CHAPTER 1

Introduction: What Does It Mean to Do the Health Humanities in Application?

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Health, Humanities, and Application

Three key concepts situate the approach of this book: health, humanities, and application. Health, in health humanities, relates to all imaginable configurations of health and well-being ranging from individual health concerns to formal health, medical, and clinical contexts. The humanities pertain to "the knowledge the human species has acquired about itself over the centuries" (Aldama 2010, 1) and include conventional humanities disciplines such as literary studies, history, philosophy, and religious studies, the arts and artistic creation, and the social sciences, where they

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examine the human condition, including disciplines such as anthropology, sociology, and psychology, amongst others. Multidisciplinary, interdisciplinary, and transdisciplinary modes also inform the configuration of health and humanities in domains such as disability studies, women's and gender studies, and the study of race and ethnicity. The concept of *application* is a central tenet of health humanities in that they are concerned with how one does things and to what particular use one puts things, fitting with a standard dictionary definition of the word *application* (*Cambridge English Dictionary*).

Health Humanities in Application is concerned with the relationship of *application* to health and humanities; that is, in *how* we *do* the health humanities. This interest fits well into the rapidly growing field of the health humanities, which consolidates knowledge and practice at the intersections of health and the humanities. At core, health and the humanities come together in application: it is *how* the humanities are used by health care practitioners, artists, individuals interested in health, caregivers, students of the health disciplines, athletes, educators, and academic researchers, amongst others, that defines the field. *Health Humanities in Application* underscores the need to articulate the deployments of the humanities in health contexts to understand the contours of the field and its applied concerns more fully.

The shape of the health humanities is quickly coming into focus even as there is much work yet to be done to define its boundaries. Klugman sees the health humanities as "a field concerned with understanding the human condition of health and illness in order to create knowledgeable and sensitive health care providers, patients, and family caregivers" (Klugman 2017, 422), and Klugman and Lamb note that "health humanities puts the humanities, arts, and social sciences in the center, rather than as an add-on to clinical and basic science" (2019, 3). Crawford broadens the focus on "health and illness" to account for the expansive potential of the health humanities as "an evolving, game-changing field that attracts different arts and humanities traditions to work more closely with the public to advance health care, health, and well-being" (Crawford 2020, "Introduction," 6).

The origins of health humanities in relation to medical humanities are articulated by Jones, Wear, and Friedman in their essay "The Why, the What, and the How of the Medical/Health Humanities" (2014). Inherent in their configuration of "medical/health" is a tension between the purposes of the humanities and the arts in the service of medicine and medical education and the role of the humanities intersecting health and

well-being broadly conceived. Victoria Bates and Sam Goodman recognize this tension in their conception of the term *medical humanities* as malleable, making its "definition problematic and arguably unnecessary" (2014, 3). The focus in medical humanities is on the biomedical sciences and their relation to "the arts and humanities, and the social sciences" and their "intersections, exchanges and entanglements (Whitehead and Woods 2016, 1). Bates and Goodman argue that the danger of entrenching a specific set of qualities in the term *medical humanities* would result in "an unfortunate narrowing of the field." Yet, the very conception of the term is rooted in the *medical*, which necessarily narrows the focus to largely biomedical contexts even when there is a "huge range of subjects and approaches" (2014, 5) in the medical humanities. *The Edinburgh Companion to the Critical Medical Humanities*, in its 36 chapters, reinforces both the breadth of the medical humanities *and* how they are range bound, returning always to contexts relating to medicine. Whether the interest is in narrative, literary expressions of illness, historical perspectives on matters of health, politics, culture, and society, emphasis threads to expressions of medical domains.

