Analysis is a comprehensive and complex process of research. It involves staying close to the data right from collection of data to the conclusions drawn from it. It involves systematically organising and managing the large amounts of data. The entire process of analysis involves moving between the data, the research questions, aims and objectives of the research, theoretical and conceptual understandings and methods employed for data collection. The present study is based on data collected from 230 cancer patients (200 patients undergoing active treatment and 30 patients undergoing symptomatic treatment) and their caregivers chosen purposely from three field areas including Bathinda, Faridkot and Sri Muktsar Sahib. Both qualitative and quantitative methods have been used for analysis of the data. The thematic analysis is done, based upon the themes that were generated from the interviews of the respondents. The major themes that are generated for the analysis are: socio-demographic characteristics of the respondents, beliefs and perceptions related to cancer, health-seeking behaviour of the respondents, concerns of cancer patients undergoing active treatment and concerns at end-of-life: Patient's, caregiver's and health care provider's perspectives.

### 7.1 SOCIO-DEMOGRAPHIC CHARACTERISTICS OF THE RESPONDENTS

In order to understand the functional aspect of any socio-cultural phenomenon, its context and content need to be understood and analysed properly. The context provides a focus to understanding of the pathway to be followed in order to gauze the existing situation. How this context actually reflects the working of a socio-cultural phenomenon depends upon the contents it is developed from. The contents form the base for proper interpretation. The first step for achieving inter-connectivity of both the context and the content throughout is to have a proper understanding of the socio-demographic factors that influence the functioning of concerned phenomenon at societal level. For the present study, information regarding age, gender, education, occupation, marital status, disease diagnosis and type of treatment of respondents were collected.

The socio-demographic characteristics of the respondents are given in Table 7.1.
Table 7.1: Socio-demographic characteristics of the respondents

<table>
<thead>
<tr>
<th>Gender Variables</th>
<th>Male (N=112)</th>
<th>Female (N=118)</th>
<th>Total (N=230)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age-wise distribution (in years)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21-30</td>
<td>18 (16.1)</td>
<td>13 (11.0)</td>
<td>31 (13.5)</td>
</tr>
<tr>
<td>31-40</td>
<td>29 (25.9)</td>
<td>28 (23.7)</td>
<td>57 (24.8)</td>
</tr>
<tr>
<td>41-50</td>
<td>22 (19.6)</td>
<td>31 (26.3)</td>
<td>53 (23.0)</td>
</tr>
<tr>
<td>51-60</td>
<td>25 (22.3)</td>
<td>19 (16.1)</td>
<td>44 (19.1)</td>
</tr>
<tr>
<td>61-70</td>
<td>14 (12.5)</td>
<td>17 (14.4)</td>
<td>31 (13.5)</td>
</tr>
<tr>
<td>71-80</td>
<td>4 (3.6)</td>
<td>10 (8.5)</td>
<td>14 (6.1)</td>
</tr>
<tr>
<td><strong>Caste-wise distribution</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Jatt Sikh</td>
<td>73 (65.2)</td>
<td>73 (61.9)</td>
<td>146 (63.5)</td>
</tr>
<tr>
<td>Majhabi Sikh</td>
<td>32 (28.5)</td>
<td>38 (32.2)</td>
<td>70 (30.4)</td>
</tr>
<tr>
<td>Ramgarhia Sikh</td>
<td>7 (6.3)</td>
<td>7 (5.9)</td>
<td>14 (6.1)</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unmarried</td>
<td>5 (4.5)</td>
<td>3 (2.5)</td>
<td>8 (3.5)</td>
</tr>
<tr>
<td>Married</td>
<td>101 (90.2)</td>
<td>101 (85.6)</td>
<td>202 (87.8)</td>
</tr>
<tr>
<td>Others</td>
<td>6 (5.3)</td>
<td>14 (11.9)</td>
<td>20 (8.7)</td>
</tr>
<tr>
<td><strong>Educational status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Illiterate</td>
<td>8 (7.1)</td>
<td>12 (10.2)</td>
<td>20 (8.7)</td>
</tr>
<tr>
<td>Upto middle</td>
<td>23 (20.5)</td>
<td>13 (11.0)</td>
<td>36 (15.7)</td>
</tr>
<tr>
<td>Upto senior secondary</td>
<td>49 (43.8)</td>
<td>56 (47.4)</td>
<td>105 (45.6)</td>
</tr>
<tr>
<td>Graduation and above</td>
<td>32 (28.6)</td>
<td>37 (31.4)</td>
<td>69 (30.0)</td>
</tr>
<tr>
<td><strong>Occupational status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Housewife</td>
<td>-</td>
<td>72 (61.0)</td>
<td>72 (31.3)</td>
</tr>
<tr>
<td>Farming</td>
<td>63 (56.3)</td>
<td>-</td>
<td>63 (27.4)</td>
</tr>
<tr>
<td>Labour</td>
<td>36 (32.1)</td>
<td>31 (26.3)</td>
<td>67 (29.1)</td>
</tr>
<tr>
<td>Government employees</td>
<td>8 (7.2)</td>
<td>11 (9.3)</td>
<td>19 (8.3)</td>
</tr>
<tr>
<td>Others</td>
<td>5 (4.5)</td>
<td>4 (3.4)</td>
<td>9 (3.9)</td>
</tr>
</tbody>
</table>

