

REVIEWS

Opening the doors wide on mental illness

GITA RAMASWAMY

Jerry Pinto, editor. *A book of light: when a loved one has a different mind. Speaking Tiger, Delhi, 2016, 175 pp hardcover, INR 399, ISBN-13: 9789386050175*

Jerry Pinto is famously known as the author of *Em and the big Hoom*, an absolutely riveting near-autobiographical account of his growing-up years with his bipolar mother. He has now followed this up with this collection of short memoirs of caregivers of those with a different mind – his evocative term for people suffering from mental illness.

This is a slim volume which should have appeared long ago, if not for the squeamishness of India's elite regarding mental illness. Nearly every family has someone squirreled away from public gaze, nearly everyone has had close brushes with some form of mental illness and it is a truism that mental health and illness are a continuum. Yet we continue to ignore mental illness, the sufferer is rarely taken to a psychiatrist, public sector "mental" hospitals are scourges on society, private sector ones are corporate rip-offs, the larger extended family is judgmental and harsh, the immediate family helpless and over-extended and in course of time, itself subject to great mental distress.

There has been a raging debate over the new mental health bill. The layperson has yet no tools to deal with mental illness in her family or herself. What we need is not just informative books, but literature of all kind – poems, stories, essays... that help connect the layperson to the layered mental illness experience. What does one do when something seems very wrong? When the caregiver becomes the abuser? When reason and routine are flung to the winds? When sadness is the way of life? When every chore is a bottomless pit to be negotiated with pain? When doctors dole out pills but do not see the patient as a whole? What does one do when medicine is refused by the sufferer? How does one retain a sense of balance when friends and family become judgmental? What is normalcy? Is there a fine line between delusion and fact, between mental health and illness?

Author: **Gita Ramaswamy** (gitaramaswamy@yahoo.com), Hyderabad Book Trust, Plot No 85, Balaji Nagar, Gudi Malkapur, Hyderabad 500 006, Telangana, INDIA

To cite: Ramaswamy G. Opening the doors wide on mental illness. *Indian J Med Ethics*. 2017 Jan-Mar; 2(1) NS:58-9:

© *Indian Journal of Medical Ethics* 2017

Great literature has usually developed around pain. With the present huge reservoir of pain due to mental illness in society, it is amazing that writers – who themselves suffer disproportionately from mental illness – have been browbeaten by society to remain silent. The few accounts in the regional languages (*Maine Mandu nahin dekha*, Swadesh Deepak, Hindi, 2003, *Odigelisina manishi: oka schizophrenic aatmakatha*, Malla Reddy, Telugu, 2016) have not got a wider readership. As the publisher of the above second cited book, I have watched readers buy the book and ask, shamefacedly, to have it wrapped up because they do not want others to know that this is the book they are reading. Writers write about their sex life, their identities as untouchable, transgender, gay, lesbian, but have yet to open up about their mental illnesses. Who am I to point fingers? I suffered a major two-year bout of postpartum depression, but wrote about it in a popular Telugu daily under a pen-name. I thought that my school going daughter would have fingers pointed at her. It is only recently that I have begun to acknowledge myself publicly as a survivor.

So we are immensely grateful to Jerry Pinto for writing in English and opening the doors wide to the literature on mental illness. Jerry Pinto's introduction to this volume is outstanding. He tells us how he tried to have the selection and editing of the memoirs open-ended and reminds us that one cap does not fit all. He is respectful of the caregivers' and family's selection of memory, how they deal with the issue on hand and how they choose to present it to the reader. He tells us how some memoirs were short-circuited because of resistance from the wider family. He agonises over how the family which is supposed to be the refuge of the child, the person, often becomes the source of persecution and how the "normal home" is a myth. He says – and I must quote here, "We have all thought," "What could I do without you?" as often as we have thought, "What am I going to do about you?" Families can create as many problems as they can help resolve.

I was disappointed however. If someone other than Pinto had edited this, one would not have had such high expectations perhaps. Some pieces touch raw nerves, yet some others are bland, some even pretentious, indicating a superficial involvement with the issue. Perhaps, because most of the authors here are writers, the eye to craft often overlooked the eye to authenticity of experience.