Health and wellness are not limited to medical contexts, and indeed they supersede such a limitation given humanity's concerns with issues such as physical fitness, mental health, the benefits of being in nature, disability, ableism, illness, and caregiving, amongst many other health-related matters that can be situated in and outside biomedical spaces. So, too, are the myriad possibilities of the humanities and the arts—and those areas of the social sciences that overlap--to expand knowledge of how we understand health as individuals, communities, and societies, how we practise in health settings, and how we implement health education for students beyond the confines of a medical education to include the breadth of domains that have an interest in matters of health. Having introduced the concept of the health humanities as a field in 2010, Crawford, Brown, Tischler, Baker, and Abrams put forward a self-described "manifesto" (Crawford "Introduction" 2020) for the health humanities in their aptly titled volume *Health Humanities* calling "for a new kind of debate at the intersection of the humanities and healthcare, health and well-being" (Crawford et al. 2015, 1). There was a need, they argued, "to address the increasing and broadening demand" for a health humanities approach as a way to account for "how arts and humanities knowledge and practices can inform and transform healthcare, health and well-being," and to create space for the large cohorts of individuals engaged in health-related work

who do not fit within the boundaries of medical humanities (Crawford et al. 2015, 1). The health humanities, they note, create space for "different disciplines … to value the contribution made by the arts and humanities" and for "new opportunities [to] emerge in health for the development and inclusion of new approaches" (Crawford et al. 2020, 1).

The concept of *health humanities* serves as a catalyst for those interested in health and wellness to situate their intellectual, practical, and personal concerns in a manner that is "more inclusive and international" than the previously constituted medical humanities (Crawford et al. 2015, 1). Crawford remarks that health humanities is beginning to mature "as an energetic, robust, and inclusive field: one that signals a more co-created and co-operative vision for how the arts and humanities can stand as an interdisciplinary, and not solely medicalized, shadow health care service" (Crawford 2020, 6; see also Banner 2019, 2).

The present book is born out of the observation that the tension articulated in the hybrid "medical/health humanities" conception of how health and humanities fit together (Jones et al. 2014, 1) has dissipated quickly as the field of health humanities has become entrenched in a process of formation that is ever expansive, including exceptional growth in baccalaureate programmes (Klugman and Jones 2021) and in graduate and research institute or centre growth (Crawford 2020). Klugman and Lamb note that the term "health humanities does not replace nor compete with the medical humanities" (Klugman and Lamb 2019, 3). Researchers, educators, students, health professionals and practitioners, creators, and members of the community recognize their interest in health and its intersection with humanities rather than seeing their approach be excluded by the boundaries of medicine. This is an important development that predicts an ever-growing field. Olivia Banner highlights the diversity of approaches in their discussion of health humanities educators, describing them as "a diverse group of bricoleurs" in their teaching and scholarship (2019, 1). Those engaged in health humanities come from a wide range of humanities disciplinary backgrounds "with divergent disciplinary and field training" (Banner 2019, 1). Jones et al. (2014) note that the health humanities arise out of a conventionally understood set of humanities disciplines, such as "history, literature, philosophy, bioethics, and comparative religion" and are augmented by a more elastic understanding of the humanities to include "those aspects of the social sciences that have humanistic content and employ humanistic methods relevant to medical inquiry and practice, particularly sociology, anthropology, and psychology" (4–5). Additionally

influential in the health humanities are "philosophical and pedagogical projects as postmodernism, feminism, disability studies, cultural studies, media studies, and biocultures" (Jones et al. 2014, 5). The over-arching challenge, then, is to account for the breadth of the field while still maintaining an understanding of what binds the immense range of interests, approaches, and practices that contribute to the intersection of health and humanities.

Situating Health Humanities: Family Resemblances

The health humanities, then, are primarily understood outside the recursiveness of medical humanities to have its own vectors of development. There is still the challenge of how to capture the diversity and breadth of the field's intellectual terrain and practical applications. This challenge is evident in the range of contributors to this book, who include physicians, creative artists engaged in dance and visual art, professors and researchers in cognitive psychology, social work, justice studies, literary studies, digital humanities, health humanities, education, pedagogy, civic engagement, media and communications, women's and gender studies, Africana studies, art education, and bioethics. The work produced by the contributors fits simultaneously within and outside their disciplines and artistic practices further complicating how we might collectively situate the volume. And yet, *health humanities* as a term captures the intersection of interests despite the breadth of perspectives that are brought to bear across the individual chapters. Ludwig Wittgenstein (Wittgenstein [1953] 1967), in his book *Philosophical Investigations*, offers possibilities for how one might account for the expansiveness of health humanities while also recognizing that individual contributions are situated within an identifiably similar category of intellectual and practical enterprise. Wittgenstein argues that a set of family resemblances can be used to identify concepts. Writing about games, specifically, Wittgenstein remarks that

