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**From Despair to Hope: Overcoming the Illness Identity**

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**Abstract**

The concept of illness identity can be defined as the degree to which a person integrates a serious health condition into his or her identity. Thus for individuals with chronic illness, the way in which they perceive themselves becomes different from the rest of the individuals. For an individual who has been suffering from a serious disease from a young age, the identity that they form for themselves is hugely influenced by this illness identity which then affects their adult lives. This study aims to look at how the autobiography titled *Hope in a Ballet Shoe: Orphaned by War, Saved by Ballet: an Extraordinary True Story* poignantly depicts the story of Michaela De Prince, who was derided as a "devils child" because of vitiligo and her journey to become one of the most successful ballerinas in the contemporary times. This work is theoretically analyzed through the lens of illness identity, racial discrimination, gender. The existing beauty myth in our society leads many individuals with

particular physical appearances to develop illness identity that prevents them from participating in the society. This paper thus focuses on the urgent need to acknowledge such situations and to bring forth solutions for the same.

**Keywords:** Illness identity, Gender, Autobiography, Racial discrimination

Having a serious illness often leads people to re-examine their life and its meaning. Most often, they are consumed by fear and despair, which extends their suffering. The purpose of this human suffering is unknown, but it helps us to appreciate the life around us. At times this suffering helps us to recognise the inner strength and power that resides in us. It is only those who recognise and understand this would be able to overcome their predicament. Time after time, it is seen that such people produce their life narratives in

**RESEARCH ARTICLE**

the form of autobiographies, biographies, memoirs, etc., which in turn helps those who are undergoing the same and gives them the hope that could possibly alter the direction of their life. Reading such life narratives continues to stress the role of the narratives in decoding and reframing the past to make sense of the present and provide an orientation for the future ( Mattingly 15). Thus telling and retelling of these experiences helps to revise the view of the self.

Illness identity can be defined as the degree to which a person integrates a serious health condition into his or her identity. Thus for individuals with chronic illness, the way in which they perceive themselves becomes different from the rest of the individuals. For an individual who has been suffering from a serious disease from a young age, the identity that they form for themselves is hugely influenced by this illness identity which then affects their adult lives. Hence memory and identity become two crucial factors for such individuals to overcome their lack of understanding and acceptance of themselves to fully acknowledging their true self. This perception of the self becomes more complicated when the person undergoes racial discrimination. Racially discriminated people tend to a longer period of time to create a confident identity about themselves due to the added complications that they have to resolve.

This study aims to look at how the autobiography titled *Hope in a Ballet Shoe: Orphaned by War, Saved by Ballet: an Extraordinary True Story* poignantly depicts the story of Michaela De Prince, who was derided as a "devils child" because of vitiligo and her journey to become one of the most successful ballerinas in the contemporary times. This work which has been co-written by Michaela along with her adoptive mother, Elaine De Prince, is analyzed through the lens of illness identity, racial discrimination, gender, thereby reading it as an extraordinary story of an extraordinary individual. This life narrative thus explores the intricate relation between illness perception, identity, experience, and individual identity.

Published in 2014, *Hope in a Ballet Shoe* narrates the story of Michaela from being an orphan in war-torn Sierra Leona to one of the most well-known ballet dancers of contemporary times. Born in Sierra Leona as Mabinty Bangura, Michaela was often considered unfortunate due to vitiligo, a disorder that is characterized by depigmented patches on the skin. Her parents were proud to have her as their daughter and celebrated her arrival, but the same could not be said for her uncle and the rest who declared, " It is unfortunate Harmatten that brings a girl child ...a worthless, spotted girl child at that, one who will not even bring you a good bride price"(10). Thus from her initial days,

**RESEARCH ARTICLE**

Michaela has been dismissed from society due to her spots." My spots scared the other children in our village . Nobody would play with me, except my cousins on occasion, so I would often sit alone on the stoop of our hut, thinking"(12).

