A community-based approach to the medical humanities

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BACKGROUND This paper discusses the rationale behind, and an approach to, the development of a graduate level interdisciplinary curriculum in literature and health care that incorporates community-based learning. Such an innovative approach emerges from the recognition that professional training in both health care and humanities programmes often does not model the kinds of collaborative relationships and professional values desired by contemporary health care students, providers and patients.

METHOD Recent trends in literary study and the medical humanities are described, along with the function (and benefits to students) of interdisciplinary classrooms and the role of community-based learning in higher education. The authors discuss their experiences teaching, and offer students' responses to medical humanities courses from which the concept for such a curriculum evolved. The paper offers advice on developing, evaluating and disseminating such a model curriculum for medical, nursing and graduate literature students.

Proposal By linking health care with graduate English literature students, such a course would promote dialogue and understanding among health professionals, enhance student awareness of the effects of illness on patients, their caregivers and families, and encourage student activism and community service. A common set of literary works would provide a shared vocabulary and opportunities for ethical, critical and personal response. Working together in a community-based project, students from diifferent programmes would learn to appreciate alternative professional and lay perspectives on common experiences.

KEYWORDS curriculum; education, medical, undergraduate, *methods; humanities, *education; interprofessional relations.

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INTRODUCTION

This paper discusses the rationale behind and an approach to the development of a graduate level interdisciplinary curriculum in literature and health care that incorporates a community-based learning component. Such an innovative approach emerges from the recognition that professional training in both health care and humanities programmes often does not model the kinds of collaborative relationships and professional values desired by contemporary health care students, providers and patients.

The authors have each taught versions of the course envisioned below. Dr Donohoe has designed courses entitled 'Literature, Medicine and Public Health' and 'The Humanities and Social Sciences in Medicine', in which medical (and sometimes nursing) students reflect upon and discuss literary selections that allow them to experience vicariously the social, economic and cultural contributors to health and illness, in the hope that the students may be motivated to undertake community service work on behalf of the disenfranchised. Dr Danielson regularly teaches an undergraduate 'Literature and Medicine in the Community' course that has attracted premedical and prenursing students, as well as humanities majors who have an interest in health care issues. Recently, she introduced a new interdisciplinary graduate course entitled 'Illness and Culture' that attracted

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Key learning points

Interdiscuplinary curricula in the medical humanites will promote dialogue, understanding and co-operation.

Audiences for interdisciplinary curricula include health professionals, graduate literature students and other relevant communities.

Literature would build a shared language for analysis of ethical and cultural health-related issues.

Community service projects incorporated into interdisciplinary medical humanities courses would promote public service and social activism.

students in Fine Arts, Gerontology, Literature, and Social Work.

This call for a new course moves us outside our separate spheres to try to imagine the basis on which diverse communities seeking to address the common goal of humanistic health care could be brought together. By linking students from health professional programmes with those from the humanities, such a course would promote dialogue and understanding among health professionals, enhance student awareness of the effects of illness on patients, their caregivers and families, and encourage student activism and community service. Medical and nursing students would have a structured opportunity to discern their own values on diverse cultural and professional issues in health care delivery. Simultaneously, humanities graduate students would learn the role of literary and cultural analysis in health professions education, and perhaps identify scholarly and vocational opportunities in the applied humanities. As nonhealth care providers, these students would enrich the conversation as all students work together to interpret the relationships between creative literature and community service.

Two activities would establish the basis for this dialogue. Firstly, reading a common set of literary works would provide a shared vocabulary and opportunities for ethical, critical and personal response. Secondly, working together in a community-based service project, students from different programmes would learn to appreciate alternative professional and lay perspectives on common experiences. Technological resources would enable conversations begun in class among students from different programmes to continue, as learners share their ideas and concerns about the literature and their community service projects.