> we see a complicated network of similarities overlapping and criss-crossing: sometimes overall similarities, sometimes similarities of detail.
>
> 67. I can think of no better expression to characterize these similarities than "family resemblances"; for the various resemblances between the members of a family; build, features, colour of eyes, gait, temperament, etc., etc., overlap and criss-cross in the same way. And I shall say: "games" form a family (32e).

Wittgenstein's concept of family resemblances is useful to define the scope of health humanities as it erases the need to distinguish the medical humanities specifically from health humanities. Indeed, the medical humanities and its longer history, operating as a distinct educational, practical, and research discipline within a set of bounds defined primarily by biomedical and clinical contexts, nestle comfortably within health humanities, which serves as an umbrella field to encompass a range of similar and divergent practices and approaches, some of which are identifiable as disciplines such as narrative medicine (Charon 2006; Charon et al. 2016), and others that are situated within health humanities through their family resemblance to each other, such as disability studies, which is inherently interdisciplinary.

The health humanities are thus well served by Wittgenstein's consideration of the "complicated network of similarities" (32e) that bind together otherwise seemingly disparate domains of knowledge and application for he asks us to consider primary the points of overlap between various domains. For example, literary studies and health, and history and health: both are grounded in the disciplinary conventions of their respective disciplines and find commonality in their relevance to understanding of matters relating to health. Similarly, disability studies and the study of sexual and reproductive health policy are configured at the intersections of numerous disciplinary approaches, such as history, politics, and ethics, that find commonality when discerned in health humanities contexts. These examples sit uncomfortably in the conception of the medical humanities as it existed prior to the identification of health humanities (Crawford et al. 2010).

The constraints of the medical humanities can be seen pessimistically by recognizing the "broader, more inclusive approach [of the health humanities] than the earlier designation, one that welcomes a range of health professionals even as it shifts the focus to embrace health and wellbeing" (Shapiro 2015, 268). Shapiro defines health humanities as "fuzzy" yet comfortable as a "big, admittedly at times unwieldy, tent" (Shapiro 2015, 269). To begin to conceive the family resemblances amongst the educators, practitioners, and students of health, medicine, and the humanities that fit within Shapiro's unwieldy tent is part of the task of those who identify health humanities as the most accurate conception to account for the breadth of interest in health and humanities.

Application and Health Humanities

A key purpose of this volume is to consider *application* as a central family resemblance, to invoke Wittgenstein, that binds together so many disparate approaches. Whether our interest lies in pedagogy, creative production, scholarship and research, health care practice, or as students of health, medicine, the humanities, and the arts, what links us together in the field of the health humanities is what we *do* when we *do* health humanities: we engage in an application in a health domain that is deeply informed by, and implicated in, an approach defined by the humanities broadly conceived. Crawford, Brown, and Charise (2020) identify “application” as a key element of how the humanities are situated in relation to “health care, health, and well-being,” and Charise (2020) emphasizes the “pressing new reasons to consider the matter of application within” the humanities.

What happens in the context of health humanities, then? *Health Humanities in Application* draws together scholars, physicians, educators, artists, community members, and health care practitioners with multiple global perspectives to address this question to demonstrate that the health humanities have immense reach in day-to-day practice, whatever the context, and that the boundaries of the field can be understood through the field’s work in action. This book has a distinctive shape beginning with pedagogical engagements, then moving to discussion of theoretical and artistic applications of creativity, and then shifting to considerations of health humanities related to disability and ableism, before finishing with considerations of social media and health, and graphic medicine and health. However, this is not the only way to conceive the shape of the volume as threading through the text are numerous other configurations, such as justice, technology, and communication, as they pertain to health, the nature of the health humanities, the nature of applied humanities and health work, amongst many other possible ways to link the individual chapters.

