Behavioural Impact of the Disease
CHAPTER – IV

BEHAVIOURAL IMPACT OF THE DISEASE

Educational impact

Since the disease is associated with pain, hearing loss and ear discharge there is a marked impact of the disease on the patients. Of all the patients studied it is the children who face a wide range of problems. The affected children who are expected to undergo the process of learning which itself is complex and requires lot of focus, find it difficult to cope with the situation. In other words the affected children react differently owing to their different socio-cultural background and upbringing. A student may just sit quietly throughout the duration of the class without making any efforts to learn or some other student may ask the teacher to speak louder or another student may himself try and go close to the teacher in order to increase his audibility. He may also try and speak loudly and in due course create a lot of problem with his peer group and teachers. He may thus give an impression of over reacting and therefore subjected to a lot of apathy and indifference which may inturn be counter productive, and an individual as such may start behaving in an abnormal manner.

Difficulty in reading the situation like; when the teacher calls the students name for attendance and the student is not able to hear it and therefore does not reply, he will obviously be marked as absent. And if the condition of the student continues he may face a severe shortage of attendance leading to a lot of problems towards the end of the year.
The foul smell caused by the discharge also becomes a matter of grave concern for a child who is already subjected to a lot of stress. His friends and classmates find it extremely difficult to communicate and for the same reason try and avoid him whether it is play, studies or any other amusement. Hence many a times he/she is sent back home by the friends or his teachers. This makes him socially and culturally isolated. Hence these things very much restrict the healthy psychological and physiological growth of the child. Thus the patient many a times stops attending the classes due to the above mentioned problems. Thus, these things very much hamper his/her performance in studies and exams.

However it can be noted that the behaviour or attitude of the person suffering from the disease also depends on the degree of impact it bears. For example there are students who, due to the disease simply sit in the class idle and come back home without making any efforts to learn. There are also students who clarify their doubts with the help of friends, teachers or parents. It has also been seen that in some rare instances the student may try and explore alternative methods of self help like depending completely on their texts instead of relying on parents, teachers or friends. This would be some sort of positive attitude which I would like to say which definitely varies from person to person. But the problem stands as it is and if the impairment goes undiagnosed for a long period of time, growth of the student becomes retarded whether or not he is an optimist. This can also be observed from the fact that the parents normally complain that their child has suddenly lost interest in studies which actually corresponds to the onset of the disease. There are
also instances wherein the parents who are serious regarding their children's future but are unaware of the disability may unknowingly put a lot of pressure on their children. Thus the disease affects during the very developmental and formative years of the student.

**Reaction of parents**

From the information collected by interviewing the affected subject it was clear that the disease has a far reaching and varied effect when the parent-child relationship was considered. Once the child was inflicted with the disease, which further results in the subsequent deterioration of the child's health, an atmosphere of discontent prevails in the family. The parents always showed a definite mode of reaction the moment they came to know about their child's disease. They expressed a range of emotions which may be classified as acceptance, lack of acceptance, shock and anger, Table 3.71. The table further reveals that, when we take different religions into account, in respect of parental reaction there is very little variation as far as the acceptance level was concerned. That is far Hindus it was 93.4 per cent, Muslims 90.8 per cent, Christians 100 per cent and Jains 83.8 per cent, which adds-up to the total of 92.7 per cent. The next significant reaction is shock which is 4.2% in the case of Hindus, 7.3% in the case of Muslims and 16.7 per cent in the case of Jains.

To begin with, the reaction of parents is one of disbelief and confusion. But once the situation is explained by the doctor they start showing a range of reactions. The situation is further complicated by recurrent pain, loss of hearing, foul discharge from ear and foul smell,
which makes the conditions much more unbearable to the parents. It was also noticed that the handicap created by the disease make the children look insensitive and isolated from their parents. They normally do not respond to their parents in the day to day work and as a result the parents start abusing and ill-treating their children in the wake of anger so much so that there have been instances wherein the parents have beaten up children for being inattentive.

The other criterion which plays a significant role in this kind of relationship is that of socio-economic status of the parents. Once again it was very much evident from the sample collected that the economic impoverishment coupled with a complete lack of awareness about the disease sooner or later forces the parents to give up all their efforts. As a result of this, the child receives no medical attention; and as the parents themselves put it, that, their children are now completely at the mercy of God. They deem-it to be more appropriate option than anything else. Even then there were some parents who were casual in their approach and who opined that children do get health problems during their growth period and therefore was not a matter of concern. Thus, under such circumstances also the child’s health gets neglected.

