Health Humanities

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1
Health Humanities

There is a growing need for a new kind of debate at the intersection of the humanities and healthcare, health and well-being. In the recent past the field of medical humanities has grown rapidly, but it is timely and appropriate to address the increasing and broadening demand from other professions to become involved, to accommodate new sectors of the healthcare workforce and the public, and to extend 'appliedness' in relation to how arts and humanities knowledge and practices can inform and transform healthcare, health and well-being. There are important cohorts of personnel in healthcare, a whole army of ancillary workers, as well as informal carers and patients themselves who have been largely left out of the medical humanities so far. Moreover, as different disciplines come to value the contribution made by the arts and humanities and new opportunities emerge in health for the development and inclusion of new approaches here, it is important that this expansion and debate is given voice and new fora are created for these new developments.

The so-called medical humanities were the first on the scene, and have developed strongly in the Anglophone world. But now the field of health humanities, subsuming arts within the term 'humanities', is fast developing a more inclusive and international capture of material as other disciplines and different nations develop their own distinctive practice and theory. Its expansion is marked by health humanities-focused research funding calls, dedicated centres and networks, and changes to existing medical humanities centres to align with health humanities, either in their more inclusive names or programmes of work. For example, we hear increased reference to

'medical and health humanities' or even 'medical health humanities'. But not everyone aligns with medical visions of healthcare or giving it this kind of primacy or privilege in new terminological marriages. Furthermore, there are multiple and often complementary contributions to health and well-being which fall outside medicine per se. In other words, medicalised humanities are not the only show in town. With increased consideration of the emergence of health humanities in the UK, US and Canada and resultant new inflections of medical humanities as 'critical medical humanities', as in Bates et al. (2014), all this merits a new publication aiming to give a flavour of the diverse range of healthcare activities and the newly discovered relationships between these and the humanities themselves. Indeed, the rise of the more inclusive health humanities marks an evolution of medical humanities.

Health humanities is marked by an ambition for the following:

- new combinations of pedagogic approaches informed by the arts and humanities in education of all professional personnel involved in healthcare, health and well-being
- advancing the health and well-being benefits of involvement in arts and humanities to informal or unpaid carers/caretakers and the self-caring public
- valuing and sustaining existing therapeutic applications of arts and humanities to the benefit of any nation's health and social well-being
- democratising therapeutic interventions whenever possible and feasible beyond specialist professionals
- championing increased sharing of the arts and humanities capacities and resources of the professional health workforce, informal carers and patients themselves in enhancing healthcare environments.

It is tempting to see the growth of interest from scholars and practitioners in the humanities in healthcare as being spearheaded by the medical humanities, an area which has recently been described as having gained the status of a 'mature discipline' (Ahlzen, 2007). Certainly, this area has been influential and has recently gained ground as an alternative to the traditional, exclusively scientific curriculum pursued in the English-speaking world and many

postcolonial nations. Changes in medical education were prompted by re-evaluations from educators and professional bodies on both sides of the Atlantic through the 1990s (Christakis, 1995; Enarson and Burg, 1992; General Medical Council, 1993; Schwarz and Wojtczak, 2002). This has involved a great deal of questioning of medical school curricula and a reappraisal of the kinds of qualities that educators are attempting to foster in tomorrow's health professionals. This in turn has led to opportunities for the development of curricula for healthcare professions to include the humanities. Classically, in the case of medicine, this has involved ethics or 'moral attitude' (Olthuis and Dekkers, 2003) or confronting students with some of the enigmas or conundrums of the discipline to make them aware of philosophical issues (Brawer, 2006). More recently this has broadened to include literature (Dysart-Gale, 2008), expanding clinical empathy (Garden, 2009), dealing with the more exasperating experiences of clinical life (Gordon, 2008), as well as developing community education and a commitment to interdisciplinarity (Donohoe and Danielson, 2004). In addition we have seen a focus on both medicine and the humanities as interpretive enterprises (Gillis, 2008), or recognition of healthcare practice as a kind of performance, analogous to being a musician (Woolliscroft and Phillips, 2003). The intention is that medicine should reconfigure its boundaries to become interdisciplinary and at the same time become disciplined through the humanities on the premise that 'arts and humanities approaches can foster significant interpretive enquiry into illness, disability, suffering, and care' (Bolton, 2008, p. 131). The notion of 'humanities' itself suggests a shared understanding of what it means to be 'humane', either as a person or as interpersonal practice. Some of the purported benefits of teaching medical humanities include the promotion of patient-centred care, combatting professional burnout and 'equipping doctors to meet moral challenges not "covered" by biomedicine' (Gordon, 2005; Petersen et al., 2008, p. 2). Yet this diversity of claimed benefits is often as confusing as it is comprehensive. Thus, there are those who point to the lack of consensus as to what exactly constitutes medical humanities and what the discipline is for (Petersen et al., 2008).