This book, in particular, invites readers to engage in what can be termed an ethics of reading whereby the act of reading the chapters recognizes what R. Clifton Spargo (2004)defines as *ethics*, which is to see the “primordial facticity of the other. [I]t is the inevitable act and persistent fact of finding oneself in relation to the other” (7). Through engagement with considerations of health, as researchers, teachers, practitioners, or individuals otherwise interested in our own or other people’s health (as a caregiver for a family member, for example) we are constantly in

recognition of others who exist with us in society and are thus in a form of *relation* to them. It is one of the roles of the humanities to help us to understand depths of this sense of relation to others, and it is the configuration of *health* and *humanities* that applies ethical dimensions to that relationship. When we encounter the health humanities in application we can situate ourselves in just such an ethical position, opening ourselves to recognition of the social, cultural, and historical complexity of health as it affects individuals and societies. Consequently, this book is constructed to bring to bear global considerations of health humanities, touching upon North American, Indian, and African contexts in addition to its other concerns.

The first three chapters, following this one, of *Health Humanities in Application* are concerned with educational applications, focusing on postsecondary contexts within which the intersections of arts and humanities practices with health concerns prove fertile grounds with which to catalyse student interest in their own well-being as well as with that of society at large. In Chap. 2, Angie P. Mejia and Danniella Balangoy show how undergraduate health sciences students can learn about the asymmetric power structures in U.S. reproductive health policy through an applied arts-based research methodology that involves intersectional analysis. The application of intersectional theory in the classroom, they argue, serves to challenge invisible privilege, as Mejia and Balangoy identify their own subject positions as "feminists of colour" to counter structures of oppressions in their institutional contexts. Intersectional analysis is conjoined with performance and reflective writing in the classroom as an arts-based research process. Students were engaged in in-class role play performance and writing relating to state-based reproductive and sexual health legislation that is restrictive that lead to learning relating to reproductive health, rights, and justice, which is critical to training effective health practitioners.

Working also from a perspective grounded in intersectional feminism and health justice, Rachel Dudley in Chap. 3 demonstrates that a feminist health humanities approach offers applied opportunities to develop impactful new courses in the health humanities. Knowledge of the development of Dudley's course, *Feminist Health Humanities*, shows how the health humanities can serve a vital role in bringing awareness to students of privilege, power, and oppression as they relate to social structures that impact health and medicine. A key experience of developing the course is recognition of how inseparable issues of health are from social and political factors relating to oppression and inequality. The health humanities

serve as *application* for the development of a new course that challenges assumptions about health and justice, as well as they serve as tools in the classroom setting.

The health humanities also serve applied purposes as a response to the COVID-19 pandemic in designing pedagogical approaches to help students cope with the disruption of the pandemic. Health humanities, art education, and bioethics are brought together by Karen Kiefer-Boyd, Michele Mekel, and Lauren Stetz in Chap. 4. Their chapter outlines the role of an online platform, *Viral Imaginations: COVID-19*, that elicited creative writing and visual art from Pennsylvanians to understand their coping during the early period of the pandemic. *Viral Imaginations* serves, in part, as an archive of collected creative works that can be implemented in K-16 classrooms to help offset the challenges of remote learning and isolation in the age of the coronavirus. A series of pedagogical interventions, theorizations, and discussions form the focus of the chapter to articulate how creative practice and the engagement with creativity focus attention on understanding our humanity amidst a health crisis. *Viral Imaginations*, as online forum extended into classroom practice, underscores the need to share and engage with others as a means of coping.