LITERARY STUDY

The 1997 Modern Language Association (MLA) Committee on Professional Employment explored 'the disparity between the expectations and assumptions about college teaching that most graduate programmes inculcate', as well as students' job placements when they left graduate school. The report urged graduate programmes to introduce students 'to strategies through which abilities developed by higher education in the humanities can be translated into proficiencies useful in nonacademic careers'.[1] For at least the last 10 years, traditional literary study has evolved from a historically based model to a theoretically based model, emphasizing social and cultural contexts as well as aesthetic and stylistic features. Literature is recognized as a repository and reflection of images and themes and as part of a dynamic cultural process in which meaning is created and contested. Courses coupling community-based service projects with literary analysis could help students identify the underlying skills in reading, writing and critical, ethical thinking that accrue to English majors and the resources that literature can provide the health care community. For example, in her article, 'Passports for Physicians', anaesthesiologist-poet Audrey Shafer identifies some of the ways that language study can encompass and move beyond bioethics case studies:

> Language is one of the fundamental means of linkage between two human beings; understanding the nuances of language, its cultural and ethnic variations, and its symbolic content are essential as any skills the clinician may possess. The study of stories can enhance 'ethical reflection.' and in fact the more complex the situation, the more language skills may help us ascertain differing value systems and multiple perspectives. Certainly the patient should not be reified into a text; rather narrative skills should be viewed as a tool for dialogic communication.[2]

Furthermore, coupling literary analysis with questions related to health care delivery would lead to discussions concerning issues such as the historical

development of medical professionalism and changing definitions of health and illness as well as the limits of professional medical care in the creation of healthy communities.

THE MEDICAL HUMANITIES

In the early 1980s, the National Endowment for the Humanities, the Association of American Medical Colleges, the Accreditation Council on Graduate Medical Education and the Society for Health and Human Values called for increased emphasis on the humanities in both undergraduate and graduate medical education.[3] By 1994, approximately one-third of US medical schools offered formal elective courses in literature, and more than 80% offered some form of humanities instruction.[4] Until recently, literature and medicine courses were typically aimed at medical students; today, most are still discipline specific and reflect traditional approaches to literature and pedagogy.[5]

Literature and health care share a fundamental concern: the human condition. Through literature, readers would experience new situations, meet a variety of people, explore diverse philosophies, commute between particular examples and universal truths[6] and develop empathy with and respect for others.[1–10] Literature's power lies in its ability to call up and articulate feelings and to evoke vicarious experience.[11] Reading stories encourages imagination, appreciation of subtleties and ambiguities, and the consideration of alternative viewpoints.[12,13] It increases the analytical skills of health professionals, in that the subtleties and ambiguities of literature are not unlike those of their patients.[14] Furthermore, reading literature encourages us all to examine the ethical dilemmas created by medical science and the economics of health care delivery.[4,10–12, 15–17]

Imaginative literature both inscribes and challenges attitudes towards the body and towards various therapeutic models, thus helping to demystify the rise and success of particular forms of clinical medicine. Cultural theory and reader-response criticism encourage students to articulate their particular relationship to a literary work: In what ways is a student's response to a work of literature contingent on his/her particular location (professional and/or personal) vis-à-vis the events or characters represented?

Various approaches to teaching literature and medicine have been described, such as the ethical, aesthetic, and empathic approaches of Jones[18] and Coulehan[19] and the cognitive developmental, affective developmental, and cultural transmission approaches of Self.[5] Today, literature is employed throughout health care for both instructional and therapeutic purposes. Courses for medical and nursing students have been well-received,[4,10–12,20,21] although publication bias may limit information regarding unsuccessful offerings. Physical diagnosis[22], psychoanalysis[23 and] medical ethics[15] are taught through poetry and prose. Poetry, creative writing, haiku, drama, essays, short stories and novels have been utilized successfully in the treatment of patients with chronic and terminal illnesses, intractable pain, and cancer, as well as depression and schizophrenia.[23–26] These media have been employed to foster greater communication among hospital staff members and between physicians and patients and their loved ones.[25–28] They are also used to teach healers about the experiences of illness, suffering and death, and thereby promote humanism in the practice of medicine.[2–28] Anthologies, scholarly journals, student literary magazines and compendia of articles on the rationale for teaching literature in medical schools and on the practical applications of literature in medicine have been published[29,30] (see also Appendix A) and an on-line database of literature, medicine and the arts can be accessed via the World Wide Web.[31]

