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“My Mother Makes Films To Cope With Her Demons”: Confronting Normality

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Introduction

My daughter's mental health condition had raised several questions about her diagnosis and recovery, and I wanted to make a film about it. I had a rich family archive which I choose to call a 'record' of all that was going on around me. In addition, I was carrying my own lived experience and several years of struggle with my daughter's condition: her hospitalizations and encounters with her doctors and therapists. I was filming her because I didn't know how else to cope with my situation. I couldn't watch the 2007 footage that I had shot during her episode until ten years after. I began questioning the ethical reasons for documenting my daughter in that state; I also wanted to investigate the circumstances that led to her diagnosis. Would she have ever been diagnosed if we had continued to live in India? Could the triggers be related to her being the product of a broken home? How can family history of mental illness be controlled? Can the impact of illness be reversed? Is mental illness a reality or is it a construct of society? What is *Normal*? How can my daughter claim agency in charting strategies for her own wellness? How can she participate effectively in mainstream communities overcoming the stigma and labels? Can art truly be instrumental in coping with mental illness and facilitate the healing process? I could address some of the questions in the film, while others continue to be a driving force in our commitment to advocacy work through film screenings and panels.¹ This has not only proven to be a very empowering experience for both my daughter and myself, but also strengthened our relationship beyond the filial bond – giving us a strong purpose outside of our immediate circle of concern.

“My Mother Makes Films To Cope With Her Demons” – these are the opening words spoken by my daughter in my film “Unfinished” (2021)¹. She continues, “...when I got my diagnosis, she picked up the camera to record our lives together.” These words not only set the tone of our film but also resonate deeply with the essence of our lives. In the safe space of the MFA program at York University, *Unfinished* became a 40-minute long

‘process-driven hybrid documentary on the subject of mental illness made from the perspective of lived experience.’ I adopted an interdisciplinary approach to explore the dimensions of wellness and mental health as delineated by the medical community. I question the boundaries that prevent participation in the mainstream, all the while investigating avenues of inclusion by adopting a family-centric model of community engagement. Through a personal enquiry, I question the labels given to mental health conditions and examine the categorization of those intangible human emotions and their impact on those who have to uphold them for the rest of their lives. At its very core, my film problematizes the notion of normality. While there are pragmatic benefits to labels of mental health conditions according to the DSM²; there are significant costs such as experiencing loss of personhood and individuality. By adopting an auto-ethnographic approach, my film attempts to present a comprehensive model centered on acceptance and inclusion. I’ve assumed accountability for the detrimental effects of labels on my daughter by engaging in a process of self-reflection, which includes delving into our family archives and revisiting my previous films.³ In conclusion, *Unfinished* remains my attempt at completing an unfinished conversation with my daughter to examine the circumstances of her diagnosis and our constant struggle with recovery and rehabilitation. I hope the film can become a beacon to guide her (and others) to navigate through the uncertainties of life.

A true partnership

‘I have put my own story on screen, with the willing participation of my daughter as creative collaborator on the film. Using multiple formats, within 40-minutes the film encapsulates our struggles that result from my daughter’s repeated hospitalization in 2020. As we both negotiate our mental states, all the while coping with the complexities in our relationship resulting from past trauma and mental health diagnosis, the film takes the viewer through a cyclical journey that unravels the nuances of my child’s episodes, my frustrating enquiry while trying to understand my daughter’s mental health diagnosis and its implications on our lives. The film throws light upon the results of familial struggle to understand and untangle the conundrum of my daughter’s illness through involvement of the “invisible” medics treating her. Throughout the process of completing my thesis film, I struggled to find ways of protecting my daughter from the impact of the illness narrative. Ultimately, by inviting her to collaborate on this project, I wanted to bring forward a truthful narrative through the perspective of her lived experience.’

Whoever is suffering from mental illness identifies with a label. So the first thing you need to figure out is who you are as a person – it has to be a process of self-discovery. You are not the illness. A diagnosis confines you and it is difficult to break loose from the label. (Chopra 2018)⁴

When we first started talking about the possibility of a film addressing mental illness, my daughter strongly articulated what she thought was necessary to include. She felt that in being diagnosed, the most damning outcome was social exclusion. We want to investigate whether by making an auto-ethnographic film we can erase or reverse our trauma because of her diagnosis. The very 'act' of making this film together compels us to go into those uncomfortable spaces where we are forced to confront ourselves, holding ourselves accountable for our choices, and exposing raw emotions and struggles. By questioning the parameters of wellness, we are attempting to point to the damning effects of stigmatization on persons struggling with mental health. Through a personal voice, we hope to offer a perspective that strengthens the capacity of humans for inclusion and empathy. We are together in this as we expose the impacts of intergenerational family trauma, with an urgency to find ways of ending it.'