* Percentages in parentheses
The demographic characteristics of the respondents given in Table shows the frequencies and percentage of the respondents categorised gender, age, caste, marital status, education and occupation.

7.1.1 Gender-wise distribution of respondents

The gender-wise distribution of the respondents is given in Pie-chart 7.1. The majority of the respondents (51.3 per cent) were females while males represented 48.7 per cent of all respondents.

Pie-chart 7.1: The gender-wise distribution of respondents

7.1.1.1 Association of gender with type of treatment: The association of gender with type of treatment is given in Table 7.2.

Table 7.2: Association of gender with type of treatment

<table>
<thead>
<tr>
<th>Type of treatment</th>
<th>Gender</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>Active treatment</td>
<td>98 (87.5)</td>
<td>102 (86.5)</td>
</tr>
<tr>
<td>Symptomatic treatment</td>
<td>14 (12.5)</td>
<td>16 (13.5)</td>
</tr>
<tr>
<td>Total</td>
<td>112 (100)</td>
<td>118 (100)</td>
</tr>
</tbody>
</table>

p=.812
* Percentages in parentheses
It is clear from the Table 7.2 that among the males, 87.5 per cent were undergoing active treatment and other 12.5 per cent were undergoing symptomatic treatment. Among females, 86.5 per cent were undergoing active treatment and other 13.5 per cent were undergoing symptomatic treatment.

7.1.1.2 Association of gender with type of cancer: The association of gender with type of cancer is given in Table 7.3.

Table 7.3: Association of gender with type of cancer

<table>
<thead>
<tr>
<th>Type of cancer</th>
<th>Gender</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>Oral cancer</td>
<td>58 (51.8)</td>
<td>-</td>
</tr>
<tr>
<td>Gall bladder cancer</td>
<td>34 (30.3)</td>
<td>29 (24.5)</td>
</tr>
<tr>
<td>Cancer of cervix</td>
<td>-</td>
<td>38 (32.2)</td>
</tr>
<tr>
<td>Breast cancer</td>
<td>-</td>
<td>45 (38.2)</td>
</tr>
<tr>
<td>Primary unknown with metastasis</td>
<td>4 (3.6)</td>
<td>6 (5.1)</td>
</tr>
<tr>
<td>Prostate cancer</td>
<td>16 (14.3)</td>
<td>-</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>112 (100)</td>
<td>118 (100)</td>
</tr>
</tbody>
</table>

*Percentages in parentheses

It is clear from the Table 7.3 that all the oral and prostate cancer patients were males and all cancer of cervix and breast cancer patients were females as these are particularly cancers of females. Among males, majority were suffering from oral cancers (51.8 per cent) and among females, a majority were suffering from breast cancer (38.2 per cent).

