

# Challenges of Caregivers of Mentally Ill Persons – A Study of Em and the Big Hoom

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**Abstract:** The stigma that mentally ill persons carry is not different from the trials and tribulations of their caretaker's confrontation with the victim and the society. The caregivers are emotionally and physically drained in the process of providing an amiable, congenial ambience to reduce the negativism of mentally ill. The physical and mental stress the caregiver undergoes due to the non-cooperation, dependence, mental incapacity of the victim is horrendous. The consistent exhaustive efforts of the care giving families to remain as a friend, companion, guide, nurse and philosopher to the victim is ever unidentified, unarticulated and unheeded. There are no support systems or incentives provided by the Government or hospitals for self-help to retrieve the emotional balance or to boost the morale of the Caregiver. The present paper explores the challenges of caregivers of a person with mental illness with special reference to Jerry Pinto's 'Em and the Big Hoom'. The story of Em (Imerald – mother of the narrator suffering from mental illness) with graphical descriptions is told from the perspective of a caregiver son, the narrator. 'The Big Hoom' refers to the narrator's father who a rampart was protecting the family from falling apart due to the bouts of Em's madness. Susan, the narrator's sister is a stoic caregiver providing very practical solutions during the need of the hour.

**Keywords:** bipolar disorder, maniac depression, schizophrenia, fear, historic approach.

Caregivers at home are seldom adulated as the focal point is always grabbed by the illness of the care receiver. The caregiver task is more demanding and stressful. The patience and the hard work that they put in is always either overlooked or taken for granted especially when they are the caregivers of mentally ill person. The stigma that mentally ill persons carry is not different from the trials and tribulations of their caretaker's confrontation with the victim and the society. The caregivers are emotionally and physically drained in the process of providing an amiable, congenial ambience to reduce the negativism of mentally ill. The physical and mental stress the caregiver undergoes due to the non-cooperation, dependence, mental incapacity of the victim is horrendous. The consistent exhaustive efforts of the

care giving families to remain as a friend, companion, guide, nurse and philosopher to the victim is ever unidentified, unarticulated and unheeded.

Indian mythology also holds mirror to the dedication, devotion and indifference faced by the caregivers. In Ramayana, Shravana Kumara who is the caregiver to his parents meets an end of his life while fetching water to his old parents from a river. The love and affection that he showed to his parents by carrying them in two baskets tied to a bamboo pole which he carried on his shoulder is commendable. In Mahabharata we have Kunti, who was caregiver of her husband King Pandu – an impotent who was born pale and weak. But King Pandu dies in his love to Madri. Feeling guilty Madri follows King Pandu after death by jumping into his funeral pyre. Both of them die leaving Kunti as a single parent to their children. Kunti becomes the caregiver of motherless children Nakula and Sahadeva, whom she raises along with her own children showing the same care and love that she shows to her own children. During her old age, she becomes the caregiver to her brother in law King Dhritrashtra who was blind and his wife Queen Gandhari who had blindfolded herself. At the end she embraces death walking towards fire along with the care recipients. Kunti is known for her patience, love and dedication for her duties.

Caregiver's challenges are categorised based on their work as caregiver stress, caregiver strain, caregiver appraisal, caregiver burden etc. by the researchers and psychologists. When the caregiver is the family member then the care given is continuous and hence more stressful. Researchers have divided caregiver stress into 'subjective' and 'objective, stress. Subjective stress refers to the personal feelings and emotional trauma that the caregiver undergoes. Objective stress refers to the changes that the caregiver's life undergoes due to the care receiver.

The present paper explores the subjective and the objective challenges of caregivers of a person with mental illness with special reference to Jerry Pinto's

'Em and the Big Hoom'. The story of Em (Imelda – mother of the narrator suffering from mental illness) with graphical descriptions is told from the perspective of a caregiver son, the narrator. 'The Big Hoom' refers to the narrator's father who a rampart was protecting the family from falling apart due to the bouts of Em's madness. Susan, the narrator's sister is a stoic caregiver providing very practical solutions during the need of the hour. Em, the mother of the narrator was a normal person who in her middle age succumbed to bipolar disorder, gradually slipped into and finally schizophrenia landed into mental depression. A caregiver ought to understand the care recipient by displaying a lot of patience. Throughout the novel we observe the caregiver son's concern to know what goes on in the head of the mentally ill mother. The urge of the son to know what went wrong with his mother, once a beautiful woman with a lovely singing voice, he writes: "I wanted to understand her predicament because I was her son and I loved her with a helpless corroded love."

