What We Can Say: Disease Illiteracy

Sunil Beniwal¹, Bharat Bhushan Sharma², Virendra Singh³

Abstract

**Aims:** To study the awareness, attitude and behavior of patients with chronic diseases in those who come for follow-up, about the nature of their disease, compliance to treatment and precautions.

**Patients and Methods:** Patients attending medical out-patient with a prescription document (discharge cards, prescription letter etc.) bearing diagnosis of the chronic disease in question based on standard criteria were studied for a period of six months. Patient with chronic disease completed a questionnaire containing questions about the nature of disease, important precautions and compliance to the treatment.

**Results:** Of the 63 coronary artery disease (CAD) patients, 27 (42.8%) were not aware of having heart disease ever in their life. Twenty-nine (44%) CAD patients noncompliant for medicines during the last month. Among 84 hypertensive patients, only 58 (69%) knew they had hypertension and 54 (64.2%) compliant with medicine. Only 40 (47.6%) of 84 avoided salt in food. Though, out of 36 diabetic patients, 34 (94.4%) percent knew they had diabetes, still, 19 (52.7%) stopped medicine during the last month. Among 29 chronic obstructive pulmonary disease (COPD) patients, only 6 (20.6%) knew they had COPD and another 17 (58.6%) knew they had respiratory disease. Only 5 (17.2%) COPD patients remembered the no-smoking advice. Out of 23 CVA patients, 17 (74%) knew that they have paralysis and 8 (34.7%) stopped medication during the last month.

**Conclusion:** It is concluded that majority of patients were ignorant about their disease, importance of compliance to medicines and about precautions of the disease. CAD patients were most ignorant people among chronic patients. It emphasizes the need of proper patient education.

Introduction

Apart from infectious diseases, non-infectious diseases are assuming important proportions in Medical OPDs (outdoors) and medical wards of a health care setting. Coronary artery disease (CAD), Diabetes, Hypertension, Cerebrovascular accidents (CVA) and Chronic Obstructive Pulmonary Disease (COPD) are important diseases of this group. In patients with these diseases, secondary prevention is important to prolong life and slowing progression of the illness. Proper compliance to medicines and lifestyle modification strategies involving mainly diet and activity are important tools of secondary prevention. It has been shown that knowledge about disease in a patient improves his treatment compliance and decreases many complications associated with a disease. It is responsibility of the health professional to understand the importance of patient compliance, factors that contribute to non-compliance and to employ techniques and approaches to overcome it.

Compliance is most significant modifiable factor guiding control of hypertension and similar long term illnesses. Compliance can be assessed in a variety of ways and self-reporting of compliance is a valid instrument of measurement.

Studies have shown that patient knowledge about treatment of disease is limited. It has been observed for a small number of diseases and that only about individual disease separately but data are scanty about majority of diseases specially in India.

We planned this study to know the awareness of patients about their disease and to assess compliance to treatment and precautions regarding risk factors and diet. We studied the patients suffering from diseases of significant public health importance like CAD, COPD, CVA, Diabetes and Hypertension.

Material and Method

This hospital based cross sectional study was carried out in medicine outpatient department of our tertiary health care centre. Patients coming to OPD for follow up visits during month of July 08 to Jan. 09 were studied. They were admitted in medical wards in the preceding period or have any document (pensioner diary, discharge cards, investigations, prescription slips etc.). Information from patients with CVA, CAD, COPD, Diabetes and Hypertension were recorded on a pre-designed questionnaire by one of investigators. The questionnaire used was a modification of Lung Information Need Questionnaire (LINQ). It consisted of information regarding name of disease, compliance to treatment and the precautions advised to them by previous health care providers (Fig. 1).