INTERDISCIPLINARY CLASSROOMS

While literary study encourages broader professional and cultural understanding, the interdisciplinary classroom directly promotes communication across disciplines and the integration of knowledge.[32] It is in professional education that most practitioners learn their disciplines' special languages and adopt their disciplines' stereotypes of those in other fields and of the public they will serve. Although physicians and nurses work together daily and the quality of the relationship between physicians and nurses may be linked to career satisfaction and longevity and key indicators as patient mortality,[33,34] medical and nursing students often lack understanding of each other's training and responsibilities. They face numerous barriers to communication in general and with respect to the care of particular patients.[35] As a result, they may encounter difficulties providing well-co-ordinated therapeutic support for patients recovering from acute illnesses, those living with chronic conditions, and these patients' caregivers.[34–36] Interdisciplinary classrooms in the medical humanities, in combination with community-based learning, would

provide unique opportunities for students from various health professions disciplines and from graduate programmes in literature to learn from each other as they negotiate the meaning of their service placement and of the literary texts.

Benefits to graduate humanities students are theoretical and practical. Over the past decade, scholars such as Arthur Frank, Arthur Kleinman, and David Morris have appropriated postmodern theory to enhance the reading of fiction in its relationship to questions of personal and cultural health and illness. Their work invites us to ask new questions of fiction such as: In what ways is health defined in this text? Are health and illness stable or mutable categories? What are the relationships between bodily and societal illness? What are the aspects of care giving and who are their best practitioners? As a final project in the 'Illness and Culture' course, a Fine Arts graduate student adapted Arthur Frank's definition of the communicating body to discuss the work of Frida Kahlo and Katherine Sherwood. A nurse practitioner returning for a Master's degree in Literature explored the representation of personality disorder in contemporary film and developed a brochure for clinicians in her rural community to help them in diagnosing patients. Community-based learning in health care enables literature students to creatively explore the relationship between literary studies and the community outside the academy. Here they can explore the ways an engaged reading can illuminate previously neglected aspects of a text as well as potential careers and volunteer opportunities in health care (e.g. poetry therapist, medical writer), and the opportunity to hone their teaching skills.

Obstacles to interdisciplinary classrooms include scheduling difficulties, competing curricular demands on health professions and humanities graduate students, a lack of interest in the humanities among some medical students, resistance among humanities graduate students to specialize so early in their career, and different levels of ability in reading and interpreting texts. These obstacles, while formidable, can be overcome through publicity, creative scheduling of electives (e.g. evening sessions), selection of challenging but not obtuse texts, and the support of deans and departmental leaders.

COMMUNITY-BASED LEARNING

Over the past decade, community-based learning has emerged as a strategy to engage students in their communities as part of their academic curriculum.[37,38] Community-based learning emphasizes the direct connection between the academic content of a course and the community service undertaken. Students participate in organized activities that meet identified course objectives and community needs. For example, in a recent interdisciplinary medical humanities course 'Literature and Medicine in the Community', undergraduates who were required to participate in a 20-hour community-based learning project provided emotional and logistical support for Alzheimer's disease patients and their families, clerked at a homeless health clinic, assisted victims of domestic violence at a shelter, and provided health education at local public schools. By reflecting on their experiences in light of the readings covered in class and their own personal development, students became conscious of the connections between academic and experiential ways of knowing[38] and become more critical thinkers and empathetic healers.

