

# Narrative: The Fear of Disfigurement in Cancer Patients

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## Abstract

Fear of disfigurement affects patients with cancer, in whom the disease or its treatment leaves them permanently marked. Contrary to our thought, disfigurement is equally distressing to male patients, and it causes severe dislocation in their lives. We describe two cases in which disfigurement caused tremendous change in our patients; these cases underline the need for psychotherapy in patients suffering from cancer.

**Keywords:** Disfigurement, dysmorphophobia, psychology

## NARRATIVE

The Encyclopaedia Britannica defines a phobia as “an extreme, irrational fear of a specific object or situation,”<sup>[1]</sup> and the list of phobias makes an interesting and entertaining reading. For the sufferer of course, the fear is very real and catastrophic, sometimes ruining the life or life threatening. One such phobia is the fear of disfigurement or dysmorphophobia, in which some sufferers are afraid of becoming deformed or disfigured, while others fear those who have a disfiguring condition. The prevalence of this condition has been estimated to be 0.8%–1.8%,<sup>[2]</sup> there is disagreement among authorities that whether it is more prevalent in men or women.<sup>[3,4]</sup>

The face is the most flaunted and pampered part of the human body. We spend so much time and effort adorning it; we value all its components, we line the eyes with kohl, shape the eyebrows, color the lips, make the cheeks rosier, and use talc to make it fairer. We are what our face is, it is our identity and recognition, for not even a mother would recognize her child if the face were to be altered.

So what happens when the face gets damaged?

Diseases often cause changes in the body that lead to disfigurement. Most body deformities can be hidden from view, but those of the face are open for all to see. It is true that in some countries both men and women cover their face with beards or veils, but damage to the face is hidden with difficulty. Disfigurement with cancer is very significant. This disfigurement causes distress, but at what level or in whom it reaches phobic levels is unknown.

Facial disfigurement is a cause of concern for most patients. It often causes anxiety and depression<sup>[5]</sup> in both patients and caregivers.<sup>[6]</sup> Many patients in the West opt for reconstructive surgery and may even demand face transplant.<sup>[7]</sup> However, most of our patients are not economically sound enough to opt for reconstructive surgery. Some studies have focused on the impact of disfigurement and the methods that can be used to reduce the same.<sup>[8]</sup> There are some patients who are more affected by disfigurement than others.

Age causes changes in the face, but does age alter an individual's outlook toward disfigurement? A young person might hold superficial looks to be very important, while an older person might give more importance to inner beauty. But, is there any such thing as inner beauty? The jury is out on this. There are many facets to age-related changes, like do wrinkles matter less or are they more acceptable to an older person than a younger one? For many of these questions, we have no answers at all, yet what we are focusing on is disease-induced changes.

In the past, I thought of disfigurement as affecting a small minority – a handful of victims of acid attacks<sup>[9]</sup> or burns.<sup>[10]</sup> I was aware that some diseases such as leprosy cause severe disfigurement if left untreated for long,<sup>[11]</sup> but then, I had little interaction with them. The pain of disfigurement and having to hide their face from everyone was something I heard only read

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about. Never had I thought of a ward of patients, many of whom had facial disfigurement, till I joined a palliative care center.

The Cipla Palliative Care and Training Centre is a fifty-bed facility mainly meant for palliative care of cancer patients. Due to the widespread habit of chewing tobacco in India, almost half of our patients have cancer of the head and neck. In most of these patients, there is moderate-to-severe damage of the face, either due to surgery or wounds.<sup>[12]</sup>

Working at the center meant interacting with patients and their caregivers, day in and day out. Sharing their fears, their hopes, and often their despair and sorrow was my daily job. I had the opportunity to meet and discuss all aspects of their disease, the physical pain, and the mental agony they suffered. Here, I learned what all textbooks of psychology could not have taught me, and my teachers were the patients.

He was a young man, though not a boy, someone barely out of his twenties, in an advanced stage of oral cancer. His wounds were infested with maggots, had a foul smell, and needed regular dressing. He came to us one evening, brought by his elder brother, seeking relief for his pain and dressing for the wounds. For long, the patient had done it himself, but when he could no longer manage on his own, he came to us.