Results

We asked questions from 63 patients of CAD, 53.63 (84.1%) were male, 18.63 (28.5%) were illiterate, 26.63 (41.2%) knew the exact diagnosis, another 10/63 (15.8%) said they were suffering from some heart problem, 4/63 (6.3%) said they have recurrent pain chest at rest, still, a big number 23/63 (36.5%) did not know about heart problem. Two patients said that they were told by doctor that they got heart attack but they don’t think so. 19/63 (30.1%) reached hospital within 6 hr, another 3/63 (4.7%) reached within 12 hours, 32/63 (50.7%) reached after 1 day. 17/63 (26.9%) thought that they would be cured, 10/63 (15.8%) thought the disease would remain the same, 27/63 (42.8%) had no idea about future course of disease, 2/63 (3.1%) thought it would increase in coming days. 42.63 (66.6%) were of opinion that medicines should be taken regularly, but surprisingly 29.63 (46%) give up medicine for one or more days in last month. Only 29/63 (46%) said they would put tablet (isosorbide dinitrate) underneath
Hypertension

Ignorant 31%
Correct 69%

COPD

Correct 21%
Partially correct 58%
Ignorant 21%

CVA

Ignorant 26%
Correct 74%

Fig. 1 : Pie diagrams showing ratio of patients with different disease groups regarding ignorance about name of the disease.

Diabetes

Ignorant 6%
Correct 94%

Fig. 2 : Bar diagram showing dietary behavior of different groups. Most of the group were not up to the mark in their adherence to dietary precaution.

tongue when they had chest discomfort, 5.63(7.9%) would like to tolerate, 21.63(33.3%) do nothing, 1 patient did local massage with an ointment, 3.63(4.7%) used an extra dose of the medication they were already taking, 4.63 (6.3%) will rush to a doctor. In their dietary behavior 35.63 (55.6%) avoided oily foods, 20.63 (31.7%) avoided salt, 9.63 (14.2%) avoided smoking and 14.63 (22.2%) made no change in their menu (Fig. 2). 23.63 (36.5%) had associated hypertension, 10.63 (15.9%) had associated COPD, 9.63 (14.2%) had diabetes mellitus type 2 (T2DM), 4.63 (6.3%) had CVA and 1.63 (1.5%) had hypothyroidism.

Knowledge about the diagnosis of CAD was found significantly (P = 0.009) associated with the gender of the patients in favor of males (Fig. 3). Duration of illness among CAD patients showed significant (P = 0.055) association with the occupation of patients and age of patients (P = 0.002). Educational status of the patients of myocardial infarction was strongly associated (P = 0.008) with there knowledge of assumption about prognosis.

Among 84 patient of hypertension, 47/84 (55.9%) were male, 34/84 (40.5%) were illiterate (Table 1), 58/84 (69%) knew that they had hypertension. 37/84 (44%) had no idea about future course of disease, 9/84 (10.7%) said it will improve, 7/84 (8.3%) said it will increase day by day, 8/84 (9.5%) said it will be cured, 23/84 (27.4%) thought it will remain the same. Only 54/84 (64.3%) were compliant to medicine throughout last month, 14/84 (16.7%) did not take medicine for 2 to 3 days and 13/84 (15.5%) usually gave up medicine in between. 40/84 (47.6%) avoided salt in food, 34/84 (40.5%) avoided oily food, 17/84 (20.7%) made no change in their dietary behavior after diagnosis and 12 (14.3%) said they should quit smoking. 23/84 (27.3%) patients also had associated CAD, 17/84 (20.2%) had T2DM, 9/84 (10.7%) had COPD-Asthma, 20/84 (23.8%) had CVA.

Gender of patients was associated (P =0.030) with their knowledge about diagnosis of HT. Working with government or not, was also associated (P =0.002) with their duration of disease. Age (P = 0.058) and Educational status (P=0.005) were also found significantly associated with the duration of disease. Educational status, in addition was found significantly (P=0.036) associated with their behavior about regularity of treatment.