An older, returning student in this course, whose community service was at a group home for five developmentally disabled men ages 35–50, found unusual connections between the play 'Wit'[39] and his role as a caregiver:

> This class has opened my eyes to a problem with the group home system…The state of Oregon requires agencies like the one for which I work to keep detailed records on the lives of residents. After I had read the play, 'Wit', it occurred to me how invasive this data-collecting really is…Is it…normal to have a person in your home who is watching you constantly in order to record your every move?

Although the student noticed this connection immediately, events in his personal life, coupled with the literature read for class, triggered his deepest insights:

> The unexpected benefit of taking this course came in dealing with my personal life. The last three months for my family have been absolutely crazy. First my grandmother died…A couple of weeks later my mother suffered a small heart attack. Then three days later, someone else close to my family died…my best friend Glen's mother…a few days after that, another one of my high school friends drowned at Winchester Bay. After my mother had been released from the hospital, the doctors found a lump under her right arm…This is where I got the most out of this class. I was writing journals about my work at the group home when I realized

> that up to this point I had been more worried about caring for the patients medically than I was about caring for them emotionally…Since I realized this, I have made an effort to pay careful attention how the guys are feeling. Wouldn't you know it, in a short time it is already paying off. The guys are more compliant and more enthusiastic…

Another student challenged herself by choosing to do her service project at a local nursing home, feeding elderly stroke patients and examining her 'own fears of disabling illness, again, and loss of independence. The project put me face to face with health issues I had never experienced. Dysphasia, dementia, depression, the effects of a stroke, and the world of the seriously ill patient and their caregivers were all concepts that I became familiar with over the quarter.' Her final reflective essay explored various readings that illuminated her experience:

> The most surprising literature that applied to my service project was [Cortney Davis' poem] 'What the Nurse Likes.'[40] I was initially shocked by this poem because of its detachment and almost mocking tone towards patients. I learned through this poem, through the narrator in [Rebecca Brown's] 'The Gifts of the Body',[41] and through my own observations that caregivers must find a place within themselves to store the experiences of their jobs. I first saw this attitude in the poem as nonchalant and disconnected, but after closely observing nurses and aides and being a caregiver myself, I see this as a form of self-preservation. The nurse in 'What the Nurse Likes' defines the things that keep her interested in her patients and competent in her job. The narrator in 'The Gifts of the Body' eventually takes a break from her job. These two seemingly contrasting medical characters both have a place of detachment that allows them to lead a life of their own and care on an emotional and physical level for their patients. Thanks to my service project and the literature of this course, I have been able to travel through the process of caring and care giving. This process has evolved from fear, revulsion, and lack of confidence to sympathy and empathy, competence and caring.

REINVIGORATING THE PATIENT–PROVIDER RELATIONSHIP

Many patients are becoming increasingly dissatisfied with the quality of the physician–patient relationship.[42–46] Some of the factors involved in producing patient dissatisfaction are a product of the medical school and residency environments, which can foster depression, anger, fatigue and loss of empathy[47] and promote ageism[48] and unfavourable attitudes toward providing care for the underserved.[49] Tending to physical symptoms often overshadows health professionals' attention to the psychological, economic, social and cultural factors that prompt many outpatient visits[50] and cause as much functional impairment as physical complaints.[51] Patients often seek help for hidden reasons, such as life stress, emotional distress, psychiatric disorders, social isolation, and simply for information.[52]

While literary study can help students learn to recognize these underlying issues and the contributions of diverse cultural factors to health and illness, community-based projects can provide an equally potent 'text' for students to read. In tandem, the two experiences would heighten students' awareness of subtle factors in their own and others' responses to clinical and ethical issues.

