Papillary carcinoma of the thyroid, ductal carcinoma in situ of a woman's breast and adenocarcinoma of the prostate are examples of such cases.<sup>9</sup> So far, there is no way of predicting who will develop symptoms and who will not. If all the detected instances were followed up therapeutically, more healthy persons would be treated. Predictive testing, hence, increases the prevalence of the disease. Whether it is *good* or *bad* for medicine to "make people diseased" in this manner is a question of value.

Correspondingly, knowledge of a detected disease may make a person anxious and ill. The uncertainty related to this kind of medical knowledge may have a negative physical and psychosocial effect.<sup>10</sup> It has been shown that technological markers, e.g. foetal ultrasound, can result in anxiety and can have a negative influence on health (Malone, 1996). In this respect the technological expansion of medical knowledge can be harmful.<sup>11</sup> This illustrates the evaluate aspects related to new knowledge, which is especially important with diagnostic methods where no treatment exists for the detected disease.

Furthermore, predictive tests embody the evaluative issue of how much pain and inconvenience a person should be exposed to in cases where the probability for a disease developing is small. Is it right to remove the colon of a patient who has a hereditary polyposis and a mutation of the APC-gene (Ponder, 1997)? There is a profound difference between a person who is ill and needs help and a person who is not ill, when it comes to exposing them to treatment and the related pain and risk (Skrabanek, 1994, p. 36).

Altogether, predictive tests can make people diseased. Firstly, they can define people who do not feel ill as diseased. Thus they transgress the initiative of the patient. Secondly, they might lead to treatment of persons who never in their lifetime would have developed symptoms. Thirdly, the knowledge of an unperceived disease may make people both ill and diseased. They force us to deal with risk and uncertainty. Hence, predictive tests represent a *medicalisation* of human conditions. At what level we will allow this to happen is not a purely factual matter, but a matter of values as well.

### *Epistemic insufficiency*

One of the difficulties due to this technological expansion of medical knowledge is, as argued, knowledge of disease without illness. But the opposite situation might also be problematic: where the patient is ill, but no disease can be detected. Is the patient then not diseased? Does he not qualify for treatment or care? If he does, by what means? Is he socially, but not medically diseased (Räikkä, 1996)?

Cases of illness without disease equally represent basic evaluative challenges to technological medicine. Despite the impressive amount of medical knowledge in ever more specialised sub-domains they illustrate an *epistemic insufficiency* in medicine. The knowledge of technological medicine is imperfect (Thomas, 1977). "There is a vast ocean of ignorance at the heart of medicine" (Le Fanu, 1999 p. 178).<sup>12</sup> This does not, however, differ from other systems of medical knowledge. All theoretical frameworks of medicine seem to be insufficient. The difference is that technological medicine appears to be *omnipotent* and *omniscient*. If the limits of medical knowledge are not acknowledged, many patients may suffer. Thus, ignorance of the *epistemic insufficiency* appears to be an issue of value. Ignoring the *docta ignorantia* in technological medicine is a matter of *good* and *bad*.

In addition there is a high turnover of medical knowledge. Yesterday's method is out-dated today. This turnover pushes the evaluative questions forward: What knowledge is *good* and how ought it to be applied? Is it immoral not to offer patients help

according to the most up-to-date knowledge? In particular it raises a practical question highly relevant for clinicians: How is it possible to be updated? When is the right time to change to a new method? How much better must a new method be before its benefits outweigh the costs of abandoning a well-established method? How are we to evaluate the efficacy, effectiveness and efficiency of new methodology?

Furthermore, technological medicine presents more possibilities for diagnosis and treatment than available resources can realise. Thus technological medicine has enhanced the problem of triage and forced us to ration resources (Reiser, 1978; Aron and Schwartz, 1984; Anspach, 1987; Rothman, 1997). Some of the patients with diseases that can be detected and treated will not receive treatment. Which patients are to be given a heart-transplant? Who shall be treated for cataracts or have dialysis and who shall not have? The questions of *whom* shall be given health care services and *who* is to decide are practical and evaluative questions. They cannot be answered by simply referring to the descriptive powers of technology or resolved by implementing more technology.

Hence, the technological expansion of medical knowledge includes evaluative challenges. Knowledge of *how* the human body works and reacts, and *what* to do to influence it, comprises the question of *when* and *how* this knowledge *ought* to be applied and when to recognise its limits.

### 3. The technological constitution of disease

Technology appears to have become a paradigm in medicine by prescribing ways of detecting, identifying and treating disease. Disease now can be measured with objective instruments (Twaddle, 1993, p. 9). *Epilepsy*, originally conceived as a spiritual influence (Hippocrates: *The sacred disease*), through technology (electroencephalography, microscopic techniques, chemical analysers) has become a disturbance of electrical activity of the brain caused by paroxysmal malfunction of cerebral nerve cells. In the same manner a variety of cardiac conditions are defined by specific ECG-patterns, ultrasound flow measurements and radiographical morphology. The ability to measure blood pressure and to identify *Helicobacter pylori* has made such signs and markers define disease.

The technological influence on the concept of disease is not, however, limited to diagnosis. The success of technology in medicine has made technology the criterion of demarcation for treatment (Brown, 1985, p. 317). The methods of technology determine what is treatable and thereby set a precedent for what is to be treated.<sup>13</sup> Medical technology has

become the measure of all things; a kind of *ars mensura*, or a *technê metrikê*<sup>14</sup> of the modern age, being the measure of what is good and bad, what is diseased and what is not diseased, what is to be treated and what is not to be treated.

Therapeutically, the technologies of corrective surgery, blood pressure regulation and artificial fertilisation have made health care professionals treat these conditions as diseases: *hypoplastic left heart syndrome*, *hypertension* and *infertility*. Decisions and prognosis have come to be based on technology (Anspach, 1987; Tijmstra, 1989). Mitcham elegantly summarises this influence of technology on concepts of medicine:

Medicine is increasingly defined . . . by the type and character of its instruments (from stethoscope to high-tech imaging devices) and the construction of special human-artefact interactions (synthetic drugs, prosthetic devices). Indeed, the physician-patient relationship, medical knowledge, and the concept of health are all affected by technological change. (Mitcham, 1995, p. 2477).