Among 36 patients of Diabetes mellitus, 21/36 (58.3%) were male, 1 had T1DM and 35 had T2DM. 16/36 (44.4%) were illiterate. Most of them 34/36 (94.4%) knew that they had Diabetes. 8/36 (22.2%) thought that disease will remain same, 13/36 (36.1%) had no idea about future course of disease, 5/36 (13.9%) said disease will progress and 6/36 (16.7%) said it will be cured. 25/36 (69.4%) knew that medicines should be taken regularly, but only 17/36 (47.2%) did not give up medicines for a single day in last 1 month, 12/36 (33.3%) patients stopped taking their medications regularly. 10/36 (27.8%) thought that disease will remain same, 4/36 (11.1%) had no idea about future course of disease, 25/36 (69.4%) said it will be cured. 10/36 (27.8%) thought that disease will remain same, 4/36 (11.1%) had no idea about future course of disease, 25/36 (69.4%) said it will be cured.

Gender of patients was associated (P =0.002) with their knowledge about diagnosis of HT. Working with government or not, was also associated (P =0.002) with their duration of disease. Age (P = 0.058) and Educational status (P=0.005) were also found significantly associated with the duration of disease. Educational status, in addition was found significantly (P=0.036) associated with their behavior about regularity of treatment.

Among 36 patients of Diabetes mellitus, 21/36 (58.3%) were male, 1 had T1DM and 35 had T2DM. 16/36 (44.4%) were illiterate. Most of them 34/36 (94.4%) knew that they had Diabetes. 8/36 (22.2%) thought that disease will remain same, 13/36 (36.1%) had no idea about future course of disease, 5/36 (13.9%) said disease will progress and 6/36 (16.7%) said it will be cured. 25/36 (69.4%) knew that medicines should be taken regularly, but only 17/36 (47.2%) did not give up medicines for a single day in last 1 month, 12/36 (33.3%) patients stopped taking their medications regularly. 10/36 (27.8%) thought that disease will remain same, 4/36 (11.1%) had no idea about future course of disease, 25/36 (69.4%) said it will be cured.
occasionally (≤4 day) and 7/36 (19.4%) usually (>4 day). 21/36 (58.3%) avoided sweets, 8/36 (22.2%) avoided salt, 5/36(13.9%) avoided both potato and rice, 8/36 (22.2%) avoided oily foods and 3/36 (8.3%) made no change in their diet. 17/36 (47.2%) had associated hypertension, 9/36 (25%) had associated CAD, 2/36 patients had associated tuberculosis, 1/36 (2.8%) had associated CVA and 3/36 (8.3%) had COPD. Age was found significantly (P=0.030) associated with the duration of diabetes.

We included 29 patients of chronic obstructive pulmonary disease (COPD). 26/29 (89.6%) were male, 14/29 (48.2%) were illiterate. 17/29 (58.6%) said they had disease of respiration, 6/29 (20.7%) knew the name of the disease and said COPD, and 6/29 (20.7%) had no idea of disease name. 4/29 (13.8%) gave past history of tuberculosis. 25/29 (86.2%) were suffering from disease for more than 1 year. 10/29 (34.5%) had no idea about course of disease, 11/29 (37.9%) said it will increase further, 4/29 (13.8%) said it will remain the same and 3/29 (10.3%) said it will be cured. 23/29 (79.3%) said medicines should be taken regularly. 17/29 (58.6%) did not miss medicine for a single day in last month, 6/29 (20.7%) missed for 1 to 3 days during last month. 11/29 (37.9%) used inhaler,rotacaps during discomfort, 3/29 (10.3%) preferred do only rest, 3/29 (10.3%) went to a doctor. 5/29 (17.2%) said they should not smoke, 5/29 (17.2%) said they avoided cold items, 9/29 (31.9%) avoided oily foods, 5/29 (17.2%) avoided salt and 11/29 (37.9%) did not know about any precaution. 8/29 (27.6%) had associated CAD, 6/29 (20.7%) had associated hypertension, and 4/29 (13.8%) had T2DM.