7.1.2 Age-wise distribution of respondents

The mean age of all respondents in the present study was 46.88 (45.88 for males and 47.84 for females). The differences between the mean ages of males and females were non-significant. The ages of the respondents ranged
between 22 to 78 years. The Table 7.4 shows the mean ages of the respondents.

### Table 7.4: Mean age of the respondents

<table>
<thead>
<tr>
<th>Gender</th>
<th>Number</th>
<th>Mean age</th>
<th>Minimum age</th>
<th>Maximum age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>112</td>
<td>45.88</td>
<td>22</td>
<td>77</td>
</tr>
<tr>
<td>Female</td>
<td>118</td>
<td>47.84</td>
<td>24</td>
<td>78</td>
</tr>
</tbody>
</table>

7.1.2.1 **Association of age with gender**: The age-wise distribution of respondents with respect to gender is given in Table 7.5.

### Table 7.5: Age-wise distribution of respondents with respect to gender

<table>
<thead>
<tr>
<th>Age group (in years)</th>
<th>Gender</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>21-30</td>
<td>18 (16.1)</td>
<td>13 (11.0)</td>
</tr>
<tr>
<td>31-40</td>
<td>29 (25.9)</td>
<td>28 (23.7)</td>
</tr>
<tr>
<td>41-50</td>
<td>22 (19.6)</td>
<td>31 (26.3)</td>
</tr>
<tr>
<td>51-60</td>
<td>25 (22.3)</td>
<td>19 (16.1)</td>
</tr>
<tr>
<td>61-70</td>
<td>14 (12.5)</td>
<td>17 (14.4)</td>
</tr>
<tr>
<td>71-80</td>
<td>4 (3.6)</td>
<td>10 (8.5)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>112 (100)</strong></td>
<td><strong>118 (100)</strong></td>
</tr>
</tbody>
</table>

*p = .318
* Percentages in parentheses

It is clear from the Table 7.5 that the maximum percentages (24.8 per cent) of respondents in the present study were the age group 31-40 years and minimum percentages (6.1 per cent) of respondents were in age group 71-80 years. On comparing the age distribution among males and females, it was found that maximum number of males (29 out of 112) were in age group 31-40 years and minimum number of males (4 out of 112) were in age group 71-80 years. Similarly, the maximum numbers (28 out of 118) of females were in age group 31-40 years and minimum number (10 out of 118) of females were in age group 71-80 years. The maximum and minimum age distribution of
males and females is similar to that of total respondents. There were significant differences in types of cancer with respect to age.

7.1.2.2 Association of age with type of treatment: The age-wise distribution of respondents with respect to type of treatment is given in Table 7.6.

Table 7.6: Age-wise distribution of respondents with respect to type of treatment

<table>
<thead>
<tr>
<th>Age group (in years)</th>
<th>Type of treatment</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Active treatment</td>
<td>Symptomatic treatment</td>
</tr>
<tr>
<td>21-30</td>
<td>28 (14.0)</td>
<td>3 (10.0)</td>
</tr>
<tr>
<td>31-40</td>
<td>50 (25.0)</td>
<td>7 (23.3)</td>
</tr>
<tr>
<td>41-50</td>
<td>49 (24.5)</td>
<td>4 (13.3)</td>
</tr>
<tr>
<td>51-60</td>
<td>38 (19.0)</td>
<td>6 (20.0)</td>
</tr>
<tr>
<td>61-70</td>
<td>23 (11.5)</td>
<td>8 (26.7)</td>
</tr>
<tr>
<td>71-80</td>
<td>12 (6.0)</td>
<td>2 (6.7)</td>
</tr>
<tr>
<td>Total</td>
<td>200 (100)</td>
<td>30 (100)</td>
</tr>
</tbody>
</table>

_p = .284_  
* Percentages in parentheses

It is clear from the Table 7.6 that the majority of respondents undergoing active treatment were in the age group 31-40 years (25.0 per cent) followed by 41-50 years (24.5 per cent), 51-60 years (19.0 per cent), 21-30 years (14.0 per cent), 61-70 years (11.5 per cent) and 71-80 years (6.0 per cent). Among the respondents undergoing symptomatic treatment, the majority (26.7 per cent) were in the age group 61-70 years followed by 31-40 years (23.3 per cent), 51-60 years (20.0 per cent), 41-50 years (13.3 per cent), 21-30 years (10.0 per cent) and 71-80 years (6.7 per cent).

