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## OPPORTUNITIES IN REFORM: BIOETHICS AND MENTAL HEALTH ETHICS

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### Abstract

This year marks the first year of implementation for both the Patient Protection and Affordable Care Act and the Mental Health Parity and Addiction Equity Act in the United States. Resultantly healthcare reform is moving in the direction of integrating care for physical and mental illness, nudging clinicians to consider medical and psychiatric comorbidity as the expectation rather than the exception. Understanding the intersections of physical and mental illness with autonomy and self-determination in a system realigning its values so fundamentally therefore becomes a top priority for clinicians. Yet Bioethics has missed opportunities to help guide clinicians through one of medicine's most ethically rich and challenging fields.

Bioethics' distancing from mental illness is perhaps best explained by two overarching themes: 1) an intrinsic opposition between approaches to personhood rooted in Bioethics' early efforts to protect the competent individual from abuses in the research setting; and 2) structural forces, such as deinstitutionalization, the Patient Rights Movement, and managed care. These two themes help explain Bioethics' relationship to mental health ethics and may also guide opportunities for rapprochement. The potential role for Bioethics may have the greatest implications for international human rights if bioethicists can re-energize an understanding of autonomy as not only free from abusive intrusions but also with rights to treatment and other fundamental necessities for restoring freedom of choice and self-determination. Bioethics thus has a great opportunity amid healthcare reform to strengthen the important role of the virtuous and humanistic care provider.

### Keywords

mental health ethics; mental illness; healthcare reform; autonomy

## INTRODUCTION

Mental illness has a tremendous impact on health throughout American and global society. By the late 1990s, medical authorities and epidemiologists demonstrated that mental illness accounted for the second greatest burden of disease globally.<sup>1</sup> In the United States, the presence of mental illness serves to exponentially compound poor outcomes and increased costs among patients. For instance, in a comprehensive report released April 2014 for the

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American Psychiatric Association, Milliman, Inc. assessed that comorbid mental illness (including substance use disorders) often doubles or triples healthcare costs for patients with chronic physical conditions such as diabetes or asthma.<sup>2</sup> The burden of mental illness is even greater at the margins of society. The US Department of Justice estimates that over half of prisoners have a serious mental illness<sup>3</sup> and researchers find that the great majority of the chronically homeless have untreated mental illness including substance dependence.<sup>4</sup> Yet we are witnessing the widespread closure of mental health clinics, psychiatric wards, and state hospital beds at academic centers and their affiliate institutions nationwide following decades of shrinking budget allocations for mental health. In response, Bioethics has largely been silent.<sup>5</sup>

American healthcare reform's great expanse offers an opportunity to reverse this trend. This year marks the first year of implementation for both the Patient Protection and Affordable Care Act (PPACA or 'Obamacare') and the Mental Health Parity and Addiction Equity Act (MHPAEA or 'Parity Act') of 2008. These two sentinel pieces of legislation are helping to overhaul the nation's healthcare system which has become better known for spending money than improving health. Healthcare reform as such is also moving in the much-needed direction of integrating care for physical and mental illness, nudging clinicians to consider medical and psychiatric comorbidity as the expectation rather than the exception. The full implementation of integrated medical and behavioral healthcare could save upwards of \$40–50 billion annually, surpassing current total expenditures on mental healthcare in the United States alone.<sup>6</sup> Understanding the intersections of physical and mental illness with autonomy and self-determination in a system realigning its values so fundamentally therefore becomes a top priority for clinicians.

Yet a brief review of American Bioethics' literature, commentary in the media, curricula within the classroom, contributions to law and policy, and consultations on the floors of America's hospitals suggests Bioethics has missed opportunities to help guide clinicians through one of medicine's most ethically rich and challenging fields. Before the 1978 Belmont Report, individual reports had been issued regarding consent, surrogacy, and decision-making for institutionalized or mentally ill (IMI) persons, prisoners, and children. Of all the available work in the field, however, the one group to be excised from policy recommendations was the IMI community. Twenty years later, the 1998 National Bioethics Advisory Commission (NBAC) Report<sup>7</sup> regarding persons with mental disorders was released and yet today, over 35 years after Belmont, we remain without sufficiently thorough policy guidelines for working with persons with mental illness in either clinical or research settings. For its first two decades of publication, the *Encyclopedia of Bioethics* did not have a section related to mental health; it was not until the 3rd edition, released in 2003, that the 'Psychiatry and Ethics' section emerged.<sup>8</sup> Core texts such as these form the backbone for bioethics curricula.

