



Research article

Patient's Consent and Autonomy in Jerry Pinto's *Em and the Big Hoom*

Nimisha Tiwari^{1*} & Aratrika Das²

^{1,2}School of Humanities and Social Sciences, Indian Institute of Technology, Indore, India. *Corresponding author.

Abstract

This paper addresses the idea of patient consent in the Indian mental health care system. Mental hospitals tend to treat patients as machines. The personhood of the sufferer is treated as invalid. The paper argues that the conventional clinical practice dehumanizes patients, neglecting their autonomy and perpetuating the stigma associated with a psychiatric diagnosis. In contrast, through the narrative voice of Imelda's son, Jerry Pinto's novel *Em and the Big Hoom* (2012) intimately intertwines the experiences of mental illness within the broader context of familial struggles. Em refuses to become a mere statistic or a diagnostic label, embodying the agency to shape her narrative beyond the constraints of clinical definitions. The novel challenges the flawed clinical gaze and provides an alternative narrative that portrays an ambitious woman who does not succumb to the definitions of her illness. These alternative narratives resist reductionist perspectives, offering a more comprehensive understanding of mental illness that transcends clinical definitions. This paper critically examines the novel's portrayal of patient autonomy and consent, shedding light on the implications for mental health care practices in India. It explores how the text serves as a catalyst for reevaluating conventional clinical perspectives and fosters a more compassionate and patient-centric mental health care system.

Keywords: Patient's consent, autonomy, mental illness, caregivers, illness narratives.



Better Education; Peace, Justice, and Strong Institutions

1. Introduction

Jerry Pinto's seminal work *Em and the Big Hoom* (2012), serves as a poignant exploration of the intricacies surrounding mental health, providing a rich canvas to examine the critical themes of consent and autonomy within the context of mentally ill patients. 'Consent' is the voluntary, well-informed, and unequivocal agreement to engage in a particular action or treatment. It implies that

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individuals have been provided with adequate information to make a decision and have the capacity to understand the implications of their choice. (Miller & Wertheimer, 2010). 'Autonomy' refers to the individual's capacity for self-governance and the right to make independent decisions about their life. It involves the freedom to act according to one's values, preferences, and beliefs. From the patient's standpoint, consent involves being fully informed about medical interventions, potential risks, and alternatives. It is a manifestation of the patient's autonomy, allowing them to participate in decisions about their healthcare actively. Autonomy, for the patient, means having the freedom to choose treatment options that align with their values and preferences (Delany, 2005). It emphasizes the right to be respected as an individual with the ability to make decisions about their own body and well-being. The novel portrays the Mendez family's experience dealing with mental illness and the Indian mental health care system.

Em and the Big Hoom is a rare novel that describes mental illness as its central theme. Imelda, the protagonist, the mother, lovingly called 'Em,' lives in a cramped apartment with her husband, The Big Hoom, her son, the narrator, and her daughter. The novel is set in the 'Bombay' of the 70s- 80s, when the first draft of the Mental Health Act, which subsequently became the Mental Health Act of India (1987), was written. The Mental Health Care Act of 1987 allowed coercive admission of people into asylums and psychiatric rehabilitation centers. Suicide was penalized, and electroconvulsive therapy (ECT) was often used as an easy way to treat the mentally ill, and the wishes of patients and their family's consent were not taken into consideration. Imelda has a mental illness. Throughout the novel, her diagnosis changes- from 'nervous problem' to 'nervous breakdown' to 'schizophrenic' before finally settling down on manic-depressive. But for her family and society, she's just mad. The novel provides an intimate portrayal of Em's bipolar disorder, capturing her manic highs and depressive lows. It describes the struggle of the mentally ill protagonist Em and her caregivers (her family) and questions India's mental health care system. The personal history of Em blurs with the social scenario of India concerning mental health. The paper delves into the ethical dilemmas faced in mental health treatment, particularly in balancing the patient's autonomy with the need for intervention. Imelda's treatment and hospitalization episodes shed light on the complexities of decision-making in the context of mental health care.

In our despair for my mother, we also went to these babas. So, it is not as if our treatment of my mother was this glowing, elegant, post-modern, caring family. We were just about as fragile, hopeless, and helpless as anybody today would be confronted by someone they love – in a state of acute vulnerability. (Pinto, English and Creative Writing, 2019)

Pinto has spoken extensively about his novel *Em and the Big Hoom* in interviews and literary events, providing insights into the book's inspiration, themes, and significance. He has often mentioned that the novel is loosely based on his experiences with his mother's bipolar disorder. He draws from his own life and family to explore the challenges, complexities, and emotional impact of living with a loved one with a mental illness. The novel unfolds through the lens of Imelda (Em), whose compelling storytelling weaves together a tapestry of familial struggles and the profound impact of mental illness on individual agency. Mental health issues often carry a stigma, and individuals may face societal pressure to conform to certain treatment decisions. The novel addresses how societal attitudes impact patients' ability to exercise autonomy and make decisions about their mental health care. Especially for women, societal expectations, cultural norms, and gender roles can influence how women experience and express bipolar symptoms.

Diagnosing bipolar disorder involves evaluating the individual's medical history and symptoms and ruling out any other possible medical or psychological conditions that may account for the signs. The novel not only delves into the psychopathology of bipolar disorder but also provides insight into the mental healthcare system in India during the early 90s through the eyes of her caregiver.