Questions: A segue to creative inquiry

How could I accurately show the experiences inside the head of a person confronted with mental health issues? We know that our minds change our bodies, but is it also possible that our bodies change our minds? This form-content dichotomy led me to social psychologist Amy Cuddy's article about power posing⁵. The evidence of power posing came from a study that Cuddy completed while at Harvard University, where participants sat in either a high-power pose (expansive posture) or low-power pose (leaning inward, legs crossed) for two minutes. Cuddy found that those who sat in the high-power pose, felt more powerful and performed better in mock interviews than those who had not. She says: 'If I strike a "high-power" pose for a couple of minutes versus a "low-power pose", then not only will I report feeling more powerful, but my body chemistry will also shift, producing more testosterone and less cortisol—a sign of lowered stress level'⁶. In light of the complexities in our relationship, how can I use my art to devise a creative strategy to uplift and empower my daughter? Occupying a prominent role in film screenings and panels, my daughter has cultivated a welcoming environment for herself with her audiences, peers, and educators. They all attentively engage with her story, conveyed in her authentic voice. This platform has enabled her to embrace the complexities of her journey and express them with a dedication to recovery and optimism. The film has been instrumental in enabling my daughter to embody a "high power" pose: a confident and empowered stance, significantly enhancing her overall well-being.

Illness, Stigma and Isolation

THE INCIDENT THAT SHOOK MY WORLD was my daughter's psychotic episode that eventually led to her diagnosis two months after. I was in complete denial and ignorant of what had just transpired in our lives. It took me a while to comprehend the gravity of the condition that would alter our lives forever. Looking back, I can say now, it was a blessing in disguise. It made me realize that nothing really is in our control. Acceptance of our circumstances is a way to look forward. Love serves as the key ingredient that fosters healing—not only directed towards our child with a diagnosis, but also towards ourselves, the primary caregivers.

Although the journey that started 17 years ago has come a full circle, I continue to be amazed at the resilience and grace with which my daughter, now a remarkable young woman, navigates relationships and embraces her condition. She seeks opportunities to flourish, grow, and recognizes her symptoms, transforming adversity into strength. Undoubtedly, my little girl, who is little no more, is my inspiration! She continues to inspire my research trajectory, strengthening my understanding of what inclusion and social justice truly mean from a lived experience perspective. Our collaborative and individual efforts in this direction illuminate the significance of our voices in driving transformative change and fostering stronger connections within and between families affected by mental illness.

Throughout history, individuals labeled as mentally ill were often subjected to moral scrutiny by both scientists and society, leading to their segregation and confinement in asylums. At this juncture, I feel compelled to take on the moral responsibility of challenging the concept of 'normality', which categorizes humans based on their abilities, assigning labels that deem some individuals more functional than others. In *Nobody's Normal*⁷, anthropologist Roy Richard Grinker meticulously traces the journey of progress and setbacks in the fight against mental illness stigma. Offering a historical perspective of belief systems over centuries, Grinker posits that stigma surrounding mental illness is a social construct deeply rooted in cultural history, emerging from the very moment we began defining mental illness. He asserts that this stigma is learned within our communities but also asserts that we possess the agency to effect change.

The stigma of mental illness is when your psychological state defines your identity; when people see you as flawed and incompetent; when you're invisible to others; or when people see your suffering but blame you for it. It is the unwanted shadow of a person, produced when a society casts a certain light on human differences. (Grinker 2021)⁷

For my MFA Thesis paper¹ I felt it was necessary to include the impacts of stigma on a person's sense of identity and self-image. A major impediment to recovery can be attributed to the attitudes of those who are deemed as 'normal'. I identify it as a key impediment in my own daughter's recovery. Fifty-seven years ago, sociologist Erving Goffman had conceived of stigma as interactional and performative, unfolding in the interactions of everyday life as a result of public intolerance, ignorance, and fear. "In any society that reveres conformity, all people will at some point in their lives experience the pain of stigma"⁸. In his view, "individuals whose personal attributes diverge from what their society expects carry the burden of stigma. They are compelled to hide or mitigate the exposure of their discrediting conditions."

In the second half of the film, Isha reads from her manuscript *Finding Order in Disorder* (2020)⁴ that she consciously attempts to hide her 'unwell' self in the fear of rejection: "When I'm extremely low and depressed my defence mechanism tells me to prove it to the entire universe, that I'm fine." I find this kind of rejection to be more prominent in the Indian society. Maybe that's the reason why my father was never 'diagnosed'. He continued to struggle with illness and addictions until his early demise at the age of 46 – the brunt of which was borne by his family.