Resultantly, routine instruction of bioethics in settings with clinicians often reduces medical ethics to a brief review of principlism and major court cases in the context of utilitarianism and deontology. Such a 'Bioethics 101' session at best alludes to vulnerable populations such as the mentally ill as an exception to a paradigm disproportionately emphasizing autonomy and informed consent.<sup>9</sup> To the extent that Bioethics has influenced clinicians

working with the mentally ill, it may have unintentionally undermined, rather than protected, the rights of seriously mentally ill patients who lack autonomy in clinical settings: those who cannot safely make treatment decisions for themselves (regarding physical or mental healthcare), and yet are often required, allowed, or left to do so. In other words, a brief didactic in bioethics may help clinicians provide better care for the average patient, but undermine care for those patients who are exceptions to the paradigm.

Bioethics' distancing from mental illness is perhaps best explained by two overarching themes, the first being an intrinsic opposition between approaches to personhood; and the second being structural and environmental forces repelling the fields of bioethics and mental health during the latter half of the 20th century. These two themes help to explain Bioethics' relationship to mental health ethics and may also guide opportunities for rapprochement.

## PERSONHOOD

As much as the field of bioethics has been an academic and sociocultural movement for individual rights and social justice over the last half-century, it has arisen from a foundation weakened by its very own strengths in caring for a vulnerable patient population such as the seriously mentally ill. An approach to personhood emphasizing the autonomous individual with 'full use of the reflecting faculty' lies at the core of Bioethics around the world, reflecting the disproportionate impact of American Bioethics globally.<sup>10</sup> A great emphasis on the liberty of the individual speaks to the significant role of American law (rather than medicine or philosophy) in shaping Bioethics' principles.<sup>11</sup>

Bioethics, certainly traditional principlist bioethics, values autonomy and its agent, informed consent, above most else.<sup>12</sup> This reflects the early impetus behind the development of bioethics to protect research subjects following the atrocities of WWII and subsequent human rights abuses uncovered in research studies in the United States and abroad.<sup>13</sup> For Bioethics in its nascent stages to have more thoroughly engaged mental illness would have indicated an apparent doubling back on the core principles it utilized to protect individuals in research settings. The image of an acutely psychotic patient tied to a gurney and forcibly being injected with an antipsychotic or requiring coerced outpatient care once discharged from the hospital is hard to reconcile on the surface with autonomy-driven human subjects protections. The inherent nature of mental illness, whereby the body part which controls decisions around treatment is the very one deemed dysfunctional, requires a level of paternalism and substituted judgment by providers that poses a challenge to hour-long bioethics courses.

Beyond the fully autonomous individual, didactic ethical cases typically employ constructs for evaluating clinical scenarios reliant upon the individual patient approaching a particular practitioner for the treatment of a specified disease understood by objective biomarkers and imaging procedures (as John Arras writes, bioethics as a field 'has traditionally wished to appear as a source of "hard knowledge"').<sup>14</sup> Contrast such a paradigm with the American mental healthcare system wherein the average patient seeking care for mental illness or substance abuse serially enters in and out of fragmented care, moving between an array of providers and often requiring the input of multiple outside service agencies, family

members, and, increasingly in the last three decades, the courts or criminal justice system.<sup>15</sup> The enigmatic nature of mental illness and the absence of so-called objective or empirical test results further muddies discourse- and constrains commentary- around patient rights and self-determination.<sup>16</sup> The nature of patient populations and systems of care within the behavioral health field thus fit uncomfortably with the case-driven disposition of most bioethicists. Forcing us to recognize broader understandings of normalcy and health, persons with serious mental illness – whether in the throes of crisis or amid a prolonged recovery – are often a challenge to discrete, idealized scenarios conducive to case discussion.