Technology is not only involved in defining disease, but also in generating knowledge of disease. It has become the *definiens* of disease and appears to have become the paradigm method of medicine. Technology constitutes the categories of the medical gaze. "The technology mediates between the seer and the seen and what is seen becomes largely constituted by technology. This is why practices change with the development of new technologies" (Cooper, 1996, p. 394). Advances in technology facilitate the identification of new markers that will be treated as disease (Whittle, 1997). Technology comprises the physiological, biochemical and bio-molecular objects and events that constitute the disease entities in both diagnostics and treatment. For example, angiography, echo-doppler and tissue-velocity-imaging have resulted in an extended classification of myocardial infarction. Thus, epistemologically, ontologically and practically, technology is involved in constituting the concept of disease.

#### *Technology, disease and value*

Does this technological constitution of disease mean that technology has enabled a descriptive conception of disease? This does not seem to be the case. As previously argued, the interventive capacity of technology and its expansion of medical knowledge is not able to transcend issues of value. The concept of disease will be subject to the same evaluative challenges as the technology that defines it. Some of these

have already been discussed. However, other evaluative aspects appear to be related to the technological constitution of disease as well.

Defining disease by setting limits to what is normal and what is pathological is a matter of value (Canguilhem, 1991). Although technology offers a method of reproducible detection and identification of diabetes, defining the limits of normality is nevertheless an evaluative issue. The limits of diabetes defined by the American Diabetes Association (ADA) or by WHO are not factual descriptions. If one applies the WHO limit instead of that of ADA, then the prevalence of the disease is almost doubled (Wahl et al., 1998). Hence, the WHO definition of diabetes makes people diseased. The definition of normality, and thus disease, is an evaluative matter (Robinson and Bevan, 1993).

Furthermore, the sensitivity to the markers used to detect disease is continuously improved, as technology develops. This *increased sensitivity* expands the range of conditions qualifying for the status of disease. Thus, technology lowers the limits of disease and increases its prevalence. The detection of increasingly milder cases results in treatment of an increasing number of conditions. In practice technologically increased sensitivity results in a *lowered treatment threshold*. Increased sensitivity and lowered treatment comprise the evaluative issues of what is *good* diagnosis and what is *good* treatment. They include issues such as futile treatment and medicalisation (Fischer and Welch 1999).<sup>15</sup>

Moreover, technology has altered the end-points of medical activity. Technology defines the entities and markers to be studied and manipulated. In practice it tends to make medicine pursue *soft end-points* like *cardiac blood flow* and *cholesterol concentration*, and constitutes such conditions as diseases. When these markers are within normal limits, the patient is per se healthy.

However, the selection of end-points is a matter of value, and manipulating soft end-points does not guarantee results in terms of *hard end-points* such as survival and morbidity. Clinically the prevalence of prostate cancer in men aged between 60 and 70 is about 1%. However, by applying transrectal ultrasound or MRI more than 40% of men in the same age group have been diagnosed as having prostate cancer (Monti et al., 1989). Technology's focus of attention is on diagnostic and therapeutic impact and not on patient outcome (Bruke, 1994; Pickering, 1996). This technological affinity to soft end-points can be conceived of as a form of medicalisation and a form of disregard of patient autonomy.

Thus, inherent in the technological constitution of disease the measure of disease is changed, the limits to

normality must be set and the prevalence of disease and the outcome of treatment are altered. Hence, the *technological constitution of disease* is a matter of value. It influences who is diseased and who is not, who is entitled to treatment and who is not, who will receive economic support, and who will not.

The objective here was neither to give a detailed description of a technological conception of disease, nor was it to give an exhaustive analysis of the evaluative issues of the disease concept. More modestly, the objective was to argue that the conception of disease is influenced by technology and that this reveals its value-ladenness. The issues of value cannot be removed from a technologically constituted concept of disease.

#### 4. Generalising technology

One important characteristic of technology is its generalising ability. Technology facilitated the study and identification of the general in the particular. The ECG and X-ray rendered an objective way to scrutinise disease.

Ophthalmoscope, bronchoscope, etc. allow him [the physician] a direct view of the conditions of many parts. Experimental medicine enables the physician to interpret his findings so as to translate the language of symptoms and tests into the language of physiological processes. Here then is a scientific approach to individual sickness (Temkin, 1963, p. 636).

Technology eliminated both the singularity of the patient and subjectivity of the physician (Reiser 1978) and strongly influenced the postulates of causation in medicine (Evans, 1991). In short, technology made medicine a science (Temkin, 1963; Cassell, 1993, p. 38).

Technology facilitates the translation of individual illness into the objective language of physiology (Ferkiss, 1969; Jonsen, 1990, p. 25).<sup>16</sup> Through technology medicine gains objective data (Jonsen, 1990, p. 25), and technology represents a standard method of detection, identification and treatment of disease. In this way technology accounts for the reproducibility of results and for the accumulation of nomological knowledge. The MRI-machine presents a standard image of the human brain and automated laboratory analysers produce positive test results when the number and shape of blood cells deviate from normal statistical values.

This abstracting and generalising characteristic has been crucial for the argument that technological medicine is value-neutral (Sundström, 1998). Nevertheless,

rather than escaping the evaluative, the generalising attribute of medicine emphasises its value-ladenness. This value-ladenness can be illustrated by scrutiny of some of the flaws of this generalising characteristic.

#### *Evaluative aspects of generalising technology*

Let me briefly mention four flaws due to technological generalisation frequently referred to in the literature and then investigate some of the value related issues. Firstly, technological generalisation is based on populations rather than on the individual. The single patient might gain from general methodology, but might also suffer from it, due to natural variation in a population (Jonas, 1985; Gadamer, 1993, Delkeskamp-Hayes and Cutter, 1993).