Certain parents also expressed the concern that even though after visiting a number of doctors the child was not cured of the disease. Thus in an act of despair and desperation the parents put an end to all their efforts which results in the chronic nature of the disease.
On the other hand there are also some parents who are far more tolerant and receptive to the condition of their children. They acted with utmost patience and understanding which was more often than not a direct outcome of their sound economic, educational background and awareness towards the possibility that their child may be infected by the disease.

The locality-wise classification of parental reaction also provides an added dimension to the disease. The frequency of occurrence of the disease in the rural areas along with a complete lack of awareness may be reason for their high level of acceptance that is 96.3 per cent (Table 3.73). Even the subjects from the rural areas expressed the view that there were many instances of ear discharge and there was no necessity of concern. Thus the outcome was that, they were seldom bothered about the disease. But unlike in the rural areas, the urban dwellers showed much more awareness of the disease, which can be noticed in the form of a marginal decrease in their acceptance level, which is 90.7 per cent. However, having said this, when we compare the frequency of the parental reaction of urban and rural localities on the whole there is no significant variation between the two.

**Sibling relationship to the patient**

The sibling relationship, that is, the relationship with brothers and sisters follows the same pattern as that of parents and teachers. The sibs do not take the behaviour of the affected patient too seriously once they come to know about the disease. It we look at the data collected (Table
3.76) we can notice that, there is very little or no variation between the acceptance and aversion levels when we take the different age groups that is infants, childrens and adults. Even the total acceptance rate (49.2%) is almost equal to the total aversion rate (50.8%). When we consider the aversion rate of different age-groups, the first two that is, the infants and children show an increased rate of aversion (44.8% and 59.5%, respectively) when compared to the aversion rate of the adults (39%). It is obvious from the information that adults being more aware of the disease, show a lower level of aversion. But on the contrary, if we take the infants and children who naturally lack the basic knowledge about the disease show very little patience when they come across the affected patient thus accounting for higher level of aversion.

Sometimes it may happen that a relative may be treated in an utterly defiant and reckless manner which leads to a complete state of aversion. There is a complete dearth of affection and compassion in this case. The affected individuals are snubbed, teased and converted into a laughing stock by their siblings, so much so that this light hearted child's play is inadvertently imitated by the elders converting it into a serious business. It may also happen that during the course of time the condition is transformed into a stigma as far as the affected individuals are concerned. This is a example of how a physiological impairment can get translated into psycho-social disability. This may provide us within idea as to how ignorant and tenderminds fall prey to the mindless and irresponsible behaviour of the siblings.
Family life of adult patient

The psychological impact of the disease can best be ascertained from the ups and downs an adult undergoes in his family life. The disease affects both the sexes alike and most of the times result in conflicts in interpersonal relations. These conflicts are again an outcome of the already existing gender imbalance in the society.

The adults form a substantial portion of the sample taken, as they were more willing to part with the information. A comparative study of both the sexes when taken in the context of the relationship like marriage, it was evident from the collected samples that females suffered more than the male counterparts (Table 3.82). The total aversion rate is more (52.7%) than the acceptance rate (47.3%). This fact is further validated by Table 3.79 wherein the acceptance rate of the female spouses towards the affected males is significantly more (73.5%) than the aversion rate (26.5%).

The locality-wise distribution of the reaction of the spouses also reveals that in the case of the reaction of female spouses towards the affected males (Table 3.81), the acceptance rate is significantly more in both rural (79%) and urban (67.4%) localities when compared to the aversion rate (21% and 32.6%, respectively). But when it comes to the reaction of male spouse towards the affected females (Table 3.84), the acceptance rate in the rural (51.4%) is marginally more than the aversion rate (48.6%) and the urban acceptance level of male spouses is marginally less (40.9%) than the aversion rate (59.1%). Thus on the
whole it can very well be said that, both in terms of locality and religion
the acceptance rate of female spouses towards the affected males is
consistently more especially when compared to the reverse scenario that
is, the acceptance level of the male spouse towards the affected females.

From the people interviewed it was learnt that there were instances
wherein the husbands of affected females were completely ignorant as to
how and why the pain and discharge had occurred. And even by the time
the husband could come to know about the disease it had reached the
stage of unmanageable proportions. This can be attributed to the sheer
negligible and a complete lack of communication between the two
spouses, so much so that the husbands did not even bother to enquire
about the reasons of the infection once they come to know about the
disease. And added to this the wife should also put up with the blame
that she herself was negligent and did not take care of her health. Most of
the times under these conditions of severe pain and mental stress she is
abused and beaten up by her husband. This only adds to the pain and
sufferings of the wife. Apart form this, the in-laws also join hands with
the husband and make the life of the aggrieved person miserable. Here
again the traditional mindset of the society which is so deep rooted and
determines the day to day life style of the people gets expressed in the
form of gender disparities.