Srikanth Mallavarapu (2018), in his chapter "Resistance, Suffering, and Psychiatric Disability in Jerry Pinto's *Em and the Big Hoom* and Amandeep Sandhu's *Sepia Leaves*," in the book *Literatures of Madness* (2018), explores the concept of mental disability in the Indian context along with the issues revolving around the lives of the caregivers, families and the close alleys of the patients. This has been examined with close reference to the model of resistance and suffering by Arthur Kleinman (1988). Mallavarapu writes about the patient's experience and how listening to and acknowledging the suffering of the disabled can help them diagnose and treat their illness. In the chapter, he discusses primary caregivers, the family, and their tryst with such medical discourses and society. Like Mallavarapu's chapter, this paper acknowledges the patient's agency in conflict with the medical entities. The 'gaze of normalcy' distorts the imagination and our understanding of 'pathological. Smitha Lamiya Rasquinha in "*Em and the Big Hoom: A Psychiatrist's Perspective*" (2020) describes a comprehensive review of the story highlighting the major instances in the novel where psychiatry takes the front seat and their significance from the perspective of a medical professional. Rasquinha claims that madness in the text is not romanticized; instead, it is shown with full complexity, honest descriptions of the mood swings accompanying the illnesses, and how the family is caught up in the system that reduces madness to a mere disability. Sufferers' experiences should be considered real, lived experiences with social, psychological, and biological contexts, with frameworks that encompass a humanistic and democratic way of seeing the diagnosis and clinical practices that are not detached from empathy. A holistic clinical gaze means not adhering to a single modality, such as the number of psychotropic drugs administered to calm mania, but taking into account the family; the past lived experiences and current living situations, social networks, etc. In the text, the subjective experiences of the patient are acknowledged and understood without keeping on a pedestal the psychiatric diagnoses of the mental health professionals.

2. Varying Landscapes of consent and autonomy: Placing Jerry Pinto's *Em and the big Hoom*

The history of the treatment of the mentally ill, consent, and mental health legislation in India spans over a century, rooted in the colonial era with the establishment of asylums in 1745. Mental health services and education also trace back to colonial times, reflecting a custodial-institutional model of care and Western psychiatry training. Significant milestones post-independence include the National Mental Health Program (1982) and India's first National Mental Health Policy (2014). During the British colonial period, the 'lunacy acts' of 1858 were enacted, influenced by the legal construction of madness in the 18th and 19th centuries. The legislation focused on the 'segregation' or 'detention' of Europeans and natives perceived as threats, leading to institutional disciplinary measures such as prisons and asylums. The Indian Lunacy Act of 1912 replaced these colonial legislations and regulated the detention of individuals with mental illness. It defined terms

like 'lunatic,' reflecting stigmatizing notions about mental health. Efforts to reform mental health legislation began in the 1950s, culminating in the enactment of the Mental Health Act (1987), which replaced the Indian Lunacy Act (Ranade et al., 2022). Despite the shift from institutional to community-based care, the Mental Health Act retained custodial elements, subjecting individuals to judicial processes for admission. While perceived as a progressive legislation, it perpetuated the medico-legal subjugation of persons with mental illness, lacking recognition of their human rights and capacity for informed consent. The Act failed to protect against human rights violations in psychiatric institutions and continued to portray individuals with mental illness as lacking decision-making capacity regarding their treatment and care.

Suicide was a crime, the only one where you could be punished for failing...So you could be miserable enough to kill yourself, but the law will pay no heed to misery. It is an old law, a colonizer's law for the colonized. (Pinto, 2012, p. 164)

This passage from Pinto's *Em and the Big Hoom* reflects a critical perspective on the historical context of suicide laws and the harshness and lack of empathy in such legal frameworks. The novel primarily takes place in the late 20th century, particularly during the 1970s and 1980s, when suicide was still criminalized, and the family of the mentally ill was exploited for money in addition to the distress caused by the manifestations of symptoms and other nuances of mental illness. Characterizing suicide laws as a product of colonization and as outdated suggests the need for a reevaluation of these laws to better align with contemporary understanding and empathy toward mental health issues. The reform came much later with the Mental Healthcare Act of 2017 in India, which specifically introduced the notion of "Informed Consent" as consent given for a specific intervention without coercion, fraud, or threat (Math et al., 2019). The MHCA emphasizes the importance of patient autonomy, meaningful involvement in treatment decisions, and the presumption that individuals with mental illness possess decision-making capacity. Despite the strides, obtaining valid informed consent, especially in individuals with mental illness, remains a complex challenge for clinicians, requiring a nuanced approach.

It occurred to me that the mad in India are not the mentally ill. They are simply mad. They have no other identity. Here, everyone was mad. They had lost their hair so that the institution could keep them free of lice. They had lost their clothes because their families had abandoned them, and they had lost their lives because they had lost their families. They were now free in a bizarre sort of way. (Pinto, 2012, p. 196)

The quoted passage from the text highlights a disturbing observation about the condition of mentally ill individuals in India, emphasizing their loss of identity and autonomy within mental health institutions. The assertion that "everyone was mad" suggests a broad categorization that overlooks the individuality and unique experiences of those struggling with mental health. This generalization contributes to a lack of personalized and patient-centric care. The narrator visits Thane Mental Hospital, where he encounters the worst of the Indian mental healthcare system. He notices how the patient's consent and presence are abysmal. All the patients look alike. They are wearing the same clothes and shaved heads. Their smiles do not really reach their eyes and their individuality is lost "crocodile of patients, all looked alike in dirty grey white clothes and near shaved heads (Pinto, 2012, p.195)."