Among 23 patient of CVA, 14/23 (60.9%) were male, 11/23 (47.8%) were illiterate, 17/23 (73.4%) knew that they had CVA. 7/23 (30.4%) had no idea about future course of disease, 8/23 (34.8%) said it will improve, 1/23 (4.3%) said it will increase day by day, 7/23 (30.4%) said it will remain the same. 14/23 (60.9%) took medicines everyday in last month, 6/23 (26.1%) did not take for 1 to 3 days and 3/23 (13.0%) usually gave up medicine in between. 12/23 (52.1%) avoided salt in food, 10/23 (43.5%) avoided oily food, 3/23 (13.0%) made no change in menu after diagnosis and 2/23 (8.7%) said they should quit smoking. 4/23 (17.3%) patients also had associated CAD, 1/23 (4.4%) had T2DM, 1/23 (4.4%) had Asthma, 20/23 (86.9%) had associated hypertension.

Discussion

Non-infectious diseases are increasingly being recognized to pose a significant health problem in India.1 CAD, CVA, COPD, diabetes and hypertension are important diseases in this group. With scientific advancement effective and safe treatments have been made available for these diseases. Such treatments make life comfortable and with them future agony of disease can be reduced significantly. India has abundance of qualified doctors and almost all effective medicines are available here. With this logic majority of patients with these chronic illnesses should be able to lead a comfortable life.

Unfortunately, the results of this study point towards not so benign state of affairs as they have uncovered the worst apprehension concerning patient’s attitude towards his illness. Despite the availability of qualified physicians and medicines, patients often fail to obtain expected optimal relief in their disease. The worst were patients of myocardial infarction. Despite remaining in hospital and taking thrombolytic treatment almost half of them did not know that they have had heart attack. It resulted in non compliance as almost 46.3%28 stopped treatment for more than one day during past month. Almost 27%,17 patients believed that disease will be cured and only 3.1%25 thought that disease might worsen, this may be another factor that led drugs not being taken regularly. Approximately 22.18 were ignorant about dietary and exercise prescription. Astonishingly, 53.9%34 did not know to put an isosorbide dinitrate/NTG tablet under tongue in case of emergency chest pain.

Among COPD patients only 20.7%36 knew the exact name of disease in comparison to study by García-Pachón E et al, where 38% knew the name of their disease. Similarly, and another study by Cécile R.L. Boot et al showed that 30% of the COPD patients did not know their correct diagnosis.10 In our study 48.2%14 of COPD patients were illiterate and another 13.8% were just literate, despite of this fact 79.3%10 admitted that drugs should be taken regularly. The reasons behind this paradox may be that course of COPD was more symptomatic as compared to other diseases in this study, and most of the patients were suffering for a longer duration (86.2% for ≥1 years). Only 17.2%35 knew about warning features and ill effects of smoking but rest were ignorant about this most important risk factor involved in development and progress of COPD.

In hypertension group only 69% knew that they had hypertension, similarly in one Chinese study 75.3% knew about hypertension.11 Similar to study by Syensson S, et al in which 57.6% were medicine adherent, our study group shows 64.3%34 were compliant to treatment.12 Most probably because in hypertension it is easier to take one or two pills daily as compared to multiple drugs prescribed in other chronic illnesses. Although 47.6%40 modified salt in their diet and 40.5% avoided oily food but amazingly only a small number of them avoided smoking, sweets and cold items. 44% did not know about future course of the disease.

Surprisingly, most patients (94.4%) suffering from diabetes knew that they had diabetes. However, 52.8% percent patients still missed the medicines at-least for one day during last month. In a study by Heather P. WHITLEY et al, 48% percent of patients were medication non-adherent; most frequently reported reasons for non-adherence were forgot (34%) and too expensive (14%) in their study.13 33% still were taking sweets in their diet. Another study of diabetes in this respect by Michell Gulabani et al in 101 diabetic patients showed that 47 (46.5%) patients considered diabetes could be prevented while only 13% of our diabetic patients thought it will be cured. Seventy one (71.3%) patients did not know the risk factors involved in the development of diabetes but they did not mention the education level of these patients.14 Fifty one (50.5%) in above study thought diabetes to be incurable which is in contrast to our study, where only 16.7% thought so but still another 31.7% in our study had no idea about future course of the disease and that’s why 74% of our diabetic patients agreed drugs to be necessary but many of them were non-compliant to treatment.