Under the pressures of market- and technology-driven and technological changes in health care delivery, the traditional model of the individual physician–patient relationship is being transformed.[53] The 1998 Medical Schools Objective Project Report I[54] emphasized key themes for the future of health professions education: understanding of, and respect for, the roles of different health care professionals, the need for collaboration in providing care for individual patients, and promotion of the health of diverse populations. Furthermore, health professionals must be able to communicate effectively, both orally and in writing, with patients, patients' families and colleagues. Our proposed educational approach aims to help physicians and nurses become adaptable, flexible collaborators.[55]

Physician and nurse scholars already recognize literary study and writing as a linguistic and cultural resource for healing:

> Literature. . .teaches something of the significance of symbol and language as the media linking human minds and personalities. Language is the instrument of diagnosis and therapy, the vehicle through which the patient's needs are expressed and the doctor's advice is conveyed. Understanding the nuances of language, its cultural and ethnic variations, and its symbolic content are as essential as any skills the clinician may possess.[11]

'Literature, Medicine and Public Health' courses taught by one of us (M.D.) combine literature with articles from contemporary medical periodicals to promote discussion about the social, economic and cultural determinants of illness.[10] The journal articles augment the literary texts by providing background on the issues raised in the stories and by suggesting areas for discussion, debate, research, intervention and physician activism.

In one session, students read George Orwell's 'How the Poor Die'[56] and Anton Chekhov's letters describing the destitution he witnessed on his journey to Sakhalin[57], along with periodical articles on socioeconomic inequalities in health[58–60] and the health consequences of economic inequities.[61] Students have commented on the regrettable timelessness of these writers' observations. In another session, they read 'The Sky is Gray',[62] Ernest J. Gaines's story of a poor, single, African-American farm mother trying to obtain dental care for her ill child, along with articles on black–white disparities in health care.[63] The discussion of barriers to care faced by the poor and by African-Americans inevitably turns to opportunities for medical students and physicians to remedy health disparities through volunteerism and activism. Students also read Doris Lessing's 'An Old Woman and Her Cat',[64] a moving fictional entrée into the daily struggles of two unwanted creatures, an aged gypsy and her adopted alley cat, trying to cope with life on the streets of London. In the same session, they discuss a study on the lifetime prevalence of homelessness[65] and a clinical review of the health problems commonly experienced by homeless individuals.[66] Students have remarked that these pieces increased their awareness of the struggles of society's dispossessed, and encouraged them to volunteer at the university's homeless clinic.

DEVELOPING A CURRICULUM

The literary works chosen for a model curriculum would be drawn from a variety of genres and focus on a broad definition of illness and on the interrelationships among community and personal caregivers, health professionals, and the ill or dying (see Appendices A and C). Sources for material are plentiful:

- essays by ill patients or their providers gathered from such columns as 'Medicine and the Arts' (*Academic Medicine*), 'A Piece of My Mind' (*Journal of American Medical Association*) and 'On Being A Patient' and 'On Being a Doctor' (*Annals of Internal Medicine*), or Mandell and Spiro's book, *When Doctors Get Sick*;[67]
- works of physician-authors such as John Keats, Anton Chekhov, Somerset Maugham, William Carlos Williams and others;
- writings of famous artists and authors about their own experiences with illness, such as Keats (tuberculosis, depression), Emily Dickinson (depression), William Styron (bipolar disorder/depression), and Flannery O'Connor (systemic lupus erythematosis);
- works by caregivers, such as Jewett's *The Country of Pointed Firs*[68] or poems and short stories by nurses as in Davis and Schraefer's *Between the Heartbeats*;
- selections suggested in *Academic Medicine*'s 'Medicine and the Arts' column; and competing representations of illness and community, as in Rudolfo Anaya's *Bless Me, Ultima*[69] and Charles Chesnutt's *Conjure Woman*;[70]
- works focusing on the health consequences of poverty, sexism, racism, homelessness and isolation, such as Grace Paley's 'An Interest in Life',[71] Michael Lacombe's 'Playing God',[72] Langston Hughes' 'Junior Addict',[73] Lars Eighner's Travels with Lizbeth[74] and John Updike's 'From the Journal of a Leper.'[75]

Students would be asked to write narratives from patients' perspectives. Topics might include: the patients' understanding of his/her disease or disability; the impact of the disease or disability on the patient's life, work, and relationships, emphasizing the physical, mental, and emotional suffering associated with the illness and its treatment; the patient's expectations of medical care; and the patient's preferences for end-of-life care and proxy decision making. Students could discuss the differences and similarities between the voices of patients and caregivers as represented in popular culture and in the medical and nursing literature.