Further, the presence of mental illness within academic circles frequently remains hidden, although increasingly less so, whether among faculty or their loved ones. While stories of cancer and disability now often appear in the literature owing to their (openly acknowledged) personal impact among those within the ivory tower, voices with mania or psychosis still remain stigmatized and hushed (notable exceptions include Kay Redfield Jamison and Elyn Saks). A philosopher's conception of an autonomous patient is predicated upon his or her own experience of reality. The absence of such perspectives within the field of bioethics undermines its ability to fully engage related content. Pervasive stigmatization likely further undermines its willingness to do so. Here, evolutionary psychology offers a contribution suggesting that cross-cultural intuitive psychological capacities serve both to limit our ability to fully recognize mental illness and prejudice us against individuals observed to be deviant or abnormal in their behavior.<sup>17</sup> Stigmatization of the mentally ill may have been an especially challenging barrier for Bioethics as an emerging field.

Finally, Bioethics must admit that it has a tendency to fixate on coolness and high-tech, futuristic advancement, the 'gee whiz ethics,' that implicates enhancing the human experience.<sup>18</sup> When one can ponder embryonic stem cells, glowing rabbits, and the advent of a 'post-human' era, why bother with tiring questions of homelessness, drug dependency, and the common occurrence of mental illness?

## STRUCTURAL FORCES

Bioethics' lassitude toward the mentally ill is in part explained by the orthogonal pull of larger sociopolitical environmental forces. A child of the late 1960s, Bioethics matured in tandem with deinstitutionalization, the Patient Rights Movement, and later, the ascension of managed care. Each downplayed if not diverted the need for bioethical input in its own way.

Deinstitutionalization of the mentally ill over the course of the 1960s and 70s invoked the idea of community-based mental healthcare delivery and seemingly negated any ongoing need for bioethicists to intervene in the name of affirming the rights of patients warehoused in state asylums.<sup>19</sup> Deinstitutionalization and subsequent mental health policy, however, have subsequently been criticized in many quarters as having failed the seriously mentally ill.<sup>20</sup> Most recently the Institute of Medicine released a report in 2012 documenting the dismantling of the mental healthcare system in the United States, writing, 'The breadth and magnitude of the problem have grown to such proportions that no single approach, nor a few isolated changes in disparate federal agencies or programs, can adequately address the issue.'<sup>21</sup> When the funding and services for deinstitutionalized seriously mentally ill persons

failed to materialize over this 40-year span, Bioethics had a limited response to such a failure of distributive justice within the healthcare system.

Rather, the dramatic intrusion of libertarian academic law circles guided discourse surrounding the treatment of mentally ill patients.<sup>22</sup> On paper, the libertarians' concern for individual rights looked similar to that forwarded by bioethicists toward human subjects in research. The motivations, however, could not have been more different. Bioethics largely evolved to protect the individual from abuse by the group.<sup>23</sup> The libertarians however wanted to protect society from individuals with 'problems in living' who were alleged to have committed crimes.<sup>24</sup> Rather than defend disorganized and bizarre dangerous acts with insanity, libertarians argued to convict alleged actors on a criminal basis of personal responsibility. Subsequently, by the 1970s all 50 states changed their laws so that persons with mental illness could only be committed to treatment if deemed a 'danger' to themselves or others<sup>25</sup> and a new wave of policy responses based on individualism and personal responsibility were ushered in under Presidents Nixon and Reagan. The resultant conflation of mental illness and dangerousness allowed for an unforgiving criminalization of disease and addiction that has come to serve as one of the pillars upon which the world's largest prison industrial complex has been built. Incarcerating more citizens per capita than any other nation in the world, (over 2.3 million – or roughly one-quarter of the world's prison population)<sup>26</sup> a significant proportion with mental illness (some estimates run as high as 60%–70%<sup>27</sup>), the overflowing corrections system of the United States has become our *de facto* 'mental health asylum'.<sup>28</sup>

Coincident with these developments, individual rights were expanded dramatically for broad groups of Americans (such as women and African Americans) who had yet to be treated equally under the law but were due equal status. Tendencies toward heightening the role of the individual were extended toward youth and the incarcerated as well as patients through the burgeoning Patient Rights Movement that was focused foremost on freeing the *competent* person from medical paternalism.<sup>29</sup> The Patient Rights Movement was not promulgated specifically with the mentally ill in mind, yet the great energy of the individual rights era subsumed the mentally ill, a problematic population in this regard when lacking decision-making capacity.

