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Stigma, shame, and blame experienced by patients with lung cancer: A qualitative study

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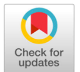

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ABSTRACT

Background: Stigma is experienced by a patient when he/she is termed as less desirable, handicapped and infected. This feeling may come in terms of feeling or enact. When the stigma is felt by the patients, it is known as shame. It is experienced by the patients as they develop the fear of being discriminated as well as they have an inferiority complex.
The aim of this study was to draw on narrative interviews with patients with lung cancer and to explore their perceptions and experience of stigma
Materials and Methods: A qualitative study (post ethical committee approval) was carried out among 40 lung cancer patients at the Gujarat Adani Institute of Medical Science. The study period was one year (May 2018 to April 2019). During the course of the study, the patients were asked to narrate about their story since starting when they were diagnosed with the disease. The interview was the selected instrument for data collection. From the data, various themes were created.
Results: Majority of the patients belonged to 51-60 years of age group. The result showed that majority of the patients had non-small cell cancer. The patients agreed that they have often experienced a situation where people avoid contact after knowing about their disease. Many of the patients accepted that smoking became one of the major reasons for their lung cancer.
Conclusions: It was found that the patients feel stigma as other people associate them to have acquired lung cancer due to their habit of smoking. This adds up when the people think that the cancer patients will not survive and they start distancing them from the patients. The stigma can have adverse implications on the patients by restraining them from seeking support and care from anyone.

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1. Introduction

Lung cancer is one of the most prominent types of cancer, leading to mortality and round the globe. Accounting to 25% deaths, lung-cancer contributes a major portion to the deaths among other types of cancers[1]. Despite the recent developments in the screening and treatment mechanisms, the majority of lung cancers are detected only at the advance stages, thereby having adverse treatment outcomes.

These give way to stigma shame and blame. Stigma is experienced by a patient when he/she is termed as less desirable, handicapped and infected[2]. This feeling my come in terms of feeling or may be enacted. When the stigma is felt by the patients, it is known as shame, is experienced by the patients as they develop the fear of being discriminated as well as they have an inferiority complex[3]. The enacted discrimination is the actual discrimination being faced by the patient. Stigma is just the fear of being discriminated and leads the patients to experience stress and further degrade the situation of patients[4]. This also results in significant mortality among the patients.

Stigma also depends on the disease from which the patient suffers[5]. It is because of the factors contributing to the disease. If the disease is the result of the activities of the patients, and he will be held responsible for the development of the disease[6]. It also depends on the consequences of the

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disease like serious disability, lack of control or disruption of human interaction. It has been noticed that stigma is attributed more towards the controllable factors than to the non-controllable factors[7].

It has been noticed in multiple studies that Lung Cancer has been associated with fear and stigma[8]. The major reason behind it is that cancer is always seen as the end of life, and no hope is seen beyond that. Patients often feel that they have lost control over their body, and they have become helplessness[9]. They further feel depressed and lose the hope to recover as they tend to lose their hair, scars appear on their skin and other physical changes add up to the already existing stigma[10].

Care and compassion are one of the most important factors that would help the caretakers and the doctors to boost the morale of stigma-stricken patients[11]. In the majority of the patients, cigarette smoking is the cause of lung cancer. It has been observed that young patients are more likely to have a stigma as compared to older patients[12].

Aim of this study was to draw on narrative interviews with patients with lung cancer and to explore their perceptions and experience of stigma

2. Material and Methods

A qualitative study was carried out among 40 lung cancer patients at the Gujarat Adani Institute of Medical Science. The study period was one year (May 2018 to April 2019). During the course of the study, the patients were asked to narrate about their story since starting when they were diagnosed with the disease. The interview was the selected instrument for data collection. From the data, various themes were created. A written informed consent was obtained from the study subjects.

3. Results

Table 1: Age Group

Age	No. of Patients
40-50	5
51-60	25
61-70	7
>70	3

The above table shows that majority of the patients belonged to 51-60 years of age group.

Table 2:

Type of cancer	No. of Patients
Non-small cell	22
Small cell	3
Mesothelioma	2
Not known to patients	13

The above table depicts that the majority of the patients had non-small cell cancer.

3.1. *Patient's experience and fear of stigma*

Majority of the patients agreed that they have often experienced a situation where the people avoid contact after knowing about their disease. The patients realized that this situation is a result of their severe disease, and the people find it difficult to converse it in such a situation. People perceive that the patient is in a dying condition, and they do not have much to say and thus avoid any kind of contact with the patients. This, in turn, becomes very embarrassing for the patients.

Furthermore, many of the patients shared that even their relatives and family members did not contact them after they were detected with cancer. Some of the patients opened up and shared about their experience with the reaction of their friends regarding cancer. Almost all of them did not have a great experience of that. One of the patients shared that his closest friend stopped visiting him once he got to know about his cancer. Many of the mesothelioma patients also suffer stigma even though it is known to be generated from asbestos.

3.2. *Resistance to blame and stigmatization*

Many of the patients accepted that smoking became one of the major reasons for their lung cancer. However, others believed that various factors other than smoking were responsible for their lung cancer. These other factors included diesel fumes, spray paint, carbon monoxide, asbestos, stress and various others. One of the patients felt the reason for her cancer was stress from the workload and that the smoking habit was being held responsible for it.

4. Discussion

It has been identified that there are two types of stigma, namely enacted and felt. The detection of lung cancer might affect the social life of the patients. It was found in the current that many of the patients believed that they acquired the disease due to other factors rather than tobacco consumption. Similar results were found in the study of Flower et al., (2000)[13] where the patients become dependent on tobacco and refuse to admit it as their cause of illness. The current study revealed that young were more affected by stigma. Therefore, they need to be encouraged against smoking. Similar results were obtained in the study of Chambers et al., (1999)[14] where the study concluded on eliminating smoking among young people in order to save them from many dreadful diseases like lung cancer. Similarly according to the study of Lehto, (2014)[15] found that lung cancer is uniquely identified as a major result of smoking by the society that develops stigma among the patients deteriorating their quality of life. The results of this

study were at par with the current study. Chapple et al., (2004)[2] identified that stigma among lung cancer patients has far reaching results. The study elaborated that even if the patients quit smoking they feel stigmatized as the disease is closely associated with smoking and tobacco consumption.

5. Conclusions

In light of the above results, it was found that the patients feel stigma as other people associate them to have acquired lung cancer due to their habit of smoking. This adds up when the people think that the cancer patients will not survive and they start distancing them from the patients. The stigma can have adverse implications on the patients by restraining them from seeking support and care from anyone. It was also found in the study that the patients do not feel that tobacco to be the major source of their disease and find various other factors to act as the contributing factor like stress and other obstacles.

6. Acknowledgement

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7. Source of Funding

None.

8. Conflict of Interest

None.

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