Secondly, no technological method is absolutely effective, nor perfectly accurate and reliable. The same blood sample tested with the same chemical analyser may give different results for consecutive tests, e.g. blood gas measurements. There is statistical variation in the results due to the technological method. This might lead to erroneous diagnosis and treatment. The test can fail to detect disease and can detect disease when there is none.

Thirdly, inter-observer and intra-observer variability reduces the effectiveness of the method. Even if there was no variation in the population and the method was perfectly accurate and reliable, there would still be variation in the application of diagnostic and therapeutic technology. Different physicians apply technology differently in different cases (Jennett, 1988; 1994). Hence, the practical implementation and particular application of even a perfect method might be flawed.

Fourthly, technology is applied to different populations than the one they are tested on. Obviously tested technology is not applied to the test population again. This calls for careful judgement. It is well-known that diagnostic procedures and types of treatment that have been tested on hospitalised patients have been applied in general practice, and methods tested on men have been applied to women, which has resulted in erroneous diagnosis and treatment.

These profound flaws of the technology of medicine present evaluative challenges. On a general basis it is argued that the generalised method in medicine is erroneous (Gorovitz and MacIntyre, 1976, Leape, 1994). How we handle this inherent error in medicine is a matter of *value* and not only of *fact*. Let me briefly investigate some of the evaluative aspects.

Firstly, the question of how we handle the insufficiency of the generalising technology is an evaluative matter. How many false positives and false negatives will we allow? What level of significance do

we accept? How much are we willing to let some patients suffer to help others? What responsibilities do health care professionals have towards the healthy persons that are treated and the diseased persons who are ignored? The very definition of confidence intervals is evaluative and the concepts of false negatives and false positives are issues related to *good* and *bad*.

Secondly, the ability to communicate the possibilities and restrictions of medicine due to its generalisation relate to ethical matters such as patient autonomy, informed consent and paternalism. Does the patient understand the uncertainty and risk? How do we act if he does not?

Thirdly, it has been claimed that the generalising method of technology in medicine tends to alter the physician's responsibility for the individual patient (Jonas, 1985; Gadamer, 1993, Delkeskamp-Hayes and Cutter, 1993). It is accused of freeing the physician from personal obligation towards the patient. "Western medicine and the modern paradigm of knowledge are heavily biased towards abstraction, we all tend to feel drawn away from the attempt to identify with the patient's experience" (McWhinney, 1997).

In other words, generalisation by technology leads to what might be called an *epistemic abstraction* from the particular patient, which has adherent evaluative aspects. Whether this *epistemic abstraction* also results in a corresponding *evaluative abstraction* from the patient will be discussed in the following section. The point here is that the generalising characteristic of technology does not make medicine escape issues of value. Handling the *epistemic abstraction* and its flaws is not a matter of how nature *is*, but of how we *ought* to live. The technological generalisation in medicine is in itself an evaluative matter.

#### **5. Technological emancipation from the subjective patient**

A crucial aspect of the technological generalisation discussed above is its abstraction from the individual person. Technology has altered the relationship of medicine to its subject matter: the patient. In other words, the objectivity of medicine is achieved by making the patient an object and liberating itself from the patient's subjective experience. However, this independence from the patient is an evaluative issue.

It is argued that before the Eighteenth Century, medicine was based on the patient's narrative of his or her symptoms. In addition to this subjective portrait of the illness, the physician observed the patient's appearance and behaviour as well as any signs of disease. During the Eighteenth and Nine-

teenth Centuries medical instrumentation enabled and extended the physical examination of patients, which made the physician less dependant on subjective narration (Reiser, 1995, pp. 1–90). The stethoscope gave the physician direct access to the disease. Measuring blood pressure gave an objective measure of internal conditions in the patient. The introduction of machines such as the ECG, X-ray and chemical laboratory analysers during the Nineteenth and Twentieth Centuries further enhanced the objectivity of medicine (Reiser, 1995, pp. 91–157). In addition to removing the subjective errors introduced by the patients, technology also reduced the number of erroneous judgements made by physicians. Technology liberated medicine from the subjective, individual and emotional factors, which confused the conception of the real objective disease. “Twentieth-century technology with all its progress had tended to push the human dilemmas of illness out of the doctor’s thoughts, and replace them with laboratory facts derived from tests on the patient’s body” (Reiser, 1978, p. 225).

Due to the generalisation in medicine the individual patient today contributes to the *Corpus Medicorum* only as one of many. The epistemic significance of the individual is reduced to a statistical entity. Accordingly, technology creates a physical distance between the physician and the patient (Jennett, 1994, p. 862), making it a ‘stranger medicine’ (Veatch, 1085; Rothman, 1991).

“Technological methods move the evidence employed in diagnosis away from the patient and reduce the impact of the patient’s particularity on the physician” (Cassell, 1993, p. 36). The capacities of technological medicine have excluded the individual patient as the epistemic basis of medicine (Le Fanu, 1999 p.194). The essential question following from this is whether the evaluative status of the patient has been altered correspondingly.

Critics of modern medicine claim that technology’s focus on the objective and the general has resulted in a neglect of the individual patient (Glover, 1977; Pellegrino, 1979; Jonas 1985; Cassell, 1993; Gadamer, 1993). This transgresses the traditional normative basis of medicine. Ever since the awakening of medical self-consciousness, the *raison d’être* of medicine has been to heal and help the individual patient.<sup>17</sup> The objective of medicine was the *good* of the particular patient. With technology in medicine there has been “a detachment from the suffering of [the] patient” (Cassell, 1993, p. 34). This is a detachment of the professional from the personal, disease from illness and signs from symptoms, making medicine face profound evaluative challenges such as medicalisation, reductionism, curative bias and paternalism. As already mentioned, there is a shift in initiative due to techno-

logy: the patient does not seek the health care system because he or she feels *bad*, but because the technological method detects something that is considered to be *bad* for the patient. The evaluative initiative is shifted from the patient to the health care system.