The understanding of application shifts to the purposes of creating art in the three chapters that follow, beginning with artist, poet, and academic Tea Gerbeza's autobiographical examination of the challenges of social definitions of disability as they intersect the experience of living in our own bodies in Chap. 5. Gerbeza outlines the theoretical perspectives on ableism and disability that inform their artistic practice. The creation of art is simultaneously exploration of the self and its relation to disability and serves as a form of ethics through which those who view the art are able to reflect upon the challenges of ableism as a set of discriminatory practices. Gerbeza creates multimedia art, working with paper and a scanner to create paper-quilled designs that reflect their experience of chronic pain. The chapter focuses on the nine works in the *Painscapes* series as they explore experiential knowledge of pain that belies medically oriented definitions of pain. "Transformation, reclamation, and restoration" are at the core of the creation of art for Gerbeza as art making involves resituating a self and body that has been medically and socially determined. Viewing *Painscapes* provides an ethical space that is partly aesthetic enjoyment and partly educational, and thus serves applied functions beyond the creation of the works themselves. How we understand pain, disability, ableism, and

ourselves situated in a complex social world results from engaging in the ethical realm of *Painscapes.*

Chapters 6 and 7 demonstrate how one can use dance to resituate the binary of the medical practitioner-patient model to a more divers and inclusive mode of understanding that places the individual at the centre of the articulation of health concerns, thus breaking down the hierarchical structures that can impede full understanding if individual health needs. Dance performance is connected to cross-cultural health communication in “Addressing Cultural Competency in Physician-Patient Communication Through Traditional Dance Exchanges.” Working in a variety of health professions and from several global locations—the United States, India, and Nepal—Shilpa Darivemula, Moondil Jahan, Lindsay Winters, and Ruta Sachin Uttarkar articulate the “Aseemkala Model” as a way to extend conventional dance movement therapy (DMT) models that primarily focus on a therapist-patient dynamic that does not account for cultural and environmental factors and that reinforces the separation of therapist and patient in clinical settings. The Aseemkala Model employs traditional dance exchanges to reconfigure incongruity in how medicine and patients interact and understand each other to allow cultural, historical, and experiential diversity to be communicated to health care providers. In “Deep Flow: A Tentacular Worlding of Embodied Dance Practice, Knowing, and Healing,” dancer and academic Jeannette Ginslov defines an embodied dance practice that has as its goal to allow for arts-based knowing and arts-based healing. Employing a dual approach, combining phenomenological research and phenomenological arts practice, *Deep Flow* is concerned with working through the lived experience. Conventional health and medical models are shifted to use one’s own body in the aim of wellness and self-understanding. *Deep Flow* is an applied practice grounded in theory. Ginslov’s discussion emphasizes application and theory by working through the methods and practice of *Deep Flow* to provide a guide for potential practitioners to consider.

The move away from overtly clinical medical contexts is one of the hallmarks of the health humanities as they privilege not only health conceived broadly, but also the range of individuals implicated in considerations of health. One of the distinguishing features of the health humanities is the interdisciplinary and transdisciplinary dimensions of the field. Our contribution, Chap. 8, is interested in what happens when we step outside our disciplinary boundaries to address the challenge of how to create art with the eyes only. We outline a research project that takes eye tracking

hardware and adapts it with custom software to allow individuals to create art using eye movements. As such an art practice opens possibilities for people with limited mobility given that only a single eye is needed to engage in art making, the *how* and *why* shifts to a community setting creating a transdisciplinary approach that not only supersedes disciplinary collaboration but also relies on shared definition of the research questions and research processes. Disability has often been defined against a physical norm that marginalizes individuals who do not fit within an arbitrary set of physical conditions, leading to ableist views of those deemed to be disabled. Our transdisciplinary approach shifts the locus away from a researcher-subject model to instead define the conditions of the research through collaboration.

Similarly, in Chap. 9, Michelle Stewart and Myles Himmelreich present a model of research collaboration that seeks to erase the distinction between research and research subject in the discussion of a project related to Foetal Alcohol Syndrome and provision of disability support services. What happens when the fundamentals of research design are challenged by the "subjects" in researchers' attempts to implement what they considered to be a health care solution? The notion of a community shifts to that which one becomes part of as a researcher, and the research project evolves to include collaboration as an essential part of community engagement and defines an important intersection of the health humanities and disability justice. The application becomes of interest to those with Foetal Alcohol Syndrome and other disabilities, as well as to researchers, artists, and educators. Disability sits uneasily as an opposition to a norm and researchers who shift the focus from a researcher-subject model gain added insights into how we conceive of disability and ability socially, culturally, and historically.