Since vitiligo affects the physical appearance of a person, the chances are the person has to face added psychological and emotional problems. Skin disorders that negatively alter appearance have the potential to affect an individual's personal and social interaction(Grimes and Miller 33). Thus this instance narrated by Michaela clearly projects the social stigmatisation that she had to undergo from a very young age which took a toll on her emotional health. There is a sense of their bodies becoming alien terrain to themselves (Charmaz 675). The realisation that their daughter would have to undergo added anxiety due to her unusual appearance made them approach the situation unlike the other parents and finally deciding " It is important that our daughter go to school to learn more than we are capable of teaching her"(12). In his book *Childhood and Society*, Erickson explains the crucial part that parents play in the second stage of the development of an individual. He explains that parents should encourage their children to explore their potential while avoiding criticism when they fail. Michaela is truly fortunate in this aspect as her parents encouraged her despite the social

stigmatization she faced. Unfortunately for Michaela, this does not last long as she loses her father to the civil war that ravaged Sierra Leona.

Michaela and her mother are then taken in by uncle Abdullah who mistreated them at every chance he obtained. " Uncle Abdullah would yell at me. You are a useless child! Look at you. How ugly you are. You have the spots of a leopard. I am wasting food and money on you. I will not even get a bride -price in return. Who would want to marry a girl who looks like a dangerous beast of the jungle? "(17). These recurring taunts and shaming from her uncle cut deep into her heart and creates a sense of being small within her. According to Erickson, this would be followed by a basic sense of self-doubt which would find its adult expression in paranoiac fears from outside and within(228). The word 'spotted devil child' has been used over and over again by her uncle resulting in an increased sense of rejection and anxiety in Michaela. Added to this, the people, due to their superstitions, blamed the spots for all the unfortunate things that happened to Michaela. " Mabinty brings us nothing but trouble . It is the spots... only a devil child can read when so young. She has brought nothing but bad luck to this family . It is time to be rid of her"(19). The implications of this disease become heavier on Michaela as she realises that she is going to be sent to

**RESEARCH ARTICLE**

an orphanage where an uncertain future awaited her.

It has been found that vitiligo that begins in childhood may be associated with psychological trauma and results in lasting effects on self-esteem (Marinho et al. 1027). These traumatic memories of childhood continue to haunt her in various ways, which is discussed in the latter part of the story. The contrast of depigmented patches is most visible in racial/ethnic groups with darker skin which leads them to experience a higher degree of emotional devastation caused by the disease (Grimes and Miller 35). This, too, could be found in the later part of her autobiography, where she explains her struggle to find an identity for herself in America.

The journey to the orphanage presents the next phase in Michaela's life. The very last words that she hears from uncle Abdullah is, " I am not her parent . My own children are not spotted, like her"(24). With these words, he goes away after taking money from Andrew Jah, the director of the orphanage. Auntie Fatmata, the caretaker of the orphanage, instantly dislikes Michaela due to her spots. She was given the number twenty-seven, which meant that she was the least liked in the orphanage. The children, too, were scared of Michaela, which further disheartened her. "I knew that they were staring at my spots. I looked down at the ground,

ashamed... I tried to join in, but whenever I approached a group the girls would turn their backs to me. Some chirped through their teeth to show disdain or disgust . Others ran away , shouting . Devil child! Leopard girl ! I dont want to catch your spot"(30). The life in the orphanage was thus equally tormenting for Michaela had it not been for Mia, whom she befriends in the orphanage. She was the first one ever to say to Michaela to be proud of who she is. " Don' t look down .Hold your chin up high"(27), saying; she helps Michaela to stand up for herself. In spite of such strong support from her friend Michaela continued to suffer in the orphanage. "Suddenly I realised that, as Number Twenty Seven , I was the least favored child in the entire orphanage. No wonder I had received the smallest serving of rice. I felt the heat rise to my face. My spots were on fire, I thought that they were glowing so brightly that everyone would look at them"(29). The more Michaela tried to set aside her thoughts on her insecurities due to the spots, the more it became evident.

"The overarching framework of illness identity comprises of four different constructs: engulfment , rejection , acceptance and enrichment"(Van Bulck, et al. 4). For Michaela, the first two stages take place during her life in Sierra Leona ." Engulfment indicates the degree to which patients feel that their disease dominates their identity... and rejection refers to the

**RESEARCH ARTICLE**

degree to which the disease is seen as a threat or as unacceptable to the self (Van Bulck, et al. 4)". The psychological trauma associated with vitiligo makes Michaela powerless enough to be dominated by anxiety, distress, etc. She undermines her individual self and perceives herself as a damaged self which then creates a sense of vulnerability in her. Thus she enters into the first two states of illness identity at a very young age. The dual nature of the sickness, the way it can make us different persons while remaining the same person (Mattingly 39), is portrayed through these instances.