Hence, there appears to be a reduction of the evaluative status of the patient corresponding to the reduction in epistemic significance; there is an *evaluative abstraction* from the patient matching the *epistemic abstraction*. This represents what might be called an *evaluative ignorance of the individual* in technological medicine.

#### *Evaluative characteristic of technological medicine*

Altogether, the technology of medicine has been characterised by the following attributes:

- i) *Interventive capacity*: Taking on an interventive and manipulative attitude.
- ii) *Epistemic expansion*: The substantial extension of *Corpus Medicorum* due to technology.
- iii) *Constituting disease*: The influence of technology on the concept of disease.
- iv) *Generalising*: The technological generalisation of medical knowledge.
- v) *Liberating from the subjective experience of the patient*: Making medical knowledge independent of the subjective experience of the patient.

The practically oriented analysis of these characteristics has revealed their inherent evaluative aspects. Within the possibilities of technology resides the question of whether it is *good* or *bad* to realise them. In concert with the potential of technology we face issues of *how*, *when*, *why*, *for whom*, and *by whom* it is to be applied. Within the knowledge of what *is* and what *can* be done with medical technology resides the challenge of what we *ought* to do. At the same time as technology expands our potential for action it urges us to define the ends of and set limits to its application. The relationship between technology and value comes particularly clear in medicine, explicitly dealing with issues of *good* and *bad* of the body (and mind).

In this study I have not dealt with the details on how in particular values relate to technology. This is the issue of another study. Here the main objective has been to argue that there is a close relationship between technology and value, particularly apparent in medicine. In other words: there is a close relationship between technology and ethics. Technology represents a Janus-face in medicine. The opposite of technology’s descriptive face is evaluative.<sup>18</sup>

### Concluding remarks: The Janus-face of medicine

The investigation of the relation between technology and value seems to be rich in consequences. Firstly, it is apparent that technology does not exclusively represent value-neutral means towards an external end. The study seriously questions the commonplace value-neutrality dictum.<sup>19</sup> The evaluative challenges related to technological medicine are not issues of conflicting external ends and cannot be resolved by agreeing upon external goals of medical activity. Technology, being inherently evaluative, constitutes medical knowledge. Technology makes medicine a scientific, but also a moral enterprise.

Secondly, even though the study has made me question the value-neutral dictum of technological medicine this is done without subscribing to one of the monistic theories of technology. The examples illustrate a wide range of value-ladenness of technology in medicine and demonstrate the difficulties of subscribing them all to one of the traditional critiques in the philosophy of technology. The monistic theories appear to fail to comprise the vast variety of value-aspects of technology in medicine. Additionally, the analysis shows the fruitfulness of a detailed approach to medical practice.

Thirdly, medicine is particularly suitable to study the value-ladenness of technology because its evaluative aspects are easily recognisable. Issues of value are widely recognised in medicine, and (bio)medical ethics is an important branch of moral philosophy (Toulmin 1986).

Hence, the conclusion of the study can be phrased: “*is* implies *ought*”, but in the sense that the matter of what *is* in medicine comprises the evaluative issue of how it *ought* to be. There is reciprocity between *is* and *ought*; between the possible and the actual; between knowledge and its application; between fact and value. That is, there is a constitutive relationship between values and technology in medicine. By stepping into the doorway (*januae*) of technology we are already in the realm of value.

### Notes

1. There appear to be many kinds of value: economic, esthetic and moral. To restrict the topic, “value” will in this study refer to moral value.
2. Value is not related to technology as such, but in the same manner as value relates to other objects and actions: they can be of value.
3. In the philosophy of medicine we can recognise both the position of technological determinism (Bennett, 1977; Hellerstein, 1983; Tijnstra, 1989; Cassell, 1993; Davidson, 1995; Muraskas et al, 1999) and the phenomenological approach (Cooper, 1996).
4. In particular, see (Illich, 1975; Reiser, 1978; Jennett, 1986; Payer, 1992, pp. 37–52; Cassell, 1993; Schneidermann et al., 1995; Tijnstra, 1989; Fischer and Welch, 1999).
5. Screening is a case that further exemplifies the difficulties of defining goals of medical treatment (Black, 1993; Stewart-Brown and Farmer, 1997; Kevnanagh and Broom, 1998; Kerbel et al., 1997; Whittle, 1997; Malone, 1996; Chevenak, 1998). The benefits of discovering disease have to be weighed against their costs, such as medicalisation of people, false positive or false negative results, detection of cases that are untreatable, anxiety among patients, and application of technological methods by doctors who lack clinical competence. The task of weighing the ends involved in such complex situations is certainly an evaluative matter.
6. The substantial increase in malpractice suits may be an indication of this.
7. Cases of detected disease without any symptoms have also been called lanthanic diseases (Feinstein, 1967).
8. Cases of health care where patients do not request help have been called non-iatropic diseases (Feinstein, 1967). Such cases seem to be of ethical relevance in profit maximising health care systems appealing to people’s uncertainty, anxiety and concern for their health.
9. Cases of detected disease that would never have become apparent to the person have been called pseudodiseases (Helman, 1985; Fisher and Welch, 1999, p. 449).
10. See for example (Tijnstra, 1989; Green, 1990; Black and Welch, 1993; Kevnanagh and Broom, 1998).
11. The way that technological knowledge may be harmful can be called technological stigmatisation.
12. The incompleteness of medical knowledge is also demonstrated by the fact that a large number of diseases have unknown aetiology. In many cases medicine can only treat the symptoms and not the causes.  
However, can technological medicine ever reach complete knowledge? Gorovitz and MacIntyre argue that medical knowledge will always be incomplete, and that ignorance of this fact makes medicine erroneous (Gorovitz and MacIntyre, 1976). Gadamer also argues that there is an epistemic insufficiency in technological medicine. “Aber trotz allen Fortschritten, die die Naturwissenschaften für unser Wissen um Krankheit und Gesundheit gebracht haben, und trotz dem enormen Aufwand an rationalisierter Technik des Erkennens und Handelns, der sich auf diesem Gebiete entfaltet hat, ist der Bereich des Unrationalisierten hier besonder hoch” (Gadamer, 1987, p. 259). Correspondingly, Paul argues that there is a theoretical insufficiency due to a gap between theory and practice in medicine, termed “Hiatus theoreticus”. This is an epistemological void typically inherent in the stock of medical knowledge itself (Paul, 1998, p. 247).
13. The technological focus on treatment has contributed to what has been called the curative bias in modern medicine, which also is rich in normative consequences.
14. See (Gorgias 356d4–e2).
15. Among these are cases that would otherwise have healed by themselves (*trivia*).