The notion that these individuals are "free in a bizarre sort of way" raises questions about the nature of this freedom. While they may have a degree of physical freedom, it comes at the cost of their mental well-being and autonomy. This paradoxical freedom suggests a lack of agency in their lives and treatment choices. The assertion that the mad in India are not viewed as mentally ill but simply as "mad" implies a reduction of these individuals to a single, stigmatized identity. This reductionism disregards their individuality, contributing to the dehumanization of those grappling with mental health challenges. The description of individuals losing their hair for hygiene purposes and losing their clothes due to abandonment by their families reeks of the stark deprivation of basic human needs. It paints a bleak picture of the neglect and isolation faced by mentally ill individuals, leaving them vulnerable and stripped of essential elements of personal dignity. "The rhythm of hospital life soothed her, suited her. Here no decisions were to be made, and no one expected you to be anything other than survivor" (Pinto, 2012, p.202). The absence of decision-making can be therapeutic, but it raises questions about individual agency and involvement in treatment decisions. The portrayal of the 'mentally ill' by Pinto indicates a severe deprivation of consent and autonomy for mentally ill individuals in India. Reduced to definitions of their illnesses and subjected to institutional practices without active participation or understanding, their ability to make informed decisions about their lives and treatment appears severely compromised. Striking the right balance between protecting vulnerable individuals and upholding their autonomy remains a persistent challenge in mental healthcare ethics.

3. Ethics of Electroconvulsive therapy (ECT)

The intersection of consent and autonomy becomes complex in the context of mental illness. Mental health challenges may impact a person's decision-making capacity, raising questions about their ability to provide valid consent. Balancing the need for treatment with respecting the autonomy of mentally ill patients is a delicate ethical challenge. The narrator scrutinizes the abysmal autonomy of the mentally ill when it comes to treatment options, the extent to which electro-convulsive therapy or shock treatment is used as an easy cure or a psychiatric intervention, and the ethical concerns associated with involuntary administration. The text brings ECT to the forefront as a prominent treatment option for Em, the mother in the narrative. ECT remains a controversial method of therapy and has been criticized as a tool often. The only reason it has endured over the years is due to its proven effectiveness in lowering psychiatric symptoms. It still claims its place in the treatment algorithm for severe psychiatric illnesses like schizophrenia and depression. During ECT, in the presence of medical professionals, a small quantity of carefully controlled electric current is used to target a specific area of the brain. At the same time, a patient is unconscious and receiving treatment. The duration is always a few seconds, and 2-3 sessions are weekly. Existing studies indicate a significant gap in awareness about different aspects of ECT among patients and their relatives (Gangadhar et al., 2010). Most participants needed more comprehensive knowledge about the procedure, informed consent, indications, effectiveness, and side effects associated with ECT. Notably, a consistent trend emerged wherein relatives exhibited slightly better knowledge than the patients, although these differences did not reach statistical significance. The limited awareness observed, particularly those without prior ECT experience, may be attributed to a need for more access to reliable sources of information. Most participants relied on the media as their primary source of information, underscoring the potential influence of media

portrayal in shaping their understanding of ECT. This highlights the need for targeted educational efforts to improve awareness and knowledge among patients and their relatives, especially those without direct exposure to the procedure.

The text offers a scathing critique of ECT. It claims that this dehumanizing practice only turns people into a mere caricature of themselves and takes away their right to bodily autonomy. Bodily autonomy stands for the ability to be self-governing of one's body. The narrator describes one college trip to Thane Mental Hospital. The instructor, without any hesitation, is allowed by the doctor to watch the patient undergoing the procedure. Although the narrator is silent about the practice of ECT, he has personally been a witness and his mother a victim. Em's stay at Ward 33 of Sir JJ Hospital was lively; she made friends with nurses, doctors, and patients alike and seemed to enjoy the hospital ecosystem; the narrator thought it was her strategy to avoid ECT. However, her visit to the Staywell clinic was a significant turning point; while being administered the ECT, she was reduced to a 'caricature of herself.' "A mark, a red angry mark, a burn mark, the place where electricity had surged into her head (Pinto, 2012, p205)." All her fond memories and cheerfulness disappeared.

Caregivers play a crucial role in obtaining informed consent by providing information, addressing concerns, and ensuring the patient's understanding. Their responsibility is to support the patient's autonomy while considering the patient's best interests. The narrator and his sister admit Em into the Staywell clinic; they are not asked before Em is given the ECT treatment, and she returns home with a 'disrupted store of their collective memories.' The narrator feels very guilty about admitting Em to the hospital, where she is administered ECT and comes back as a shell of a person, with something shifted inside of her. Caregivers should respect and promote patient autonomy, recognizing that the patient's values and wishes are central. While they may provide guidance and support, the ultimate decision should align with the patient's autonomy, fostering a collaborative approach. The patient and the caregiver are given a negligible say in the treatment. Em's identity and self-perception, including memory, are distorted or altered. Em does not fully comprehend the cognitive side effects. Informed decision-making requires a comprehensive understanding of the potential changes in identity and memory, allowing patients to make choices aligned with their values and preferences. Yet in Thane Mental Hospital, representing India's broken healthcare of that time, patients' autonomy and individual rights are not recognized, nor are they informed of the potential consequences of the chosen treatment, emphasizing the importance of transparent communication, informed consent, and a patient-centered approach in psychiatric interventions.

4. Psychiatry's claim over mental illness

So, the end of psychiatric medicine is to iron out all differences and produce identical paper dolls? (Pinto, 2012, p.198).