The advent of managed care in the last decade of the 20th century also served to steer Bioethics away from the mental health field. By weakening the influence of clinicians, managed care not only helped to break the hegemony of the doctor within the doctor-patient relationship, but also shifted the balance of power outside of the actual doctor-patient dyad as lengths of stay shortened drastically, behavioral health was 'carved out' of many insurance plans, reimbursement for psychotherapy withered,<sup>30</sup> and direct-to-consumer advertising and the web-based retail of pharmaceuticals undermined physician expertise. Professional societies such as the American Medical Association and the American Psychiatric Association had little success in stemming these tides. It seems likely that a natural reaction was to guard the remaining territory over which professionals retained authority. Indeed, such bodies were not known to have invited further intrusion by additional outsiders. The physical separation of academic bioethicists (whether on general graduate campuses or at academic medical centers) from behavioral health providers (increasingly

located in separate buildings or campuses altogether as revenue waned) structurally further hindered engagement.

This is not to suggest that Bioethics has completely neglected mental health ethics. Psychiatric and mental health ethics occasionally crop up nested within discussions around end-of-life care and research ethics (especially with schizophrenic or incarcerated patients) involving topics such as informed consent, coercion, and competence. Additionally, the field contributed to nosological discourse that helped to remove homosexuality from the DSM. Another notable exception of Bioethics' involvement has been neuroethics. Biotechnological advancements have allowed for an array of brain imaging techniques, pharmacologic enhancement, and neurogenetic and bioinformatics testing. However more remains to be explored and, aside from a handful of stalwarts, the engagement of Bioethics with classic mental health issues over the past four decades has been spotty and oftentimes only at the periphery of either field.<sup>31</sup>

## LOOKING AHEAD

Despite the aforementioned characteristics and trends estranging Bioethics from the mental health field, there is much to be said for a successful and provocative union. Such a union may have the greatest implications for international human rights if American bioethicists can re-energize an understanding of autonomy as not only free *from* abusive intrusions but with rights *to* treatment and other fundamental necessities for restoring freedom of choice and self-determination.<sup>32</sup>

Bioethics is uniquely situated to help illuminate the shadows strewn between the toughest decisions facing the medical profession involving coercion and incentives, provider authority and patient rights, and individual versus population perspectives. One of Bioethics' greatest strengths is its interdisciplinary nature. Who better to tease out nuanced approaches to mandated care including involuntary commitment, the nosology of psychiatric disease, and the criminalization of disease than teams of colleagues spanning the disciplines of philosophy, law, medicine, psychology, cognitive science, sociology, and anthropology? Delineating societal, state, and professional obligations to the mentally ill to fully realize parity and decriminalization can help re-enfranchise wide swaths of America's population and help guide one of medicine's deepest influences within our social fabric.

Bioethics has experienced a maturation casting doubt upon the succinctness of autonomy<sup>33</sup> and the thoroughness of informed consent (cf. Applebaum's work on the 'therapeutic misconception').<sup>34</sup> Advanced directives similarly have been re-evaluated as the ability of an individual to accurately project hypothetical future decisions has been drawn into question.<sup>35</sup> Such reconsiderations dig at fundamental notions of agency, self-determination, and present- and future-selves. Comprehensive discussions of informed and uncoerced decision-making must *a priori* involve considerations of altered mental states, impairment, and psychosis. Incorporating nuance from the rich substrate of the mental health field can help clinicians in all specialties better understand ethical frameworks relevant to clinical care such as care ethics and virtue theory, which help counter an excessive reliance on autonomy.<sup>36</sup> Bioethics

has a great opportunity amid healthcare reform to strengthen the important role of the virtuous and humanistic care provider.

Ultimately, Bioethics' contribution to the mental health field challenges the relationship between concise principles and vulnerable populations. Perhaps Bioethics has now established itself on a secure-enough foundation to help tackle more nuanced clinical problems that affect patients at the margins of society but at the center of healthcare systems and clinical care.

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