16. For example, the stethoscope enabled the physician to listen to sounds from vessels. The classification of these sounds (Korotkoff) gave a general method of measuring blood pressure. This facilitated the correlation of blood pressure and certain pathological states.
17. See (Hippocrates: *The oath; On the art* III). Both Plato and Aristotle recognised that the challenge in medicine was not the content of medical knowledge, but how it should be applied in particular cases (*Phaedrus* 268a7–c4; *Nicomachean Ethics* 1104a4–6; 1137a10–25; 1097a11–4; 1143b18–32; 1180b5–23).
18. Temkin discusses the “Janus-face” of medicine in the context of the history of medicine (Temkin, 1977). The one face looks into the past, enabling the other to view into the future of the profession. In this study the concept of ‘the Janus-face of medicine’ is applied to emphasise the relationship between medical technology and ethics. The one face looks into the world of how things *are*, the other how they *ought* to be.
19. In the philosophy of technology the value-neutrality dictum has also been characterised as the voluntarist position (Winner, 1977, pp. 53–54; 60–63; 76–77).

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# Medicine and the rise of the robots: a qualitative review of recent advances of artificial intelligence in health

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**ABSTRACT**

Artificial intelligence (AI) has the potential to significantly transform the role of the doctor and revolutionise the practice of medicine. This qualitative review paper summarises the past 12 months of health research in AI, across different medical specialties, and discusses the current strengths as well as challenges, relating to this emerging technology. Doctors, especially those in leadership roles, need to be aware of how quickly AI is advancing in health, so that they are ready to lead the change required for its adoption by the health system. Key points: 'AI has now been shown to be as effective as humans in the diagnosis of various medical conditions, and in some cases, more effective.' When it comes to predicting suicide attempts, recent research suggest AI is better than human beings. 'AI's current strength is in its ability to learn from a large dataset and recognise patterns that can be used to diagnose conditions, putting it in direct competition with medical specialties that are involved in diagnostic tests that involve pattern recognition, such as pathology and radiology'. The current challenges in AI include legal liability and attribution of negligence when errors occur, and the ethical issues relating to patient choices. 'AI systems can also be developed with, or learn, biases, that will need to be identified and mitigated'. As doctors and health leaders, we need to start preparing the profession to be supported by, partnered with, and, in future, potentially be replaced by, AI and advanced robotics systems.

**INTRODUCTION**

Artificial intelligence (AI) has been defined by Alan Turing, the founding father of AI, as 'the science and engineering of making intelligent machines, especially intelligent computer programs'.<sup>1</sup> AI in health uses algorithms and software to approximate the cognition undertaken by human clinicians in the analysis of complex medical data. AI research has been divided into subfields, based on goals such as machine learning or deep learning, and tools such as neural networks, a subset of machine learning.<sup>2</sup> AI has the potential to significantly transform the role of the doctor and revolutionise the practice of medicine, and it is important for all doctors, in particular those in positions of leadership within the health system, to anticipate the potential changes, forecast their impact and plan strategically for the medium to long term.

The impact of automation and robotics have been felt by blue-collar jobs for a while. A recent working paper by the National Bureau of Economic Research found that the arrival of one new industrial robot

in a local labour market coincides with an employment drop of 5.6 workers.<sup>2</sup> Last year alone, there have been news reports of apple-picking robots,<sup>3</sup> burger-flipping robots<sup>4</sup> and a barista robot that makes you coffee.<sup>5</sup> *Nature* even ran an editorial on sex robots.<sup>6</sup>

There is a false sense of security in assuming that automation will only impact blue-collar type work that requires more manual, repetitive actions and less intellectual input. PwC released a report based on a survey of 2500 US consumers and business leaders, which predicts that AI will continue to make in-roads into white collar industries.<sup>7</sup> A large stockbroking firm ran a trial in Europe of its new AI program this year that showed it was much more efficient than traditional methods of buying and selling shares.<sup>8</sup> A Japanese insurance firm replaced 34 employees with an AI system, which it believes will increase productivity by 30% and see a return on its investment in less than 2 years.<sup>9</sup> The *Washington Post* used an AI reporter to publish 850 articles in the past year.<sup>10</sup>

Not even the jobs of computer programmers, the creators of the code for AI, are safe. Microsoft and Cambridge built an AI capable of writing code that would solve simple math problems.<sup>11</sup> Lawyers are not exempt either. Late last year, an AI was able to predict the judicial decisions of the European Court of Human Rights with 79% accuracy.<sup>12</sup>

Compared with other industries like hospitality or airlines, health has been a relative slow adopter of electronic systems, such as electronic health record (EHR) systems, which have only recently become mainstream.<sup>13</sup> Similarly, although AI is now embedded in many forms of technologies such as smartphones and software, its use in the front-line of clinical practice remains limited. Nevertheless, research in this area continues to grow exponentially.