This young man, let's call him Rama\*, had been leading an exemplary life. He worked in a gymnasium, as a trainer who maintained a good physique. He neither smoked nor chewed tobacco, but developed carcinoma of the tongue. For long, he ignored the symptoms and denied that anything was wrong with him, till it became very obvious and too painful to bear. The disease had eaten through half of his tongue and he had to seek medical help. The oncologists recommended surgery that removed a part of the tongue. Autologous skin grafting was done to cover the damage to the face, it was clearly not very successful.

Rama stopped meeting his friends and relatives, in fact avoided everyone whom he knew. He had lived alone in the city while his parents were in a village nearby. When the disfigurement became obvious, he shifted to a town where his brother lived, where none knew him. There he spent some months, hidden from society, virtually a hermit. As time passed and it became increasingly difficult for him to manage, he came to our center.

His mother and brother told us that he had broken all contacts with his friends. Earlier, he was not a loner, actually he was quite a popular person in his area; he had heaps of friends with whom he had spent years. He blocked them out of his life. At the center, he was comfortable with his mother and sister but nobody else. We noted that his looks engaged him most of the time, and he spent a considerable time watching himself in the mirror. Mixing little with other people at the center, he was one of the most inconspicuous of patients.

In the 2 months of his stay at the center, he was never visited by his friends; his mother told us that he had forbidden them from visiting him. He behaved so oddly with those who visited

once that they did not visit again. In a rare bout of frankness, he told the nurse that he did not want his friends to see his disfigured face. Yet there was a strange thing that he did, he showed many patients his old photographs. He allowed his new acquaintances to see the damage his disease had done, but he did not like his old friends to see the same.

Rama was relatively young, healthy, good looking, and earning well when the disease struck him. Till then, he had an active life, full of adventurous sports and trekking. He spoke little of his past life, and the memories of the old days remained mostly bottled up in his mind. His feelings about his disease and his disfigurement remained with him, a secret that he took to his death.

He taught us one thing. Men may be very casual of their appearance, but they too become distressed when disfigurement hits them. We often talk of the beauty within, but the superficial looks of a person are more important to some, since this is what the world sees. The fear of his own disfigurement left him lonely and friendless, and this was how he died, bereft of friends and companions, with only the closest of his family.

Cancer often causes a great impact on behavior of the patient, through disfigurement, as happened in another patient, let us call him Krishna\*. In his late fifties, Krishna was a marketing professional diagnosed with stomach cancer. His disease and treatment caused changes in his body, like colostomy could be hidden by clothes, his dysmorphophobia overtook him.

The marketing profession involves interaction with people; many successful people from this profession are extroverts. So was Krishna, but as the disease set in, he began to withdraw from his large circle of friends and acquaintances. His disfigurement was not visible to others, but it was his phobia that distanced him from everybody. The once garrulous and fun-loving person became a recluse, brooding over his disfigurement. During the course of his disease, he had almost a year of disease regression, his doctors told him that he could resume his duties. Krishna would not, he loathed letting his friends, colleagues, and acquaintances see him. He spent most of his time alone at home; away from the eyes of others.

When he came to our center, he opened up a bit with other patients, probably he was more comfortable with other patients. He found that he could relate with other patients, his fellow sufferers but not with his healthy friends. His behavior in the center came as a surprise to his family, who were pleased to find that he regained much of his old self when interacting with other patients.

In these two cases, psychiatric help may not have altered the course of the disease, but it could have made a difference in the life of the patients. In fact, it was cases like these that made us focus on the psychology of patients in palliative care. At present, medical treatment at the center is complemented with psychological support, physiotherapy, music, and other diversion therapy. These do alter our patients' quality of life,

and that is what palliative care is about, and this is what we learned from our patients.

There is also some learning from these patients, psychological analysis and treatment is necessary for such patients. It would be difficult for a physician or nurse to decide which patient really needs it, as this falls in a different domain. A routine involvement of a psychologist would be helpful for patients of cancer, even those without disfigurement so that such phobias may be detected and managed early.

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