The auntie threw her head back and cackled. Listen to the ugly one, Sombo. This spotted child, the ugliest girl I have ever seen, thinks she can tell me what to do. Then Auntie Fatmata raised her switch and struck me first and then Mabinty Suma. She struck us over and over again, raising welts all over our bodies. Finally, she said to me, Now you are stripped as well as spotted. (30)

These repeated insults and disgrace that Michaela faced could be seen contributing to the gradual development of illness identity. The way that Michaela looks at herself and experience her spots changes. The illness perception that she has now becomes mostly negative due to the degrading experiences she has undergone. It is from these perceptions that she creates

illness identity." Illness identity not only expresses how a person views the disease and the treatment, but also how much the disease has affected the way they think about themselves and the degree to which the illness became integrates into one's sense of self" (Van Bulck, et al. 4). Added to this, as Erickson explains, when children are criticised and controlled or prevented from asserting themselves, they may feel a sense of shame and a lack of self-esteem, which will also affect their future life. Thus there is an act of belittling that Micheala brings on herself.

According to Kim, "younger patients have the confidence to successfully cope up with the illness while not giving up their fears related to illness." This aspect is also found in Michaela. Despite all the misery that she had to undergo, Michaela still dares to dream again when she hears that American Families will adopt them. However, we see that Michaela is fearful that she might not get adopted because by now, it has penetrated into her mind that she is ugly, which reinstates the reality that people with vitiligo often withdraw because they anticipate being rejected (Prasad). This becomes true for Michaela. Thus the promise of a better life soon becomes a distant dream due to the illness perception that she has developed. During these times, Michaela comes across the picture of a ballerina in a magazine that creates an urge in her to survive. Fortunately, it is with this

**RESEARCH ARTICLE**

picture Michaela finally meets her adoptive mother, Elaine de Prince, who adopts Michaela but also Mia and finally helping them to start a new life in America.

Life in America marks the next phase in Michaela's life. Even as she enjoys her new life, she realises that spots on her skin will continue to haunt her even in a place like America. Even in America, people continued to gaze at her spots. It is during her life in America Michaela begins to face the repercussions of the illness identity that she had created. There is a lack of self-esteem and confidence, which constantly made her undermine herself. Even when she knew that she was a gifted dancer, there was a constant struggle to overcome the insecurity in her before every performance. While trying on her costume for her first ballet, she tries to hide her spots because she felt ashamed. But her mother, who realises this, encourages her by saying, " they looked like a sprinkling of pixie dust or glitter"(77). Thereafter Michaela gradually learns to accept her spots which are the third state in the illness identity."It is believed that acceptance might enable patients to deal better with challenges of the disease ,and that acceptance leads to better self care "(Van Bulck 5).

As Michaela adapts herself to the spots on her skin, she faces another challenge. Michaela understands the racial prejudice that exists in America and soon

begins to face its repercussions. She becomes more disheartened when she realises that it existed in the world of ballet when she overhears a mother complaining," Black girls just shouldn't be dancing ballet. They're too athletic. They should leave the classical ballet to white girls"(93). Thus for Michaela, the challenges she has to face due to the vitiligo becomes more complicated due to her colour.

In addition, racial discrimination has been shown to predict diagnosable psychological outcomes, such as generalised anxiety disorder and social anxiety disorder, along with psychological symptoms like anxiety, hostility, and anger, general psychiatric symptoms, perfectionism, and suicide risk. Negative mental health outcomes such as depression and psychological distress are robust for adults as well as adolescents and across racial minority groups.(DePetris,4)

Thus Michaela becomes the subject of whispered comments, insult, and isolation due to her colour. The internalisation of these stigmas further leads Michaela to devalue herself. The self-stigma that arises in her due to the illness identity, which has become complicated due to her colour, has its root in the concept of beauty that exists in society. "For racialised woman the possibility of owning beauty becomes impossible in the context of a western philosophical tradition that has

**RESEARCH ARTICLE**

specifically defined beauty as whiteness and has used beauty to define whiteness"(Cheng 205). The disparagement of the beauty of coloured women like Michaela further causes damage to their self-esteem and make them feel unworthy.