**QUALITATIVE REVIEW METHODOLOGY**

This paper summarises the past 12 months of health research in AI, across different medical specialties, and discusses the current strengths and weaknesses, as well as challenges, relating to this emerging technology. The author notes that much progress has been made by AI developments in health over the past two to three decades and has focused on the past 12 months because of some of the exponential gains made, mainly due to improvements in computer hardware technologies. The author has specifically restricted his review to recent research in AI published in high-ranking peer-reviewed medical



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journals. The selection criteria involved keywords relating to artificial intelligence, machine learning, deep learning and algorithms relating to medical diagnosis, planning and treatment.

This qualitative review is not intended to be a systematic review, and the author has restricted the research to AI research that will likely to have the most impact to clinical practice, a judgement that is subjective to the author's own experience and expertise as a specialist medical administrator in both academia and practice. The time period of around 12 months is because the exponential growth and improvements in AI technology means that any data presented that are older may no longer be applicable.

The focus of the review is to provide a high-level update of recent AI research in health to ensure that medical practitioners, especially those in leadership roles, are made aware of how quickly AI is advancing in health, so that they are made ready to lead the change required for its adoption by the health system.

## FINDINGS

### AI in medical diagnosis

AI has now been shown to be effective in the accurate diagnosis of various medical conditions. For example, in ophthalmology, an AI-based grading algorithm was used to screen fundus photographs obtained from diabetic patients and identify, with high reliability (94% and 98% sensitivity and specificity), to determine cases that should be referred to an ophthalmologist for further evaluation and treatment.<sup>14</sup> In another study, researchers showed that an AI agent, using deep learning and neural networks, accurately diagnosed and provided treatment decisions for congenital cataracts in a multihospital clinical trial, performing just as well as individual ophthalmologists.<sup>15</sup>

In relation to skin cancer, researchers trained a neural network using a dataset of 129 450 clinical images and tested its performance against 21 board-certified dermatologists on biopsy-proven clinical images. The neural network achieved performance on par with all tested experts, demonstrating that an AI was capable of classifying skin cancer with a level of competence comparable with dermatologists.<sup>16</sup> In another study using routine clinical data of over 350 000 patients, machine learning significantly improved accuracy of cardiovascular risk prediction, correctly predicting 355 (additional 7.6%) more patients who developed cardiovascular disease compared with the established algorithm.<sup>17</sup>

Clinical neuroscience has also benefited from AI. A deep-learning algorithm used MRI of the brain of individuals 6 to 12 months old to predict the diagnosis of autism in individual high-risk children at 24 months, with a positive predictive value of 81%.<sup>18</sup> Similarly, in another study, a machine learning method designed to assess the progression to dementia within 24 months, based on a single amyloid PET scan, obtained an accuracy of 84%, outperforming the existing algorithms using the same biomarker measures and previous studies using multiple biomarker modalities.<sup>19</sup>

### AI in psychiatry

AI may be good at diagnosing physical illness, but what about its use in psychological medicine and psychiatry? The emerging literature has also shown that AI is proving to be useful in these clinical areas. For example, researchers built a predictive model based on machine learning using whole-brain functional magnetic resonance imaging (fMRI) to achieve 74% accuracy in identifying patients with more severe negative and positive symptoms in schizophrenia, suggesting the use of brain imaging

to predict the disease and its symptom severity.<sup>20</sup> In another study, researchers demonstrated that a linguistic machine learning system, using fMRI and proton magnetic resonance spectroscopy (<sup>1</sup>H-MRS) inputs, showed nearly perfect classification accuracy and was able to predict lithium response in bipolar patients with at least 88% accuracy in training and 80% accuracy in validation, allowing psychiatrists the ability to predict lithium response and avoid unnecessary treatment.<sup>21</sup>

It is one thing for AI to be able to recognise patterns on images from radiology and pathology tests. Can AI be as good as psychiatrists when it comes to predicting mental health conditions that do not have a clear biomarker? A landmark paper of a meta-analysis of 365 studies spanning 50 years published by the American Psychological Association found that prediction of suicide was only slightly better than chance for all outcomes, and that this predictive ability has not improved across 50 years of research, leading the authors to suggest the need for a shift in focus from risk factors to machine learning-based risk algorithms.<sup>22</sup>

Researchers at the Vanderbilt University Medical Centre created machine-learning algorithms that achieved 80%–90% accuracy when predicting whether someone will attempt suicide within the next 2 years, and 92% accuracy in predicting whether someone will attempt suicide within the next week, by applying machine learning to patients' EHRs. In other words, when it comes to predicting suicide attempts, AI appears to be better than human beings, although the clinical applicability in the real world remains unproven.<sup>23</sup> In another study, researchers used machine-learning algorithms to identify individuals at risk of suicide with high (91%) accuracy, based on their altered fMRI neural signatures of death-related and life-related concepts.<sup>24</sup> These developments in AI are now being applied. Facebook is one of several companies exploring ways to use AI algorithms to predict suicide based on mining social media.<sup>25</sup>

### AI in treatment

So, we have established that AI can be helpful in predicting mental health conditions, but can AI also be helpful in the provision of psychological treatments? Researchers found that soldiers are more likely to open up about post-traumatic stress when interviewed by a computer-generated automated virtual interviewer, and such virtual interviewers were found to be superior to human ones in obtaining more psychological symptoms from veterans.<sup>26</sup>

What about robot surgeons? Robotic surgical devices already exist, but they still require human control—is AI able to perform autonomous surgery without human input? In a robotic surgery breakthrough in 2016, a smart surgical robot stitched up a pig's small intestines completely on its own and was able to do a better job on the operation than human surgeons who were given the same task.<sup>27</sup> What is even more impressive is that late last year, a robot dentist in China was able to carry out the world's first successful autonomous implant surgery by fitting two new teeth into a woman's mouth without any human intervention.<sup>28</sup>

### AI's current strengths

So, based on the available evidence, what is AI good at today? It is clear that AI's current strength is in its ability to learn from a large dataset and recognise patterns that can be used to diagnose conditions. This puts AI in direct competition with medical specialties that are involved in diagnostic tests that involve pattern recognition, and the two obvious ones are pathology and radiology.