The narrator describes his visit to Thane Mental Hospital. The students and social workers start an intellectual debate about the idea of 'normalcy' and 'deviation' in the context of ECT. The students discuss R.D. Laing and his foray into antipsychiatry theories. The narrator remains mute as he disapproves of the intellectual debate that again reduces the mentally ill to a commodity, an unwanted part of society. The narrator's disapproval of the administration of ECT results in him

avoiding the discussion altogether; he is highly critical of what ECT has done to his mother, so he chooses not to engage in the discussion. Existentialism, a prominent philosophical perspective, intricately mingles with psychiatry by framing mental illness as an inherent facet of an individual's life. Within existentialist tenets, the concept of autonomy holds paramount importance, acknowledging the intrinsic independence of individuals while recognizing instances where mental illness impedes this autonomy. In the realm of psychiatric theory, R. D. Laing's perspective introduces a provocative paradox, suggesting that the mentally ill may possess autonomy comparable to the sane (Laing, 1984). This challenges the conventional recommendation for enforced treatment, adding a layer of moral complexity to psychiatric interventions. As we navigate this landscape, the text urges a shift in perspective, advocating a clinical understanding of psychiatric diagnosis and a profound ethical inquiry into the intricate interplay between autonomy, medical practice, and broader ethical considerations within psychiatry.

Em's journey through her treatment procedures was never linear; she found a home at Sir J.J. Hospital, room 33- a government hospital where she felt safe and at home. She was admitted to the Staywell clinic run by Dr Alberto D'Souza. Here, she underwent Electroconvulsive Therapy (ECT) without her or her family's consent, a decision that her family deeply regretted. The narrator describes the way people with mental health conditions are treated in those hospitals, strapped with force and powerless as they struggle weakly. Such inhumane treatments have a 'remarkable success rate.'. The text highlights the dehumanizing impact of such treatments, which are implemented to bring patients back to societal norms without acknowledging their personal stories. This raises concerns about patients' autonomy, as they may not have a say in the treatments administered.

But it seemed as if all psychiatric medicine was only at the symptoms. Mute the paranoia. Calm the rage. Raise the endorphins. Underneath, the mystery continued, unchanged. Underneath, somewhere in the chemistry of her brain, there was something that could not be reached. (Pinto, 2012, p. 216)

The psychiatrists who diagnosed Imelda as 'manic-depressive' experimented on her with lithium drugs. It kept her afloat for a good two years. The medication administered especially for bipolar patients helped relieve stress and anxiety, but it led to prolonged depressive states; Em's mania seemed to have calmed down even though she still refused to do ordinary daily tasks or take a bath. The drug brought the feeling of 'damnation.' Em's paranoia and her 'hallucinations' were back. The enemy, living in the ceiling fan, wanted to harm her and her family and had been there since the son's birth. The enemies have even driven her outside the house, barefoot with her son, which put their safety in danger. The text's representation of lack of empathy among social workers and psychiatrists and the administration of drugs reflects how patients are objectified to bring them back to the prescribed norms of behavior, the medicine prescribed as a routine without taking into account their narratives. A mentally ill patient, in the eyes of a psychiatrist, is just a 'mad person' who needs to become 'normal' (Malla et al., 2015). The reduction of complex experiences to diagnostic categories overlooks the nuances of each patient's narrative. This reductionist approach challenges patients' autonomy by neglecting their personal histories and self-perceptions.

Ian Hacking redefines the word 'normal' in the context of mental illness. "Normal" is knee-deep intermixed with power relations. It does not simply encapsulate regular, usual, or common. Since the time of Aristotle 'normal' stands for 'good health, someone's chosen destiny' (Hacking, 1990, p. 169). In contrast, the disease is deviation. The pathological has to be separated, a bad omen, restricted and isolated, even eradicated. Psychiatry compromises a whole set of techniques and instruments, tests, procedures, application levels, and targets. It works in a "diagnostic style of reasoning" (Tremain, 2015, p. 40). It is a particular type of power, a hierarchy that does not work as an apparatus or institution but reinforces a set standard of normalcy. Disciplinary normalization is taken that could arrest, punish, or discipline the 'deviant'. Its main target remains to produce a mind that acts by the societal idea of 'normal' that can be regulated, transformed, stabilized, and homogenized by a set normalcy standard. Healthcare professionals rely on diagnostic labels, to assign treatment options for individuals, and neglect their personal history. For example, one such label to classify individuals into different categories of mental illnesses, a hegemonic Diagnostic and Statistical Manual (DSM) is used, which has become a manual for psychiatrists since the beginning when the discipline was institutionalized. It works to objectify and compartmentalize the human mind. Currently, in its fifth edition, DSM is used as a constitutional framework for putting deviants into different categories. The 'deviant' is labeled as 'abnormal.' Psychiatry has lost touch with sufferers' narratives; the inexpressibility of sufferers' embodiment is counted as one of the traits of the illness (Zatti & Zarbo, 2015). Pain is reduced to clinical terms, and humans are reduced to automated diagnostic labels. To acknowledge the alternative story a patient has to tell, to accept the dimensions of illness that are separated from his self, his personhood, yet remain ingrained in his consciousness, the collective consciousness needs to be re-addressed too.