Despite this apparent hegemony of medicine, as we shall see in the present volume, medicine does not have exclusive claim upon the action. We intend to outline how a variety of other disciplines

have sought to incorporate the arts and humanities, or have attempted to relate the arts and humanities to practitioner education, practice with clients, professional development and the wider development of the discipline. The hitherto more narrowly defined medical humanities therefore do not necessarily have a monopoly over the work undertaken. In particular, the vast body of practical work undertaken globally in the expressive therapies demands and deserves admission to the health humanities. Here, practitioners and researchers are often actively seeking places where they can develop ideas and place them on a more theoretically mature footing, as well as providing a means of bringing this work more fully to the attention of scholars in the medical humanities, those in practice, and those who teach the health professionals of the future.

In this chapter therefore we propose to provide a brief tour through some of the developments in the humanities and arts throughout healthcare. Whilst not an exhaustive summary, we should be able to provide the reader with some indications of how diverse disciplines have attempted to incorporate the humanities, and how humanities scholars have built the healthcare disciplines into their purview.

One of the key concerns linking the healthcare disciplines and the humanities is the notion of meaning. In a variety of healthcare settings, meaning plays a central role in the effort to understand the individual's life-world (Kvale, 1996), and as Stetler (2010) adds, their personal and social realities, patterns of action and behaviour. A consideration of meaning is central to both the humanities and healthcare because people ascribe specific values and purpose to their experiences, conduct and relationships. Matters are made meaningful when people understand and make sense of their actions, feelings and thoughts. Often this occurs through people creating narratives about themselves and events in their world. This understanding involves a continuous interpretative process which is informed by the individual's prior knowledge, experiences, emotions, beliefs and attitudes. As Stetler (2010) notes, this process forms the individual's current sense of reality.

The distinctive contribution of the humanities, as disciplines that have often been at the forefront of interpreting human experience, is perhaps most pronounced where the notion of meaning is concerned. This is perhaps easiest to appreciate if we remind ourselves of the distinction between 'meaning' and 'information'. Human

beings seldom function in a way which is directly like computers as they process information or data. This difference was emphasised by Jerome Bruner (1990), an influential advocate of a culture- and action-orientation in the study of thinking and experience. According to Bruner, rather than being best conceived of as 'data processing devices', it is more appropriate to consider human beings as continually seeking meaning, interpreting their environment, other individuals and themselves in a process of dynamic interaction with the world around them. As Stetler (2010) says, meaning therefore can be understood as a dynamic, situational and dialogical concept.

This grounding of meaning in interaction and dialogue places it firmly in the territory of the humanities. As Gendlin puts it, 'meaning is formed in the interaction of experiencing and is something that functions as a symbol' (Gendlin, 1997, p. 8). This process of symbolisation is often undertaken through the use of the spoken word, but can also be expressed by other means, such as movement, art, sculpture, performance, thinking or writing. Equally, the way that all these activities are actualised or realised through the body places the healthcare disciplines – with their preoccupation with bodily matters – clearly in the scope of meaning-making. For Merleau-Ponty (1962) it is through the lived body that we anchor ourselves to the world. Elaine Scarry (1985) goes further. For her the body's capacity to suffer is fundamental to the construction of culture and society. Our pain, she suggests, is at once the most irreducible of subjective experiences and the most incommunicable. For example, pain is rarely rendered in detail in most novels, yet haunts the warp and weft of human cultures.