Writing about the experience of disability in Ghana in Chap. 10, Festus Moasan examines how the concept of disability cannot be detached from time and place. Moasan outlines how disability is understood differently in the Global North, where it is largely seen through a rights-based lens, and the Global South, where medical and moral/religious models dominate. Working from a phenomenological study he conducted in Northern Ghana in Konkomba communities, Moasan uses the voices of individuals with disabilities to understand how basic citizenship rights, such as the right to work, are denied to people with disabilities. People born with a disability lead a fraught and perilous life, yet health humanities, combined with disability studies, offers the opportunity to shift the epistemology of

disability in Ghana through a resituating of language and terminology relating to disability. Moasan follows Ikem Ifeobu's (2020) insightful articulation of a framework within which African health humanities practices might engage "to avoid the imposition of paradigms alien to African culture, as is evident in its history" (230). While the health humanities have "consolidated an international appeal" (Ifeobu 2020, 231), it is clear that the young field is rooted in Europea and North America, which makes contributions like this chapter especially valuable in furthering dialogue about a global health humanities.

The understanding of *personhood* in relation to COVID-19 social media political discourse in India is the focus of Chap. 11. Rimi Nandy, Agnibha Banerjee, and Santosh Kumar examine how human bodies are understood historically in relation to pandemics, focusing on the challenge of how to view diseased bodies and the volume of dead bodies that arise due to pandemics. Bruno Latour's Actor Network Theory is combined with Gilles Deleuze and Felix Guattari's articulation of networks as a form of rhizome to understand the complex relationship of human life to disease as a type of non-hierarchical interconnectedness. Linked to Giorgio Agamben's concept of *bios*, referring to a conception of personhood as sovereign, and his concept of *zoe* as a kind of bare life, the effects of COVID-19 are seen to shift the place of the human from *bios* to *zoe* as the social and political needs require individuals to be subservient to the needs of public health as a whole. Using several conversations from Indian Facebook pages, the authors use a health humanities approach to examine how COVID-19 patient bodies have been politicized through a social network that is itself reflective of the social world.

The closing chapters shift to applications in graphic medicine to demonstrate the varied potential of the application of comics into health care contexts. Spencer Barnes in Chap. 12 is interested in how encapsulation as a mechanism through which information is transformed in visual and text-based forms to create effective narratives. Visual storytelling is one way that experiential narrative of a health experience or concern can be conveyed, and social media platforms afford opportunities for such narratives to be constructed and disseminated. Through a case study of a "small story," such as one might find in social media, Barnes demonstrates that mixes of media (such as 360-degree video and audio narration) can be arranged using several types of narrative structure to help viewers—patients, caregivers, health care providers—gain cohesion of the health experience or concern.

Likewise, Tatiana Konrad uses a health humanities lens to read a graphic novel and its consideration of medical progress in Chap. 13. Health humanities widens the perspective from a graphic medicine perspective to include consideration of individuals and issues beyond the medical and clinical contexts. The graphic novel *Kindred: A Graphic Novel Adaptation* (2017) serves as an example of how history, culture, medical progress, and racism can be understood. Racism is shown to be a disease that the United States has struggled to contain across the centuries. Reading the narrative of racism in *Kindred: A Graphic Novel Adaptation* as a pathography (or illness narrative), Prorokova-Konrad argues, allows the pathological nature of racism to be conveyed and reinforces the urgency with which it must be dealt with.

Writing in 2010, Crawford et al. noted the boundaries of the medical humanities, remarking that "The very term 'medical humanities' encapsulates the dominant force in the discipline. Historically, medicine has captured the intellectual and clinical high ground" (Crawford et al. 2010, 6) and called for a new approach that would result in "an inclusive health humanities" (Crawford et al. 2010, 7). Such an inclusive field of endeavour has indeed developed rapidly as researchers, educators, students, practitioners, and members of the community, recognize the place of their inquiry, work, and practice within the space of the health humanities. As *Health Humanities in Application* demonstrates, the realm of the health humanities is ever expanding as they open themselves to new ways to understand the intersections of health, the arts, and the humanities.

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