I grew up being told that my mother had a nervous problem. Later, I was told it was a nervous breakdown. Then we had a diagnosis, for a brief while, when she was said to be schizophrenic and treated as one. And finally, everyone settled to calling her manic-depressive. She had only one word for herself through it all: mad. (Pinto, 2012, p. 207)

The above quote from the text presents a personal and poignant perspective on the diagnostic process and labeling within the mental health field, particularly as it relates to the Diagnostic and Statistical Manual of Mental Disorders (DSM). The progression of terms used to describe the speaker's mother's condition reflects the evolving nature of psychiatric diagnoses. From a vague "nervous problem" to a more specific "nervous breakdown," followed by the diagnostic labels of "schizophrenic" and "manic-depressive," this journey highlights the lack of consistency and precision in psychiatric terminology over time. The narrator's mother seems to reject the various diagnostic labels imposed on her. Instead, she maintains her self-perception, encapsulated in the simple yet powerful term, consistently referring to herself as "mad." Through the text, Pinto criticizes DSM, the broader psychiatric system, and the reductionist tendency within psychiatric diagnoses, as the complexity of the mother's experience is distilled into a series of labels. What might be interpreted as one disorder at a given time may evolve or be reinterpreted later. This fluidity challenges the notion of psychiatric diagnoses as stable and objective entities. The labels assigned do not fully capture the complexity of Em's experiences. The mother's self-identification as "mad" underscores the neglect of the patient's perspective within psychiatric diagnoses. It suggests a disconnection between clinical language and the individual's understanding of their mental health.

The individuals suffering from mental illnesses must have the agency to narrate their own experiences and decide for their own needs, i.e., nothing about me without me, and parallelly, for the erasure of the politics of disavowal. (Bérubé, 1998, p.85)

Em's diaries and letters help connect her to herself while she reclaims her stories through her ramblings. Through her diaries, we witness the grim aspects of women's workplace, the glass ceiling, where women are lured into prostitution. Em's family sees her as a means of money-making and is unhappy with the big Hoom's marriage proposal. Those stories hide in them: suicidal tendencies, paranoia, delusion, the loss of identity that comes with overriding interpersonal bonding, failures in those interpersonal bonds, and self-harming, which very often encapsulates the causes and consequences of mental suffering. The DSM can only bracket the symptoms, but each patient and what their families go through cannot be fully defined and diagnosed through the bullet points printed on its pages.

Psychiatry claims to have immense, almost indisputable knowledge of the workings of the human mind. According to Aubrecht (2012), psychiatry tempts the masses with offers to eliminate mental anguish. The information, discourses, and practices of psychiatry are used to create the language of mental health. The unquestionable authority of psychiatry and its allied medical enterprises in defining, interpreting, and treating mental abnormalities that are caused by any mental pain reflects the hegemonic grip of knowledge and power at interplay at the level of pain and the way it is discussed and interpreted across various cultures and times. psychiatry became the lead authority in defining 'normalcy.' In the public and private spheres, the way we conduct ourselves, the way we eat and sleep, express our sexual feelings, and use common sense and language each is minutely studied, albeit without empathy, in a commercialized way to distinguish 'normal' people from 'deviant' and pathological,' and to categorize and cure the 'pathological,' the 'mad.' The narrator's mother in the text consistently refers to herself as "mad," rejecting the various diagnostic labels imposed on her. This self-identification underscores the disconnection between clinical language and the patient's understanding of their mental health. Patients should have the agency to narrate their experiences, and their perspectives should be considered in the diagnostic process. The crux of consent lies in the realization of choices, a profoundly subjective process involving contemplative expression and cognition exercises. Power structures and societal norms may influence the dynamics of consent, potentially obscuring the true expression of individual decisions. Consequently, the complexities surrounding consent extend beyond the overt expression of will, necessitating a deeper exploration of its nuanced dimensions.

5. Medical Discourses and Em's Counter Diagnostic Narrative

A diagnosis helps cure. But it also pigeonholes the patient. She is manic-depressive; he is schizophrenic, into your box (Pinto, 2012, p. 212).

Imelda's diaries, personal letters, and conversations with her children reveal her fragmented, dislocated past. Her needs and desires are often considered irrelevant, whether fate or society. Her ramblings reflect her repressed consciousness. Her wishes are marred by societal factors such as family, religion, marriage, medicine, the arrival of her children, and ultimately, her mental illness. Em hides nothing. She is very vocal about her condition. But we can observe the sense of shame radiating from her son as she tells others in the hospital that she tried to kill herself. In our

collective consciousness, illness has always been a condition that needs to be corrected; health is a norm. While Em speaks brilliantly in her 'manic stages,' people who suffer from mental illnesses are believed to be incapable of speech. The privilege of 'rhetoric ability' is denied to them. Thus, they are denied the agency to tell their stories, and their first-hand experiences are considered faulty or invalid. Wilson and Beresford (2002) speak of the 'psychiatric diagnostic empire' where mentally ill patients are denied agency over their narrative; they are reduced to being "voiceless invalid creatures."

In contrast, memoirs, Imelda's letters, and ramblings incorporate the emotive and cognitive states of her psychological dimension and experiences. Rita Charon's *Narrative Medicine* (2006) talks about patients as 'living documents' – how patients' stories should be regarded as a literary text, with attention given to context, overall narration, and spoken and unspoken words. Jerry Pinto creates a strong connection between mental illness, medical discourses, the hospital ecosystem, and Em's stories. Shoshana Felman notes in *What Does a Woman Want? Reading and Sexual Difference* (1993) "Madness is the impasse confronting those whom cultural conditioning has deprived of the very means of protest or self-affirmation" (2). The traditional role of a woman in India was unquestioning obedience to a man: in the parent's house, the daughter obeyed the father; after marriage - to the husband; in the event of the husband's death - to the eldest son. Religious scriptures dictated a strict hierarchy and inherited social norms and customs. As we trace Em's history, we find that the strict patriarchal system has gripped her life, too. Loss of individual identity, displacement, and her family's constant coercion into her private life make her unhappy. Her dreams of further education are shattered when she has to support her family financially, forgetting her dreams and making her dissatisfied with life. Mathew John M along with K Balakrishnan, in their article titled, "Jerry Pinto's *Em and the Big Hoom*, Heteronormativity and The Text of Madness" (2019), analyze the significance of gender roles, adherence to norms and behavior patterns along with cultural aspects in the novel, that play a role in the exacerbation of Em's illness, highlighting her bittersweet relationship with shifting roles, especially the notion of motherhood.