Meaning, then, is often embodied, but it is also contextualised. In Bruner's (1990) view, meaning always emerges as something that is formed in situated action. In this sense, meaning is a reflective response to being involved and in action; in other words meaning is about doing things. As Giddens (1991, p. 284) says, in the human disciplines we are confronted with 'phenomena which are already constituted as meaningful. The condition of "entry" to this field is getting to know what actors already know, and have to know, to "go on" in the daily activities of social life'. Bruner saw meaning-making as foundational to the creation of human cultures, and the proper conduct of the human disciplines as being to elicit insights about how the participants who are involved in culture make sense of it.

The notion of meaning integrates past, present and future. Meaning is created on the basis of traces of earlier experience which the individual deploys to entrain and interrogate the current situation, and meaning also emerges through the incorporation of a possible or expected future into the current action. As part of this meaning-making process, the meanings derived from the sensory data of experience are shaped through social negotiation and narratives (Polkinghorne, 1988) that describe and are grounded in the social actor's thoughts, feelings and reflections on their life practice. In an important sense this form of meaning-making is cultural or collective and results from the social, co-creative interaction between humans as social beings. One important role of the arts and humanities in healthcare is to dramatically expand the scope of the social negotiations and verbal or visual narratives available as we make sense of health and illness. It is through the arts and humanities that we have access to the meanings, narratives, adjudications and interventions of a multitude of other people across the broad sweep of history and different cultures. The arts and humanities rescue us from the sometimes stultifying localism or myopia of a particular discipline or social situation. In healthcare, stories, novels and poetry can illustrate a huge range of social and health problems from the perspective of the writer (Calman, 2005). Similarly, music, art, drama and a multitude of many other kinds of creative expression and craft can narrate health and illness experience and viewpoints. Within the medical humanities, as Charon (2006a, p. 191) points out, doctors have for a long time been turning to literary texts and ways of thinking that help us to enter the subjective worlds of patients, see others' experience from their own perspectives, appreciate the metaphorical as well as the straightforward communicative power of words, and be moved by what we hear.

This scope for stories to enhance and liberate our experience whether we are patients, carers or health professionals is underscored by Sarbin (1997, p. 67), in his article 'The poetics of identity', where he argues that 'imaginings influence the construction of identity … that imaginings stimulated by stories read or stories heard can provide the plot structures for one's own self-narratives'. As Diekman et al. go on to argue, 'fiction's narrative form and its ability to transport the reader into a vivid and involving fictional world are powerful persuasive tools in and of themselves' (Diekman et al., 2000, p. 180).

Indeed, earlier work suggests that the more people feel 'transported' by their reading, the more likely they are to be persuaded by it (Green and Brock, 1996). Even when stories are fictional, they play a vital role in enabling readers to form beliefs and expectations around their reading (Diekman et al., 2000), implying that fiction may be an influential mechanism for changing health practice and health behaviour. Of course, we need to retain awareness that not all storytelling is read or heard – for example, storytelling, digital or otherwise, can be achieved in individual, successive or moving images.

Therefore, the notion of meaning is central to the project of the health humanities. The human context of suffering and healing is uniquely susceptible to illumination by literature and the arts, irrespective of the particular health specialisms involved. Indeed, it is the search for meaning and integration in patients' experiences which brings together often disparate points of view on a condition. As Stetler (2010) goes on to argue, meaning has both a social and a narrative dimension. Through the incorporation of multiple stories, meaning can develop a dynamic quality which is not exclusively based on the participant's experiences, but evolves in a process of co-creation, where the individual responds to those around him or her as well as the stories they encounter. In an important sense then, meaning in healthcare is a joint construction, created, as Swanson (1992) maintains, through people doing things together. In this sense, the concept of meaning is the result of the integration of the experiential, pre-reflective dimension with the discursive, narrative dimension.