Contrary to the heterogeneous nature of CVA the patients were highly compliant second only to diabetes in our study, probably because of obvious disability associated illness which makes the treatment apparently necessary. According to Croquelois et al awareness was inversely correlated with older age and good recovery in CVA patients.14

Although chronic illnesses included in our study are disparate, however, while comparing different diseases it was found that COPD patients (48.2%) and CVA patients (47.8%) are more illiterate than other diseases (CAD 28.6%, Hypertension 40.5%, Diabetes 44.4%). In contrast to above observation hypertensive patient have more government employee 20 (23.8%) than others.
Table 2: Awareness about future of the disease

<table>
<thead>
<tr>
<th>Variables</th>
<th>Answers</th>
<th>CAD (63)</th>
<th>COPD (29)</th>
<th>Hypertension (84)</th>
<th>Diabetes (36)</th>
<th>CVA (23)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name of disease</td>
<td>Total no.</td>
<td>63</td>
<td>29</td>
<td>84</td>
<td>56</td>
<td>23</td>
</tr>
<tr>
<td>Correct diagnosis</td>
<td>26 (41.3%)</td>
<td>6</td>
<td>58</td>
<td>(20.7%)</td>
<td>34</td>
<td>17</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(69%)</td>
<td>(94.4%)</td>
<td></td>
<td>(73.9%)</td>
<td></td>
</tr>
<tr>
<td>Partly correct diagnosis</td>
<td>10 (15.9%)</td>
<td>17</td>
<td></td>
<td>-</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Ignorant</td>
<td>27 (42.9%)</td>
<td>6</td>
<td>26</td>
<td>2</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Duration of disease</td>
<td>≤6 month</td>
<td>25 (39.7%)</td>
<td>2</td>
<td>19</td>
<td>5</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(6.9%)</td>
<td>(22.6%)</td>
<td>(13.9%)</td>
<td>(65.2%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>6 month-2yrs</td>
<td>11</td>
<td>5</td>
<td>15</td>
<td>10</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(17.2%)</td>
<td>(17.9%)</td>
<td>(27.8%)</td>
<td>(21.7%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>&gt;2 yrs</td>
<td>27 (42.9%)</td>
<td>22</td>
<td>50</td>
<td>21</td>
<td>3</td>
</tr>
<tr>
<td>Future course of disease</td>
<td>Will be cured</td>
<td>17 (26.9%)</td>
<td>3</td>
<td>8</td>
<td>6</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(10.3%)</td>
<td>(9.5%)</td>
<td>(16.7%)</td>
<td>(34.8%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Remains same</td>
<td>10</td>
<td>4</td>
<td>23</td>
<td>8</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(15.9%)</td>
<td>(27.4%)</td>
<td>(22.2%)</td>
<td>(30.4%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Will Improve</td>
<td>7</td>
<td>1</td>
<td>9</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>(11.1%)</td>
<td>(10.7%)</td>
<td>(11.1%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Will Worsen</td>
<td>2</td>
<td>11</td>
<td>7</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(3.2%)</td>
<td>(37.9%)</td>
<td>(13.9%)</td>
<td>(43%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>No idea</td>
<td>27 (42.9%)</td>
<td>10</td>
<td>37</td>
<td>13</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(34.5%)</td>
<td>(44.1%)</td>
<td>(36.1%)</td>
<td>(30.4%)</td>
<td></td>
</tr>
</tbody>
</table>