Em often expresses her experiences of madness and depression through vivid and imaginative metaphors. Through these monologues and conversations with her children, she not only articulates her struggles but also reclaims a sense of individuality and agency. Em's critical self-awareness of her illness is translated and explained through metaphors. Em describes depression as the 'tap' that has come undone. Throughout the novel, depression is described by various terms- 'tower,' 'Prison,' 'quicksand,' 'nighttime,' and 'despair.' But the imagery of the leaky tap comes repeatedly whenever the mother holds the rein of her narrative. Em describes depression as another reality from which she has no escape. Amidst Em's frequent suicide attempts, hospitalization, and inability to leave her home unattended, the Mendez family is caught in an endless nightmare. But the way Em describes her condition through monologues captures the rambling of mania and paints the picture of a very humane, vulnerable woman behind and apart from her illness, which is very different from the narrator's description of her mother's illness.

Em's way of battling depression is through her stories and monologues, which often tend to make her family uncomfortable, but they also represent how rich and poetic her imagination is. Her philosophical thoughts and ideas on life, death, taboos of sex, corporate realities, and motherhood show her to be an intelligent woman, not just reduced to the definition of her illness:

"She was playing out her insecurities. This was allowed by her 'condition.' She could say what other normal women could not" (Pinto, 2012, p55). Em's idea of motherhood is unconventional. It is very firmly attached to her idea of illness. When Susan dresses for her date Em tips her on bodily harm she can induce on her date if the date tries to rape her. She paints an unflattering picture of sex, saying this is her duty as a mother. Em chants "Mother most horrible, mother most terrible, the mother standing at the door, mouth full of a dribble" (Pinto, 2012, p51). And when the narrator tries to console her with comforting lies, she acknowledges her roles are somewhat limited thanks to her illness. The narrator is shocked to hear her mother talk about her sex life, which is stale, and she has never been too enthusiastic about it. She even suggests jokingly her husband hire a mistress or a maid and she would not mind. Em's stories skip from one memory to another, from her marriage to adoption to vacation, her work life, and her friends.

While the narrator expresses reluctance in believing his mother's stories and finds the letters a tad bit romantic to his taste, he also admits that young Imelda portrays a different aspect of herself through those letters and has a particular creative genius, lamenting the loss of the writer Imelda. Em speaks of her past experiences in the first person. She is eager to tell her stories to her children. Margaret Price gives the term 'creative incoherence' – a counter-diagnostic way of storytelling (Price, 2009), debunking the popular discourse through the 'alternative' discourse – 'incoherence.' This is an alternative world of ideas, an incessant stream of thoughts that lack colloquial diction and is inconsistent and unreliable but still helps in meaning-making and revelation of truth. It solidifies the 'I' in the narration. The concept of incoherence is taken from Charlotte Linde's concern with life writings, a negotiating task between the reader and the writer. This incoherence is seen as a creative meaning-making strategy. Linde suggests a strategy of incoherence works in opposition to the construction of text. Such narratives deconstruct text as a site of meaning-making. Such 'disembodied' 'unsituated' text requires a negotiation between the reader and the writer. The construction of text should be such that there is no discrepancy in the meaning of the making process. The reader consciously understands the strategically disorganized incoherence intended by the author, which may be devoid of linearity.

Em's incoherence excels as she narrates her marriage story, giving a different spin each time. She discusses various definitions of motherhood and pregnancy and creates new creative names for her kids. And her 'personal interpolations' are why she has to leave her high-paying job. These 'further negotiations' aid in the resistance of hegemonic discourses of normalcy and try to give an alternative and more empathetic way to understanding mental illness. Therefore, Price introduces essential incoherence in these narratives that serve as a "strategic advantage rather than accommodated as an impairment" (Price, 2009, p.19). Em has deliberately converted this incoherence into a meaning-making tool, using it as a strategy to subjugate the societal definition of madness; these psychiatric discourses are replaced with the truth of the sufferer's embodiment. The idea of incoherence as a device, a suitable language for the mentally ill, is also addressed by Iqbal Judge in his article titled "Decoding Insanity: An Analysis of Narrative and Stylistic Devices in Jerry Pinto's *Em and the Big Hoom*" (2016). He talks about the language used as a device to showcase the unconscious and the lapse into insanity, which is generally indicated by the ruptures in language and sudden free flow of speech, often perceived as incoherent ranting. In this novel, the language flows like an uncontrollable tidal wave, erupting through the speeches and writings of Em.

The Diagnostic and Statistical Manual of Mental Disorders, 5th Edition, DSM-V (2013) identifies Schizophrenic and Bi-polar individuals with primary traits like a pattern of unstable and intense interpersonal relationships characterized by alternating between extremes of idealization and devaluation', disturbances in thinking (cognition), emotional responsiveness, and behavior, 'identity disturbance', 'recurrent suicidal behavior, threats, and gestures, or self-harming/mutilating behavior,' 'affective instability due to a marked reactivity of mood' and 'chronic feeling of emptiness.' Em refuses to create a halo around such unstable and incoherent traits or treat them like an enemy. She accepts that she is mad. She turns her stories into tools to express her thoughts and moods, documenting a counter-diagnostic narrative. Her incoherent stories tend to absorb and eradicate the stigma and shame attached to that incoherence. Her anecdotes and letters, both poetic and deeply personal, creative and symbolic expressions, add layers of meaning to her experiences, making them more accessible to herself and those around her. This act of self-expression becomes a form of empowerment for Em, allowing her to shape her narrative and assert a degree of control over her own story. Through metaphorical language, Em engages in a process of defining and understanding her madness on her terms. This can be seen as a way of reclaiming agency in the face of mental health challenges, as she refuses to be solely defined by her condition. It also serves as a means of connecting with her children and fostering a deeper understanding of her inner world.