An editorial on recent studies point to the future of computational pathology, suggesting that computers will increasingly become integrated into the pathology workflow when they can improve accuracy in answering questions that are difficult for pathologists.<sup>29</sup> However, Google researchers used an AI in a study to identify malignant tumours in breast cancer images with an 89% accuracy rate, compared with 73% achieved by a human pathologist.<sup>30</sup> In another study, deep learning algorithms achieved better diagnostic performance than a panel of 11 pathologists, in a simulated time-constrained diagnostic setting, in detecting lymph node metastases in tissue sections of women with breast cancer.<sup>31</sup>

Similarly, radiologists are grappling with the potentially disruptive applications of machine learning to image analysis in their specialty, but remain as a profession optimistic that AI will be able to provide opportunities for radiologists to augment and improve the quality of care they provide to their patients.<sup>32</sup> However, AI systems continue to improve in their diagnostic and predictive capabilities in radiology. For example, a machine-learning model, using three-dimensional cardiac motion on cardiac MRI, was able to predict survival outcome independent of conventional risk factors in patients with newly diagnosed pulmonary hypertension.<sup>33</sup> It is also interesting to note that the first United States Food and Drugs Administration approval for an AI application in a clinical setting is for a deep learning platform in radiology, to help doctors diagnose heart problems.<sup>34</sup>

### Can AI completely replace the role of a doctor?

AI may be as good as, or even better than, humans when it comes to formulating diagnoses based on recognising patterns on images, but is AI ready to take over the complete role of a fully trained medical practitioner? So far, the answer appears to be—not yet. In the first direct comparison of diagnostic accuracy, physicians were found to vastly outperform computer algorithms in diagnostic accuracy (84.3% vs 51.2% correct diagnosis in the top three listed).<sup>35</sup> Bear in mind that this study compared doctors with relatively simple symptom checker applications.

In a more recent study, Watson, IBM's AI platform, took just 10 min to analyse a genome of a patient with brain cancer and suggest a treatment plan, compared with human experts who took 160 hours to make a comparable plan.<sup>36</sup> In another study, Watson found cancer treatments that oncologists overlooked, by discovering 'potential therapeutic options' for 323 additional patients after analysing 'large volumes of data', including past studies, databases and genetic information.<sup>37</sup> It should be noted that these superior performances in the theoretical setting has not translated well into real-world clinical practice, based on recent reports of poor clinician adoption at a major American cancer centre.<sup>38</sup>

As such, it would seem that AI systems may be better than human doctors in coming with diagnoses or management plans, if they are provided with sufficiently large amounts of data that are beyond what humans can manually analyse.

## DISCUSSION

### Challenges of AI in health

It is clear from the qualitative literature review that AI in health has progressed remarkably, even within the span of 12 months looked at. It is likely that much of this recent progress is due to the increasing presence of large training data sets and improvements in computer hardware, in the form of memory and computational capacity. However, there are some challenges that need to be considered as AI usage increases in healthcare. One of

the concerns that has been raised is the issue of legal liability. If a medical error occurs, who is to be held liable? A robot surgeon is not a legal entity, so should the patient sue the owner, the programmer, the manufacturer or someone else? Could an AI ever be subject to criminal liability? These AI dilemmas are not unique to health—for example, there have already been a few high-profile self-driving car accidents, some resulting in fatalities. These are some of the issues that legal experts have been grappling with that are still unresolved.<sup>39</sup>

The other issue to consider is the potential for AI to greatly reduce the number of medical errors and misdiagnoses, and therefore reduce medicolegal claims. What happens when the ability of AI surpasses that of the average doctor? If a doctor relies on the recommendation of an AI tool, which ends up being wrong, is it still the negligence of the doctor if that tool has already been proven to be more reliable than the average doctor? An argument has been put forth, although under the US legal system, to suggest that a by-product of an increased use of AI in health is that doctors will practise less defensive medicine, by ordering less unnecessary tests, because they will be relying on the recommendations of AI systems that are better diagnosticians than they are.<sup>40</sup> In fact, there may come a day that it would be considered negligent for a doctor *not* to consider the recommendation of a health AI system if that becomes the standard of care.

There is also the matter of morality and ethics with AI. The best way to illustrate this issue is by describing the classic 'trolley problem'—if you are in a trolley that is going down a track that is about to hit five workers, and you can redirect the trolley by turning it onto another track but there is one worker on it, is it morally permissible to turn the trolley to spare the lives of five workers by killing the single worker?<sup>41</sup> This dilemma is particularly pertinent to self-driving cars, as that scenario could realistically actually happen in real life—what should the self-driving car in the event of an accident do in an attempt to reduce the number of injured humans? Should the self-driving car prioritise the passengers over the pedestrians? Who gets to make these decisions? The programmer or the passenger?

Researchers have attempted to resolve this issue by suggesting that self-driving cars be equipped with what they call an 'Ethical Knob', a device enabling passengers to ethically customise their autonomous vehicles to choose between different settings corresponding to different moral approaches or principles. In this way, the AI in self-driving cars would be entrusted with implementing users' ethical choices, while manufacturers/programmers would be tasked with enabling the user's choice.<sup>42</sup> Similarly, an AI in healthcare can be provided guidance as to the moral wishes of the patient—for example, does the patient want to maximise length of life or the quality of life?

This brings us to another real issue with AI—inherent bias. AI systems can be inadvertently programmed to have bias because of the biases of the programmers or, with the development of self-learning algorithms, actually learn to be biased based on the data it is learning from. In addition, AI systems find it more difficult to generalise findings from a narrower dataset, with minor differences from a training set potentially making larger-than-intended impact on a prospective set of data, creating potential bias. A recent study demonstrated that AI can learn to have racist or sexist biases, based on word associations that are part of data it was learning from, sourced from the internet that reflected humanity's own cultural and historical biases.<sup>43</sup> Strategies to minimise and mitigate such biases will need to be in place as adoption of AI by health increases.