"Papa, elsewhere" – understated, awful even. Sukant Deepak recalls his talented writer-father, Swadesh Deepak (do read his *Maine Mandu nahin dekha*, Rajkamal, 2003 – his memoirs as a psychiatric patient) who is bipolar. When he disappears one

day, his family is glad, though the psychiatrist says, "Just pray that he is not alive. You have no idea what he must be going through without his lithium." Sukant Deepak's is a short black piece, barely ten pages, but runs the gamut of mental illness – the crazed suffering of Swadesh Deepak, the attempts at treatment, the caregivers' patience running thin, and finally, the unimaginable suffering of Swadesh on the loose. I read this piece again and again and every time, was shocked by the pain it conveyed under the near-bland prose.

The next piece, "My mother, the professor", is written under a pseudonym – Leela Chakravorthy, by a woman who could not bear to put her name to the memoir of a girl raised by a tortured mother who was treated for her illness only at the late age of 67. This in a highly educated family where the woman of the house is a professor. Would a fracture of say, the wrist been untreated for this long period? This again, is a story told tautly – a story of great pain and suffering that stretches into Leela's own life, her life with her husband and her daughter. Leela wonders all the while if not forgetting also means not forgiving.

Parvana Boga Noorani's "You didn't know her when she was normal" is the third hard-hitting piece – this time of a schizophrenic(?) mother who loves her children, but also holds a sharp knife to her daughter's throat threatening to kill her. The child that is Parvana is so vexed by her mother that she tells her father, "Why don't you divorce her?" Indian daughters only too often see Jekyll and Hyde in their "normal" mothers, often loving, sometimes very cruel and restricting. Mothers

often are cruel to socialise their daughters into survival in Indian society. How much more traumatic is the experience with a sick mother.

"My mother's breast" by Amandeep Sandhu struck me more for the son's role as the extraordinary caregiver of his mother rather than of the illness. Patricia Mukhim in "Daniella" learns that empathy is what matters most to a person with depression, not being given advice. This, of course, is easier to hear than put into practice as she discovers when faced with her bipolar daughter Daniella.

"Abhimanyu, our son", is a very short piece – the father talking of the experience with their autistic son. Glossing over the heartaches makes it easier for the reader but robs the piece of its nuances. "Roger, over and out" – is the long piece about a brief romance with a schizophrenic. Beautifully written, evocative certainly, but would have been more in place in a book of short stories? Though, who are we to say that every piece should match the intensity of Deepak and Chakravorthy?

What does one gain by this painful recounting? Pinto deals with this upfront in his introduction – his answer would be different every day, he says. The only thing he is sure of is that it doesn't get easier or more bearable by not talking about it.

Speaking Tiger has done the Indian reader a disservice by making this valuable book a hardcover and pricing it at Rs 400. This is a book everyone should be able to buy and read.

Understanding scientific surgery

GEORGE THOMAS

Ian Harris. *Surgery, the ultimate placebo. Coogee, NSW: New South Publishing, 2016, 240 pp, Kindle edition, INR 889, ISBN-10:1742234577.*

The tremendous and unquestioning regard, in which modern medicine has been placed, has been tempered somewhat by the realisation that every technological advance does not necessarily mean an improvement in disease outcomes. Better understanding of scientific methodology has led to the development of evidence-based medicine and evidence-informed healthcare.

In this book, Dr Ian Harris, a practising orthopaedic surgeon in Australia, examines the discipline of surgery with a sharp eye. His basic contention is that many surgical procedures do not

have a sound basis. He makes a compelling case for the use of the methodology now available to us to put to test surgical procedures with a view to eliminating those which are not useful and which are being practised today merely because they have the sanctity of age.

He begins by emphasising the difference between a placebo and the placebo effect. A placebo, by definition, has no therapeutic effect. It is well known, however, that patients (and doctors!) may perceive an effect that is not actually there. The perception of an effect beyond that of any specific effect is defined as the placebo effect. Dr Harris emphasises that the benefit seen is not due to the placebo, which, by definition, has no effect.

The obvious question is, is that a bad thing? Surely anything which makes a patient feel better should be good, whether it is real or not.

In the chapters that follow, Dr Harris gives several reasons why the placebo effect is not a good idea. He argues strongly

Author: **George Thomas** (george.s.thomas@gmail.com), Orthopaedic Surgeon, St Isabel's Hospital, Chennai, INDIA

To cite: Thomas G. Understanding scientific surgery. *Indian J Med Ethics*. 2017 Jan-Mar; 2(1) NS:59-60.

© *Indian Journal of Medical Ethics* 2017