Several approaches to community-based service learning are possible. One is modelled on 'The Family Stories Workshop.'[27] In this programme, students placed in nursing home settings work with patients' relatives to develop life stories of residents suffering from dementia, which they then recount to staff caregivers. Another model, developed by Rita Charon,[8] has small groups of students observe each other performing open-ended interviews with a single

patient; all students are eventually allowed to interact with the patient. Each student then writes an account of the patient's illness using the narrative voice of the patient. Students then share their writing with each other and with the group. Alternatively, as patients' case histories (including the medical record), oral case presentations, and published case reports are formative instruments that shape as well as reflect the thought, the talk and the actions of trainees and their teachers, students would analyze these for 'language maladies' and suggest remedies for the maladies.[76] Another approach, open to both pre- and nonprofessional students, involves placements at local health clinics, where students work in a variety of capacities, serving the needs of the organization and its clients/patients and recording their observations in 'Incident/Reflective Journals.' In fact, a key component of community-based service learning and one that unites all these approaches is the Reflective Journal.[77–79]

Portions of the curriculum would be devoted to representations of health and disease in immigrant literature, cultural differences among patients, caregivers and providers, and issues of diversity and access to care. Guest speakers from the community would share their experiences with the students. Questions to be considered might include: What are the cultural barriers affecting health care delivery? What resources can help us identify those barriers? In what ways can literature and community projects help us to address such problems? From the reading, community project, and self-reflection, can we identify areas where health care providers 'misread' a situation? Areas where care and healing are at odds with the goals of professional care givers? Areas where the patient (or the nurse, or the community) is offered respite unavailable in bio-medicine? and in what ways does imaginative literature include and exclude different community voices?[80,81]

CURRICULUM EVALUATION

Curriculum evaluation would be both formative and summative. Formative evaluation would include a review of syllabus materials and methodological approaches by a local advisory board. Community placements supervisors might be invited to evaluate student participation in their programmes. Faculty would analyze the discourse utilized by students in their reflective journals, in terms of the capacity of students to notice interconnections between community placement and literature. Students would evaluate, through numerical ratings and narrative responses, reading selections, classroom discussions, community placements, teaching methodologies and instructors.

Summative forms of evaluation would include administering the RIPLS (Readiness for Inter-professional Learning Scale), designed to assess the strengths of beliefs in the benefits of interprofessional learning held by health care students, at the beginning and end of the course.[55] Follow up interviews one or more years after completion of the curriculum might address the following:

- effect of the course on students' attitudes toward and involvement with other health care providers, their patients, and their patients' caregivers;
- ways in which graduate literature students changed their scholarly agendas and/or career goals;
- health professionals' current reading, writing and community service activities.

FOLLOW-UP AND DISSEMINATION

Students would be encouraged to submit their creative and nonfiction work to essay contests and to literary, medical and nursing journals. They would be encouraged to offer panels or round table discussions to inform other students of interconnections and insights. Faculty would publish their curricula and share their experiences with local colleagues in health professions and humanities education, and at national meetings of organizations such as the American Society for Bioethics and Humanities, the Modern Language Association, the American Studies Association, and national medical organizations.

CONCLUSION

Interdisciplinary curricula in literature and health care that incorporate a community-based learning component offer potential benefits to health profession and graduate humanities students, including greater understanding of the nature of health and illness, enhanced communication among providers, improvements in the provider–patient relationship, and development of skills and attitudes likely to benefit students in their future endeavours. Ideally, students will be motivated to read more broadly, think more critically, and become more involved in public service and social activism.

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APPENDIX

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