Yet again, her mom gives her the courage to carry on her life by stating the inevitable truth of life, " there will come a day when these girls will no longer be a part of your life and you will no longer care about what they once said about you(96)". " It took a long time for me to learn how to ignore the jealousy and bigotry that would enter my life"(97), says Michaela. Soon it becomes a mission in her life to prove to the world that a spotted black girl like her could dance ballet. With her sheer hard work and dedication, Michaela overcomes the hurdles that life placed in her path. Michaela achieves this by going through the fourth state in illness identity, which is termed enrichment. " Some people feel that their disease has changed their values and how they look on life and that their disease actually enabled them to grow as a person"(Van Bulck,et al. 6). Adapting to her life as a coloured woman with vitiligo means a continuous tension between oppositions: the self versus the body, struggle versus surrender, the idealised body versus the real experienced body, social identification versus self-definitions, struggling with versus against illness (Charmaz 658). This struggle leads

Michaela to gain deeper levels of awareness about herself. Having realised this, Michaela says," Now I look at every encounter as a means of touching a life"(170). Keeping this in her mind, she begins to see every hurdle as an opportunity to learn and grow, which finally helps her to overcome the illness identity that was pulling her down and to replace it with a stronger and genuine identity that helped her to succeed in life.

Towards the end of the autobiography, Michaela narrates an episode where she asks her parents the reason for adopting her and her sisters. The response her mother gave was " We were blessed, and with blessing comes responsibility"(178). It is this very answer that led Michaela to write her autobiography. She realises that she too was blessed in many ways and the only element she found in herself to share was the hope that she carried in her. "I had been blessed with a hardy dose of hope. It was hope that enabled me to survive in Africa in the face of abuse, starvation, pain and terrible danger. It was hope that made me to dare to dream , and it was hope that helped that dream to take flight . Yes , I would share my hope"(179). The autobiography that she then writes explores the ways in which the creation of illness narrative becomes a reflective process, where the suffering is effectively converted into a tool for empowerment (Mattingly 43).

**RESEARCH ARTICLE**

The illness identity that Michaela develops due to vitiligo projects the reality of how the outer appearance of a person is given more priority than their character. The existing beauty myth in our society labels certain sections of our society as not beautiful, due to which they remain in the first two stages of illness identity. For example, people who undergo treatment for cancer find themselves subjected to physical changes, which then is taken up by society to isolate and ostracize them. The same happens to the victims of acid attacks who withdraw themselves from the public eyes and isolate themselves to domestic and private spaces. Thus people like these remain in the first two states of illness identity, unable to find a true individual identity due to the lack of support from society. "Baldness and impotence among middle aged man, acne and short stature among adolescent males...cosmetic concerns among the elderly are culturally marked conditions that express the narcissistic preoccupation of modern Western society"(Klienman 43). Thus the high standards of beauty which have been set up by society thus contribute to the illness identity among these individuals. The aforementioned statement also presents how the illness identity that develops among individuals has its root in the social construction of an illness. The biological condition of the illness is overwritten by the social systems around

us, thereby making their illness experience a socially constructed one with cultural meanings embedded in it.

This research could be taken further by exploring the concept of illness identity based on gender with a special focus on transgender. Equally important is to look into the concept of space as a site of performance of power, where individuals with illness identity are often restricted or deemed to be unworthy of accessing it. Yet another area to be focused on is the intimate social relationships and economic struggles that predominate the lives of individuals with illness identity, which further brings into question the themes of power, class structures, conflict, and freedom. If the role of culture in creating meaning is taken into account, this research could also be studied under the broader field of auto ethnography.

Our lives unfold in ways that surprise us, that force us to recognize the uncertainty of things (Mattingly 210). But in the end, it always gives us the courage to move forward. With her life narrative, Michaela reveals how even in the most unlikely circumstances, hope could blossom and change one's life. Her story becomes a beacon for hope for all, especially for the coloured women who suffer from vitiligo. Her decision to overcome the illness identity and to embrace her life for what it is reminds us that human existence is worth all of it and much more.



RESEARCH ARTICLE

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**RESEARCH ARTICLE**

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