If we look at the flip-side of the situation, that is if the males are
affected, treatment given by their female spouses is markedly different
and is one of utmost care, concern, and caution, not only by the wife but
by the whole family. This is also probably the reason as to why the males seldom complain about the disease. Here again the underlying gender disparity prevalent in our society comes to the fore.

The cogency of the above given facts can further be proved by the behaviour of the children, grand children and other siblings towards the affected female parent. The affected old female is deliberately kept out from the vital family decisions. Her opinion is no longer considered relevant even for the day to day conduct of the family affairs. The younger family members were of the opinion that they are fedup of the dumb behaviour of the affected person as they have to keep on repeating and shouting at her and therefore there was no point in taking her views seriously.

**Reaction of neighbours**

The neighbours who normally reside in the same locality as that of the affected individuals, did show some concern but were limited in their act of showing help when it comes to keeping check of the health of the affected individuals. There have been some instances wherein the neighbours were actively involved in taking the affected individuals especially the children to the doctors but once again they lack the proper awareness and followup which is required for the disease. And on the contrary certain cases were witnessed wherein children owing to their foul smelling discharge were treated as outcastes and were not even allowed into the houses of their neighbours. And here, when we look at the age-wise split up of the acceptance and aversion levels (Table 3.87),
the acceptance level for infants (65.6%) is more than their aversion rate (34.4%). But in the case of children the aversion rate (58.9%) is more than the acceptance rate (41.1%). And finally, the aversion rate for adults was higher (57%) than the acceptance rate (43%). And if we take the total acceptance and aversion rates of the neighbours towards the affected individuals it is 43.4 per cent and 56.6 per cent respectively.

A locality-wise correlation of the neighbour residing in rural and urban areas and their behaviour with that of the affected individuals (Table 3.89), shows a common kind of relationship in both localities. The acceptance rate (48.5% and 40.4%) is relatively lower than the aversion rate (51.5% and 59.6%) in both the urban and rural localities respectively.

**Reaction of friends**

With regard to the relationship between the friends and the affected individuals when seen from the point of view of children and adults, it is generally found that the aversion rate is higher than the acceptance rate (Table 3.92). Especially in the case of children the aversion rate (74.2%) is significantly more than the acceptance rate (25.8%). This is owing to the fact that the children, when compared to the adults lack the awareness of the disease and seldom care for the consequences. As a result of this there are always quarrels between the affected and the non-affected children. When these circumstances are compared to that of adults the aversion rate (66.6%) is only relatively more than the acceptance rate (42.4%). And again the reasons behind this slight change
is once again the same level of awareness which is definitely more in the
case of adults. The only difference being that, the form of aversion
changes that is, the behaviour aversion becomes that much calibrated
and selective which leads to the isolation of the affected adults. There
have been many instances wherein the affected adults were deliberately
kept out of social gatherings which only adds to their frustration.

**Reaction of other relatives**

When it comes to the reaction of the other relatives towards the
affected individuals the behaviour follows the same pattern as that of the
neighbours and the friends. The acceptance level is generally lower than
the aversion level towards all the three age-groups (Table 3.97). Especially if we take the children, the aversion rate is 69.9 per cent
which is significantly more than the acceptance rate 30.1 per cent.
Similar is the case with the infants, where the aversion rate (64.8%) is
more than the acceptance rate (35.2%) and adults aversion rate (64.3%)
is more than acceptance rate (35.7%). The under laying reason behind
this kind of relationship is once again the defiant attitude of the other
relatives which was very much noticed during the family gatherings; as
mentioned by the affected individuals.

**Impact of the disease on the patient himself**

The end result of putting up with the reactions of his spouse,
parents, neighbours and other relatives, the affected individual invariably
feels a sense of loneliness and isolation. The hearing loss which results
from the disease not only makes him unbearable to the people around
him, but also a strange kind of a guilt and frustration starts settling in his mind. This is further aggravated by his inability to carry out his day to day job or business, which is his only means of livelihood. There have been instances wherein he cannot even move about safely on streets and roads because of the hearing loss, which results in the sense of fear and uneasiness in his life. The patient ultimately remains withdrawn completely devoid of any kind of external help.

Thus the reaction of the affected individual on himself is nothing but a cumulative effect of the reactions which he comes across from the people with whom he meets every day.

On the whole it can be said that the very reason behind the behavioural pattern noticed in all the three cases that is, neighbours, friends and other relatives and towards himself is a complete lack of input awareness regarding aspects relating to health and hygiene. However, it should also be remembered that there were evidence of the fact that even economically and educationally well off members of the society fall short of understanding the plight of the affected subjects.