Table 3: Compliance awareness

<table>
<thead>
<tr>
<th>Questions</th>
<th>Answers</th>
<th>CAD (63)</th>
<th>COPD (29)</th>
<th>Hypertension (84)</th>
<th>Diabetes (36)</th>
<th>CVA (23)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is it necessary to take drugs regularly? (knowledge)</td>
<td>Yes</td>
<td>42 (66.7%)</td>
<td>23 (79.3%)</td>
<td>61 (72.6%)</td>
<td>25 (69.4%)</td>
<td>16 (69.6%)</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>10 (15.9%)</td>
<td>3 (10.3%)</td>
<td>10 (11.9%)</td>
<td>4 (11.1%)</td>
<td>1 (4.3%)</td>
</tr>
<tr>
<td></td>
<td>Not Sure</td>
<td>11 (17.5%)</td>
<td>3 (10.3%)</td>
<td>13 (15.5%)</td>
<td>7 (19.4%)</td>
<td>6 (26.1%)</td>
</tr>
<tr>
<td>Did you leave drugs occasionally? (behavior)</td>
<td>Yes</td>
<td>23 (36.5%)</td>
<td>8 (27.6%)</td>
<td>28 (33.3%)</td>
<td>15 (41.7%)</td>
<td>9 (39.1%)</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>40 (63.5%)</td>
<td>21 (72.4%)</td>
<td>56 (66.7%)</td>
<td>21 (58.3%)</td>
<td>14 (60.9%)</td>
</tr>
</tbody>
</table>

(CAD 19%, COPD 13.4%, Diabetes 19.4%, CVA 17.4%). It may be attributable to increased stress imposed on them as a part of their hard jobs or they were inclined to use our government health facility more frequently because of insurance reasons (Table 1).

Most of Diabetic patients (94.4%) knew the name of their disease (CAD 41.3%, COPD 20.7%, Hypertension 69%, CVA 73.9%). Almost 43% of CAD patients were totally ignorant about the disease what they have in comparison to only 5.6% of diabetic, 20.7% of COPD, 31% of Hypertension and 26.1% of CVA. Most of COPD patients (79.3%) did not know name of disease although 59.6% said they have respiratory problem. 75.9% COPD patients, 59.5% of hypertension and 63.9% of diabetic were suffering since >2 yrs, in contrast patients diagnosed having CAD (39.7%) and CVA (65.2%) had higher number of recently diagnosed patients (<6 months). When we compare patient’s knowledge about future course of disease about more than one third patients in any disease had no idea about that.

In other responses CAD and CVA patients have more positive attitude, 26.9% of CAD patients and 34.8% of CVA patients thought disease will be cured and only 3.2% of CAD and 4.3% of CVA thought it will worsen in comparison 37.9% patients of COPD thought disease will be worsened day by day (Table 2).

Most of COPD patients (79.3%) thought medicines should be taken regularly in comparison to only 66.7% of CAD. Although 69.4% of diabetic knew drugs should be taken regularly 58.3% of Diabetic leave medication during past month (Table 3).

Medicine OPD remains full of patients; therefore, to educate each and every patient is impossible by a caregiver in a tertiary care centre. Group education may be the answer to some extent. Patients with a particular disease can be educated in groups in wards during their admission or discharge about their disease, risk factors and importance of medication. Written diagnosis of disease to patient in simple language may increase patients’ knowledge about their disease.16

Conclusions

Concept of ‘Patient education’ is very real and need of developing countries like India to overcome big challenge imposed by these important chronic health problem. Unfortunately, life threatening conditions like CAD is ignored by most of the patients. Patients are used to stop medication in between and they are ignorant about risk factors. Health professional should devote some time to educate the patients during their health visits. CAD patients need more knowledge than other chronic health problem. Medicine can relieve agony of patients for a brief period while educating them provides life long relief.
Acknowledgement

We are highly thankful to Dr. Rajeev Yadav, Associate Professor, Department of Preventive and Social Medicine, S.M.S. Medical college, Jaipur for his valuable support in study designing as well as analysis of results. Without his contribution this article may not come to an end.

References