The social world, including the social world of healthcare, is always meaningfully pre-interpreted and meaning is constitutive of social phenomena (Schutz, 1962). For a number of key thinkers concerned with the human condition, from Max Weber to Alfred Schutz, it is meaning that distinguishes between a mere probabilistic relationship between cause and effect and a genuinely explanatory understanding (Eberele, 2010). In the healthcare disciplines this is no less so than in the social sciences. In the contemporary idiom, meaning is one of the major 'trending topics' in present-day medical research, with an increase in attention to existential, spiritual and religious issues in relation to illness (La Cour and Hvidt, 2010).

Meaning is intimately bound up with what we do, how we use words and images or other media, deploy techniques and act on the

world around us. As Wittgenstein famously claimed, 'the meaning is the use' and that understanding the meaning of something involves being able to continue our course of action – 'now I know how to go on' (Wittgenstein, 1953). Meaning, like healthcare itself, is therefore often about doing things together. And in doing things we are often engaged, literally and metaphorically, in using tools. From equipment itself to particular ways of thinking and talking, the use of tools and technologies is ubiquitous. There is a reciprocal relationship between the tools humans invent and the social, representational and relational systems that emerge and co-constitute our development. As Vygotsky (1978) argued, the mediating signs and artefacts people use to understand and represent the experiential world form a generative basis for human experience, social life and culture. Within individuals' consciousness, encounters with the uses and meanings of these signs and artefacts give rise to interpersonal, collective mental structures and processes (Toulmin, 1978). In Vygotsky's view, the tools we construct and use to mediate these symbolic activities change the ways humans think. By building tools, people build the material basis for consciousness, transforming the environments and restructuring the functional systems in which they act and learn (Vygotsky, 1978; Wartofsky, 1983). In so doing, they launch developmental trajectories of thought and action that resonate broadly, spanning dimensions of the individual and the collective, the material and the symbolic.

Fundamental to the idea of health humanities is the assumption that it is through the arts and humanities then that we can fully grasp the meaning of events and experiences in healthcare. Moreover, it is through the arts and humanities that we can also come to an understanding of the effects that technologies, tools, techniques and health-related ways of thinking have upon us. Echoing Clemenceau's comments about war, one might even say that health is too important to be left to the doctors. The arts and humanities represent a wealth of experience in musing upon the human condition and in thinking critically about texts and images, be they literary, scientific or part of the burgeoning genres of health education advice or self-help – thinking about how human beings are conceptualised and constructed, how we are persuaded of courses of action, how the science of health fits into a historical or political context. Thinking about the conceptualisations, presuppositions and epistemological

commitments of healthcare is not to do away with them, but rather, as Judith Butler (1993, p. 30) puts it, to free them from their 'metaphysical lodgings in order to understand what political interests were secured in and by that metaphysical placing'. In other words, we can be empowered to question the apparent certainty and epistemological privilege of healthcare knowledge. As Butler (1993, p. 30) goes on to say, 'to problematize the matter of bodies may entail an initial loss of epistemological certainty, but a loss of certainty is not the same as political nihilism … the unsettling of matter can be understood as initiating new possibilities, new ways for bodies to matter'.

Bodies 'matter', in Butler's sense, across the whole range of healthcare disciplines, and in a variety of areas of practice we can see people applying ideas, techniques and other insights to make sense of what is happening. The arts and humanities have long held a place in nurse education (Dellasega et al., 2007) and a good many researchers and educators in the discipline have deemed it appropriate to include the arts and humanities to inculcate an appreciation of the fullness and complexity of human experience. Moreover, in a reflective fashion, they have been applied to make sense of what nursing is all about. A widely reproduced quotation attributed to Florence Nightingale established the affinity between the arts and nursing:

> Nursing is an art: and if it is to be made an art, it requires an exclusive devotion as hard a preparation, as any painter's or sculptor's work; for what is the having to do with dead canvas or dead marble, compared with having to do with the living body, the temple of God's spirit? It is one of the Fine Arts: I had almost said, the finest of Fine Arts … there is no such thing as amateur art and there is no such thing as amateur nursing. (McDonald, 2004, pp. 291–292)