The last issue that needs to be considered relates to how AI uses data. In the past, EHR systems used to require that data be

properly entered into the correct categories for the right queries to be made to extract useful information. However, the advent of fuzzy logic, a form of AI, now allows for free-text unstructured text to be queried and categorised in real time to provide meaningful information.<sup>44</sup> The quality of the information extracted is still dependent on the accuracy of the data being entered, as patient-reported outcome measures may still be unreliable.<sup>45</sup> In addition, sophisticated AI systems can link disparate health data from separate databases together to form connections that may otherwise be missed.

As such, AI is now being applied to the large health data repositories because of the amount of free-text stored and also because AI, through machine learning, needs access to vast amounts of data. However, the issue of data ownership and privacy needs to be considered. A relevant case study is the recent finding by the UK's Information Commissioner that a National Health Service trust breached privacy laws by sharing patient data with Google for Google's DeepMind Streams app.<sup>46</sup> Although this app did not directly use AI, the alleged data breach demonstrates that need for the development of a data governance framework that takes into account data ownership, privacy principles, patient consent and data security.<sup>47</sup> Current privacy laws may need to be reviewed to ensure they are relevant even as social media and other large technologies like Google start using AI to commercialise the big data they have collected from their millions of users.

### Future of AI

There is no turning back from the rise of AI in all aspects of our lives. AI already resides in the smartphones that a lot of us own, in the form of smart digital assistants. But AI has progressed beyond helpful chatbots. For example, Google's AI group, Deepmind, unveiled AlphaGo, an AI that took just 3 days to master the ancient Chinese board game of Go with no human input, as reported in *Nature*.<sup>48</sup> This version of AI was able to win against its previous version (that famously beat the world champion in Go previously) 100 games to 0. More recently, AlphaZero, another AI from Google, learnt the rules of chess in 4 hours by playing against itself 44 million times and went on to beat Stockfish, a well-established chess program.<sup>49</sup>

AI researchers are already developing AI algorithms that are able to learn, grow and mature like human beings do, through self-reflection<sup>50</sup> and experiencing the world firsthand.<sup>51</sup> AI can currently analyse large amounts of data much faster than humans can using today's hardware. However, quantum computers, which may outperform the classical computers we have today by many factors, are already in development and only a few years away.<sup>52</sup> In addition, scientists have made a pioneering breakthrough by developing photonic computer chips—that use light rather than electricity—that imitate the way the brain's synapses operate, which means that computers may be able to process data at the speed of light in the near future, compared with human nerve conduction speed that is slower than electricity as it is.<sup>53</sup>

With dramatic improvements in computer software and hardware coming online, and increasing access to large datasets that are increasingly being linked together, it is no wonder that Ray Kurzweil, a Google AI expert and well-known futurist, believes that AI will surpass the brainpower of a human being by 2023 and reach what he terms 'singularity' in 2045, which is when AI will surpass the brainpower equivalent to that of all human beings combined.<sup>54</sup>

### Implications for medical leaders

Those of us who are medical leaders in healthcare, in particular, in the public health system, know that the health system is traditionally risk averse and tends to be a slower adopter of new technologies. Nevertheless, it is essential that medical leaders like us are aware of the potential impacts that new health technologies will have on the current and future health system.

As such systems are introduced into our health services, medical leaders need to ensure that there are strong and robust governance structures in place to ensure that there is appropriate review of these new technologies prior to implementation, in terms of their safety, cost-effectiveness and that staff are credentialled to use the new technologies. A data governance framework will also be required to oversee how data are managed internally, the data standards and quality expected, how data are received, how data are secured and how data are shared externally to different stakeholders, in compliance with relevant laws and regulations. An appropriate training regime should also be implemented to ensure that staff are aware of their ethical and legal responsibilities when it comes to data management, especially as it relates to the use of social media.

Medical leaders will also need to constantly scan the horizon for future developments in the field of AI, and consider future risks and opportunities, in order to plan accordingly. AI and automation will have an impact of the health workforce, and workforce planning will need to take this issue into account. The opportunities offered by AI to improve the care of patients need to be taken into account when new IT systems are introduced, in particular, where AI can assist in interrogating large amounts of health data, which may be unstructured or separated into different silos.

Medical leaders should also be aware that AI systems are not just relevant for clinical care—AI systems are increasingly being applied in the management setting. AI can be used to support, and potentially replace, the role of managers, including in health, in financial management, priority setting, resource allocation and workforce management. We will need to consider how AI can support us in our roles, now and into the future.

Lastly, medical leaders will need to be change agents and lead the change as AI transforms the healthcare system in the coming years. We will need to ensure that the patient experience and needs are always prioritised, and that compassion and kindness are not replaced by efficiencies and metrics. As leaders of clinicians, we will need to manage the anxiety of the clinical workforce through potential uncertain times, by refocussing any changes on improving patient care. Ultimately, medical leaders are still doctors, and our duty of care is to our patients.

### CONCLUSION

It is evident from this qualitative review of recent evidence that AI research in health continue to progress, and that AI is proving to be effective in most aspects of medicine, including diagnosis, planning and even treatment. As a profession, we need to have a mature discussion and debate about the legal, ethical and moral challenges of AI in health, and mitigate any potential bias that such systems may inherit from their makers.

Regardless of whether the AI singularity comes to pass or not, AI in health will continue to improve, and these improvements appear to be accelerating. There are clear challenges for the adoption of AI in health for health services, organisations and governments, and a need to develop a policy framework around this issue. As doctors and health leaders, we need to start preparing the profession to be supported by, partnered with, and, in future,

potentially be replaced by, AI and advanced robotics systems. We have an opportunity now to literally shape the development of humanity's future autonomous health providers, and we should be leaders in this space rather than passive observers.

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