6. Conclusion

Through the novel *Em and the Big Hoom*, Pinto explores the grey area of consent and autonomy regarding the mentally ill. A grave concern that is underlined in the entire novel is the capability of the mentally ill to make their own decisions. Their impairment does affect their decision-making, and the stigma and discrimination that results from the perception that they are highly likely to harm others and themselves pushes them further away from procuring and choosing from the treatment options available. The family and patient's involvement in the management of their illness remains passive, and due to inadequate information provided and poorly structured mechanisms of patient-centered care that only allow access to the bare minimum, the patient's self-esteem and self-efficacy are diminished even further. They are no longer the anchor of their life, and their voices do not matter. By highlighting the different environments of the two hospitals, treatment procedures, and the medical discourses that accompany them, the author tries to portray patients' need for their voices. Em employs different metaphors to ease her speech and provide proper coherence to the listener. However, towards the novel's end, she wishes for a quick end: "Nobody knows what I am going through. What I suffer only I know" (Pinto, 2012, p. 51). Patients and their families face the unpredictability of the illness and the inability to understand what lies beneath it. Patients cannot explain everything they feel; they cannot put the emotions they experience into words. Yet, Imelda's mental illness is not just reduced to her psychiatric symptoms. Instead, her emotions are portrayed in the full complexity of cognitive, sensory, and emotional experiences. The family's experience dealing with mental health services is just like any other Indian family battling the mental illness of their loved ones, with consent treated as a foreign concept. The identity and self-perception of the patients are shaped by their surrounding social experiences, other people's behavior, and responses towards them. Pinto, through his novel, tries

to fight the stigma attached to mental illness while also trying to expose India's broken healthcare system that aims to produce 'identical paper dolls' devoid of pain.

The subjective experiences of Imelda are acknowledged and empathized with, while the author demands they be considered a vital part of the process of diagnosis. It might be the faster way to reduce stigmatization. The family goes through varied and collective experiences, but the author also gives space to her individual experiences and stories. The novel aims to bring a change in the discipline of psychiatry that is reduced to DSM labels and democratize and humanize institutional interventions and study of mental health, bring out the repressed voices of those battling mental illness, and redress the reader's and society's perspective on mental health, the shift of focus on a more holistic approach. The novel challenges the flawed clinical gaze and provides an alternative narrative that portrays an ambitious woman who does not succumb to the definitions of her illness. Rather than attributing Em's mental health challenges to a sudden and isolated process, Pinto highlights the influence of her life experiences and multifaceted identity as a woman fulfilling roles as a daughter, wife, and mother. These alternative narratives resist reductionist perspectives, offering a more comprehensive understanding of mental illness that transcends clinical definitions. Imelda's storytelling in the novel serves as a powerful medium to confront the dehumanizing tendencies within the mental health care system. The novel underscores the importance of recognizing and respecting patient consent and autonomy, advocating for a more holistic and empathetic approach to mental health care. Em emerges as an ambitious woman who refuses to be defined solely by her illness, challenging prevailing stereotypes and emphasizing the significance of preserving individual agency. While symptomatic relief is achievable, there are deeper, uncharted dimensions of mental health that remain untouched by existing approaches. This opens a discourse on the philosophical and ethical considerations surrounding psychiatry's claim over mental illnesses and the need for more holistic and transformative approaches to mental health care.

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References

- Aathira, A. S., & Poongodi, A. (2022). Echoes of Chaos in Jerry Pinto's *Em and the Big Hoom*. *Journal of Positive Psychology and Well-being*, 6(1), 1650-1658.
- Ali, F., Gajera, G., Gowda, G. S., Srinivasa, P., & Gowda, M. (2019). Consent in current psychiatric practice and research: An Indian perspective. *Indian Journal of Psychiatry*, 61(Suppl 4), S667.
- Aubrecht, K. (2012). Disability studies and the language of mental illness.
- Beauchamp, T. L. (2010). Autonomy and consent. *The ethics of consent: Theory and practice*, 55-78.
- Bérubé, M. (1998). *Life as we know it: A father, a family, and an exceptional child*. Vintage.