"And through all this, I told myself, and with all this, I told myself, I'll try and understand her. I'll try and figure out how this happened to my father, a man with a future who had given it all up to make sure the present was manageable. For her, For us". (p.149)

Tracing out the reason for her behaviour, Em replies to her son's question:

"After you were born, someone turned on a tap. At first it was only a drip, and I felt it as sadness. I had felt sad before...who hasn't? I knew what it was like. But I didn't know that it would come like that, for no reason.

I lived with it for weeks."(p.12)

The narrator also asked his father about Em's condition and the Big Hoom had pointed at the wires which carry electricity and had said that the nerves like the wires carry thoughts to the brain. The narrator had understood that:

"Thoughts, like electric currents, and inside my mother's head they ran uncontrolled – flashing and sizzling. I carried that image with me through my childhood for what ailed my mother and took her to hospital..."(p.10)

The caregiver son's confusion regarding his role and responsibility can be seen in his words:

"I didn't know how to deal with what we were as a family, either. I didn't really know what we were as a family. I only knew that something was wrong with all

of us and that it had something to do with my mother and her nerves". (p. 9-10)

The love and concern without any complaint or anger comes so naturally to Em's caregivers is because of their acceptance of Em with all her flaws. The Big Hoom never speaks a word against his wife which makes the children easily accept their mother as she is. He is the main caregiver who shoulders the responsibility of taking care of his children, cooking, washing the dishes, cleaning bathroom whenever Em slits her wrist in the bathroom filling it with the stench of blood and going to job to provide financial support to the family. The narrator writes:

"The Big Hoom rarely came home from work in the evenings with sweets for us when we were children, but he never forgot the two bundles of Ganesh Chaap Beedi".( p.7)

Susan and Baba (Em addresses the narrator with that name) display great qualities of caregivers, the one being practical and the later emotional. When they return home from watching the movie Coolie, Em is in the bathroom in the puddle of blood. Without wasting time the narrator pulls the immersion rod to warm some water, Susan calls the Big Hoom and their granny, the narrator pours water on Em and Susan cleans Em, the narrator prepares tea with lots of sugar "I had read somewhere that sugar helps with shock", cleans the bathroom filled with clots of blood and as the smell of the blood reminds him of iron. He immediately rushes to the shop and buys iron tonic to compensate Em's blood loss.

The objective disturbance (social stigma) that the son as a caregiver faces can be seen in the following paragraph: "One day, under the large mango tree that stood in the school yard, with a bunch of schoolboys standing around me, mocking me for being the son of a mad woman, I thought suddenly and automatically: "I want to go home". And then I thought as suddenly, "I don't want to go home". I remember thinking, "if I go on like this I will go mad". I tried not to think too much about home."(p.148)

It is too harsh to bare the remarks of the people about his mentally sick mother - "Poor thing, she's gone mad!" ... "Tsk, Tsk, what a shame ... her brain is devoid of oxygen supply" ... "What can her family do? She's a bit mental..."

The subjective stress is immeasurable. As a caregiver to his mother, giving her company in her whimsical temperaments, being part of her pain, the narrator writes that he had turned into an atheist –

“I would have prayed to any god, any god at all, if I could have been handed a miracle, a whole mother, a complete family...” (p.67)

“I lost my faith as an hourglass loses sand”. (p.67)

“And if God were capricious, then God was imperfect. If God were imperfect, God was not God”. (p. 67)

His love and concern to his mother is changed into fear of his future.

“If there was one thing I feared as I was growing up...

No, that’s stupid. I feared hundreds of things: the dark, the death of my father, the possibility that I might rejoice the death of my mother, sums involving venire callipers, groups of school boys with nothing much to do, death by drowning.

But of all these, I feared the most the possibility that I might go mad too”.(p 58)

His confidence gets shattered. He writes: “I wasn’t sure I would ever be able to deal with the world. It seemed too big and demanding and there was no fixed syllabus.”

The book *Em and the Big Hoom* read in the light of historical approach a better understanding of the author and his world can be acquired with empathy. The traumas and trails the writer undergoes unravel the great pain the caregivers undergo which most of the time goes unnoticed and unacknowledged.

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