Goffman explains:

Some form of stigma exists everywhere in the world, but what is stigmatized always varies according to place and time. Under the right circumstances, virtually anything – skin colour, religion, poverty, sexuality, medical illnesses, physical disabilities, disfigurement, being a victim of rape, having a child out of wedlock, and even being divorced – can lead to a discredited identity. (Goffman 1963)⁸

Goffman investigates the world of people considered abnormal by society. Stigmatized people do not have full social acceptance and are constantly striving to adjust their social identities. He relies extensively on autobiographies and case studies to analyze stigmatized persons' feelings about themselves and their relationships to 'normal' people. He looks at the variety of strategies that stigmatized individuals use to deal with the rejection of others and the complex images of themselves that they project to others. Goffman discusses several responses that stigmatized people can take. For example, "they can use their stigma as an excuse for their lack of success, they can see it as a learning experience, or they can use it to criticize people considered normal. Hiding, however, can lead to further isolation, depression, and anxiety and when they do go out in public, they can feel more self-conscious and afraid to display anger or other negative emotions. Stigmatized individuals can also turn to other stigmatized people or sympathetic others for support and coping. They can form or join self-help groups, clubs, national associations, or other groups to feel a sense of belonging. They might also produce their own conferences or magazines to raise their morale"⁷. A present-day case in point is the work done by Will Hunt, a schizophrenia survivor who now works as a counselor and trainer. He is the author of *Harm Reduction Guide to Coming Off Psychiatric Drugs*⁹. His crusade to empower patients adopting the 'Harm Reduction' model through his outreach initiatives (webinars, seminars and free publications)⁵ is commendable. In a webinar led by the Fireweed Collective in May 2021, he provides strategies for patients to become aware of the role of medication in their recovery. Drugs cause changes in brain chemistry and it is imminent to question their efficacy in improving a person's overall quality of life.

Ishaa was diagnosed in Canada, three years after we migrated. Although her mental health diagnosis has helped the family understand her condition, and also helped Ishaa cope by accessing community health support, it continues to be the key identifier of her personality.

Conclusion:

Nobody's normal. And since we have for so long used the concept of "Normal" to decide who we accept into our social world and who

we reject, it's about time that we recognize that normal is a
damaging illusion. (Grinker 2021)⁷

While the legacies of shame and secrecy persist, Grinker expresses optimism, suggesting that we stand on the brink of eradicating the marginalization of the mentally ill. He observes that in the twenty-first century, mental illnesses are increasingly acknowledged as a natural and visible aspect of human diversity. This reason perhaps gave us the courage to 'come out' and articulate our lived experience in a stark manner in our film. In his book, Grinker intricately weaves together his family's four generations of engagement with psychiatry, which includes his grandfather's analysis with Sigmund Freud, his daughter's journey with autism, and culminates in his own research on neurodiversity. Through a blend of personal narrative and scholarly inquiry, he draws on cutting-edge scientific findings, historical archives, and cross-cultural research conducted in Africa and Asia. This international exploration leads readers to uncover the origins of, and differences in, cultural responses to neurodiversity.

Today my daughter stands at the threshold of publishing her memoir titled "Finding Order In Disorder", which chronicles her mental health journey and the societal obstacles she faced and ultimately overcame. I believe that our collaboration on this film has helped us acknowledge and navigate mental health through a model of self-acceptance. Being actively involved in the 'image-making' process has strengthened her identity, giving her the confidence to build a resilient future for herself. The process of filming has not only deepened the bond between mother and daughter but also provided closure to some of the issues that were causing barriers in our relationship. Through this process, I began to see my daughter as a whole person, appreciating her unique strengths and limitations. Our shared experience has deepened my respect for her and allowed me to fully appreciate the person she is. "Unfinished" remains more than a film to me; it is my genuine attempt at completing an unfinished conversation with my daughter; it is an attempt to examine the circumstances of her diagnosis and our constant struggle with recovery and rehabilitation. "Unfinished" represents my sincere offering – a legacy I hope to leave behind, one that will resonate with caregivers confronting similar challenges. The film continues to serve as a powerful emblem for those who struggle with acceptance of their psycho-social identities. Due to the fear of judgment, families often withdraw and isolate themselves from their communities, grappling with their loved one's crisis without seeking help or understanding how to navigate the situation effectively. It took me several years before I could reach out for help, ask questions, understand the system and accordingly advocate for my daughter's wellbeing. Now I am serving on several family advisory committees at different mental health organizations that makes me feel part of a larger movement towards human rights and disability justice. I strongly believe that every small step, every caregiver's contribution, and every voice raised can play a crucial role in paving the way to eradicate stigma surrounding mental illness. Together, these efforts have the revolutionary power to shift cultural norms and attitudes, ultimately leading to the normalization of mental health discussions and the cessation of stigma and judgment. It is a risk worth taking. My daughter and I have chosen to use our vulnerability to strengthen our values. We are steadfast in our dedication to continue the work we started

together, with the aim of enriching the lives of families through the sharing of impactful stories rooted in lived experience that have the potential to profoundly alter their trajectories. It's a risk worth taking, and one that we're prepared to fight for.

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