- Charon, R. (2008). *Narrative medicine: Honoring the stories of illness*. Oxford University Press.
- Clark, H. (Ed.). (2008). *Depression and narrative: Telling the dark*. State University of New York Press.
- Dan, A., Grover, S., & Chakrabarti, S. (2014). Knowledge and attitude of patients with psychiatric disorders and their relatives toward electroconvulsive therapy. *Indian journal of psychological medicine*, 36(3), 264-269.
- Delany, C. (2005). Respecting patient autonomy and obtaining their informed consent: ethical theory—missing in action. *Physiotherapy*, 91(4), 197–203. <https://doi.org/10.1016/j.physio.2005.05.002>
- Donaldson, E. J. (Ed.). (2018). *Literatures of madness: Disability studies and mental health*. Springer.
- Duffy, R. M., & Kelly, B. D. (2019). India's Mental Healthcare Act, 2017: Content, context, controversy. *International Journal of Law and Psychiatry*, 62, 169–178. <https://doi.org/10.1016/j.ijlp.2018.08.002>
- Felman, S. (1993). *What does a woman want? Reading and sexual difference*. JHU Press.
- Felman, S., & Evans, M. N. (2003). *Writing and Madness: (literature/philosophy/psychoanalysis)* Stanford University Press.
- Foucault, M. (1988). *Madness and civilization: A history of insanity in the age of reason*. Vintage.
- Frank, A. W. (2013). *The wounded storyteller: Body, illness, and ethics*. University of Chicago Press.
- Gangadhar, B. N., Phutane, V. H., & Thirthalli, J. (2010). Research on electroconvulsive therapy in India: An overview. *Indian Journal of Psychiatry*, 52(7), 362. <https://doi.org/10.4103/0019-5545.69268>
- Hacking, I. (1990). *The taming of chance* (No. 17). Cambridge University Press.
- Kapoor, A., & Pathare, S. (2019). Section 377 and the Mental Healthcare Act, 2017: breaking barriers. *New Drugs and Clinical Trials Rules Examined*, 4(2), 111-114.
- Kelly, B. D. (2016). Mental health, mental illness, and human rights in India and elsewhere: What are we aiming for? *Indian journal of psychiatry*, 58(Suppl 2), S168.
- Kleinman, A. (2020). *The Illness Narratives: Suffering, healing, and the human condition*. Basic books.
- Kocsis, R. N. (2013). Book review: diagnostic and statistical manual of mental disorders: (DSM-5).
- Laor, N. (1984). The Autonomy of the Mentally Ill: A Case-Study in Individualistic Ethics. *Philosophy of the Social Sciences*, 14(3), 331–349. <https://doi.org/10.1177/004839318401400303>
- Linde, C. (1993). *Life stories: The creation of coherence*. Oxford University Press.
- Malla, A., Joobar, R., & Garcia, A. I. (2015). "Mental illness is like any other medical illness": a critical examination of the statement and its impact on patient care and society. *Journal of Psychiatry & Neuroscience*, 40(3), 147–150. <https://doi.org/10.1503/jpn.150099>
- Mallavarapu, S. (2018). Resistance, Suffering, and Psychiatric Disability in Jerry Pinto's *Em* and the Big Hoom and Amandeep Sandhu's *Sepia Leaves*. *Literatures of Madness: Disability Studies and Mental Health*, 183-197.
- Math, S. B., Basavaraju, V., Harihara, S. N., Gowda, G. S., Manjunatha, N., Kumar, C. N., & Gowda, M. (2019). Mental Healthcare Act 2017 – Aspiration to action. *Indian Journal of Psychiatry*, 61(10), 660. https://doi.org/10.4103/psychiatry.indianjpsychiatry_91_19
- Miller, F. G., & Wertheimer, A. (2010). The Ethics of Consent: Theory and practice. In *Oxford University Press eBooks*. <http://ci.nii.ac.jp/ncid/BB00401159>

- Pathare, S., & Kapoor, A. (2021). Decisional Autonomy and India's Mental Healthcare Act, 2017: A Comment on Emerging Jurisprudence. *Mental Health, Legal Capacity, and Human Rights*, 155.
- Pinto, J. (2014). *Em and the Big Hoom: A Novel*. Penguin.
- Poli, A. (2021). Mental illness and radical caregiving in Sepia Leaves and Em and the Big Hoom. *Narrative Art and the Politics of Health*, 211.
- Price, M. (2009). Her Pronouns Wax and Wane: psychosocial disability, autobiography, and counter-diagnosis. *Journal of Literary & Cultural Disability Studies*, 1(1), 11-33
- Ranade, K., Kapoor, A., & Fernandes, T. (2022). Mental health law, policy & program in India – A fragmented narrative of change, contradictions and possibilities. *SSM - Mental Health*, 2, 100174. <https://doi.org/10.1016/j.ssmmh.2022.100174>
- Rasquinha, S. (2019). *Em and the Big Hoom-A Psychiatrist's Perspective*. *Muller Journal of Medical Sciences and Research*, 10(2), 89-89.
- Renz, U. (2019). 2 Epistemic Autonomy in Descartes, Spinoza and Kant: The Value of Thinking for Oneself. In *Edinburgh University Press eBooks* (pp. 33–49). <https://doi.org/10.1515/9781474419703-005>
- Showalter, E. (1985). *The female malady: Women, madness, and English culture*. New York: Pantheon Books.
- Tremain, S. (2015). This is what a historicist and relativist feminist philosophy of disability looks like. *Foucault Studies*, 7-42.
- Zatti, A., & Zarbo, C. (2015). Embodied and exbodied mind in clinical psychology. A proposal for a psycho-social interpretation of mental disorders. *Frontiers in Psychology*, 6. <https://doi.org/10.3389/fpsyg.2015.00236>

About the authors

Nimisha Tiwari is a Research Scholar (English), School of Humanities and Social Sciences, Indian Institute of Technology, Indore, India. Her areas of research are Medical Humanities, Health Humanities, and Bioethics.

Aratrika Das is Assistant Professor (English) in the School of Humanities and Social Sciences, Indian Institute of Technology, Indore. Her research interests include nineteenth-century British literature, the Gothic, Medical Humanities, and writing pedagogy. She received the Young Researcher Seed Grant 2022-2024 from IIT Indore. She is currently working on projects, including "Teesta and Siliguri in Maps, Memories, and Music," funded by the India Foundation for the Arts, which focuses on methods of archiving the social, ecological, and cultural practices of South Asia and "Critical Thinking and Writing Lab IIT Indore," funded by the JP Narayan Center for Excellence in the Humanities 2023-25, which seeks to create pedagogical tools and theoretical vocabulary from South Asia.