There is growing commitment to having a nursing curriculum that involves a full appreciation of the complexity of the human condition (Davis, 2003). Hence, argue Ferrell et al. (2010, p. 941), because nursing is an intrinsically artistic endeavour, as well as a scientific practice, the education of nurses in formal academic programmes and through continuing education for those in practice can be enhanced through inclusion of arts and humanities. Ferrell et al. contend that the humanities and arts are vital to remind nurses

that illness is 'a profound human experience' (p. 942) and express the hope that by incorporating the arts into education, practice and professional development, nurses can be moved to a new understanding which engages emotions and self-reflection, enables them to hear and appreciate stories and gain insight into thoughts and experiences that are often repressed. Also in nursing, it is possible to illuminate some of the practices and policies in the present day through analysis of the history of the discipline. For example, Reeves et al. (2010) show how the organisation and regulation of disciplines such as nursing can be traced to the development of 16th-century craft guilds. This has its legacy in the present day where territorial knowledge claims, discipline-specific hierarchies and difficulties in collaborative working can be traced back to the guild-like structure of the different professions in healthcare.

The use of arts and humanities in learning for nurses has also been encouraged by the use of inquiry based learning or problem based learning and the desire to encourage nurses to engage in reflection about their practice where poetry and novels can aid this task, as can reflection about the teaching process itself (McKie et al., 2008, p. 163). There are pleas for the rubric of nursing to extend beyond evidence based practice to include information literacy, the humanities, ethics and the social sciences (Jutel, 2008). Especially in mental health, the arts have been employed as diversional and therapeutic interventions and activities – it is suggested that 'art offers a showing of human experience in unique ways' (Biley and Galvin, 2007, p. 806), and in this way it can facilitate shared understanding of people's experiences.

At the same time as these educational initiatives and pleas for the inclusion of the arts and humanities are going on, there are critical voices raised. For example, Wallace (2008) describes how an appreciation of Henrik Ibsen's *Enemy of the People* helps us gain a critical purchase on the processes of governance in healthcare. The arts and humanities then can assist critical reflection on what is happening to us as human beings in relation to the policies and institutions in which we are embedded. Bishop (2008) challenges the assumption that the humanities should merely exist to make medicine perform 'better' in a narrow technical sense, or provide professionals with 'narrative competencies' that they might otherwise miss acquiring. Instead, he charges, humanities can enable us to challenge

this narrow instrumental view of human activity at its very roots. Medical humanism might promise intimacy and care but is it, asks Bishop (2008, p. 21), also about control? This potential to develop a philosophically attuned awareness of what is going on in healthcare offers the opportunity to mount informed critiques and stage novel debates about the meaning of health and healthcare which go beyond the customary question of 'what works'.

In other disciplines too, there are signals that the arts and humanities are being relied upon to play a role. In occupational therapy there were some early signs that literary works were being drawn upon to create reflective discussion (Murray et al., 2000). Occupational therapy has a long history of engagement with the creative arts (Thompson and Blair, 1998), with evidence that this is appreciated by patients, particularly if they are able to set their own goals and terms of engagement (Lim et al., 2007). Especially in mental health and particularly in Australasia, there is a continued emphasis on the role of the arts and creativity in occupational therapy (Schmid, 2004). For example, some of Schmid's participants described using creative activities to look with their clients at issues like hope and inner strength, adaptation and making changes, and developing clients' creativity.

At the same time there is growing interest in creative disciplines such as dance and drama in physiotherapy (Christie et al., 2006). As well as specific manipulations and exercises, there is an increasing appreciation of the patient's life story and narrative in making sense of their experience in therapy. For example, Soundy et al. (2010) show how the process of recovery from a sports injury makes use of a variety of narrative patterns, seeing accounts of injuries and the rehabilitative process as being like a quest, a search for restitution or a lapse into chaos or despair. The value of seeing the larger life context is apparent, and this can be enhanced through the use of stories, life narratives and vignettes in student learning.

The arts and creative therapies as disciplines in their own right have made inroads into fields as diverse as cancer care (Carlson and Bultz, 2008; Puig et al., 2006), mental health care (Perry et al., 2008), including forensic contexts (Smeijsters and Gorry, 2006), dementia care (Mitchell et al., 2006) and social care work with children (Lefevre, 2004). There are lively programmes of innovative practice ongoing in the so-called 'expressive therapies' (Malchiodi, 2006) such as dance