7.1.2.3 Association of age with type of cancer: The age-wise distribution of respondents with respect to type of cancer is given in Table 7.7.
Table 7.7: Age-wise distribution of respondents with respect to type of cancer

<table>
<thead>
<tr>
<th>Type of Cancer</th>
<th>Age group (in years)</th>
<th>Gall bladder cancer</th>
<th>Oral cancer</th>
<th>Breast cancer</th>
<th>Cancer of cervix</th>
<th>Prostate cancer</th>
<th>Primary unknown with metastasis</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>21-30</td>
<td>8 (12.7)</td>
<td>11 (19.0)</td>
<td>3 (6.7)</td>
<td>5 (13.2)</td>
<td>1 (6.3)</td>
<td>3 (30.0)</td>
<td>31 (13.5)</td>
</tr>
<tr>
<td></td>
<td>31-40</td>
<td>20 (31.7)</td>
<td>15 (25.9)</td>
<td>12 (26.7)</td>
<td>7 (18.4)</td>
<td>1 (6.3)</td>
<td>2 (20.0)</td>
<td>57 (24.8)</td>
</tr>
<tr>
<td></td>
<td>41-50</td>
<td>15 (23.8)</td>
<td>12 (20.7)</td>
<td>11 (24.4)</td>
<td>12 (31.6)</td>
<td>3 (18.7)</td>
<td>-</td>
<td>53 (23.0)</td>
</tr>
<tr>
<td></td>
<td>51-60</td>
<td>8 (12.7)</td>
<td>14 (24.1)</td>
<td>13 (28.9)</td>
<td>3 (7.9)</td>
<td>3 (18.7)</td>
<td>3 (30.0)</td>
<td>44 (19.1)</td>
</tr>
<tr>
<td></td>
<td>61-70</td>
<td>8 (12.7)</td>
<td>6 (10.3)</td>
<td>4 (8.9)</td>
<td>7 (18.4)</td>
<td>4 (25.0)</td>
<td>2 (20.0)</td>
<td>31 (13.5)</td>
</tr>
<tr>
<td></td>
<td>71-80</td>
<td>4 (6.4)</td>
<td>-</td>
<td>2 (4.4)</td>
<td>4 (10.5)</td>
<td>4 (25.0)</td>
<td>-</td>
<td>14 (6.1)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
<td><strong>63 (100)</strong></td>
<td><strong>58 (100)</strong></td>
<td><strong>45 (100)</strong></td>
<td><strong>38 (100)</strong></td>
<td><strong>16 (100)</strong></td>
<td><strong>10 (100)</strong></td>
<td><strong>230 (100)</strong></td>
</tr>
</tbody>
</table>

p= .031

* Percentages in parentheses

Table 7.7 shows that majority of gall bladder cancer patients (31.7 per cent) were in the age group 31-40 years, majority of oral cancer patients (25.9 per cent) were in the age group 31-40 years, majority of breast cancer patients (28.9 per cent) were in the age group 51-60 years, majority of cancer of cervix patients (31.6 per cent) were in the age group 41-50 years, majority of prostate cancer patients (50.0 per cent) were in the age group 61-80 years and majority of cancer patients with primary unknown with metastasis (30.0 per cent) were in the age groups 21-30 years and 51-60 years. There were significant differences in types of cancer with respect to age.
7.1.3 Caste-wise distribution of respondents

The respondents in the present study belonged to three castes namely Jatt Sikh, Majhabi Sikh and Ramgarhia Sikh. The distribution of respondents is given in Pie-chart 7.2.

Pie-chart 7.2: Caste-wise distribution of respondent

In the present study, majority of respondents were Jatt Sikh (65.2%) followed by Majhabi Sikh (32.2%) and Ramgarhia Sikh (6.3%).

7.1.3.1 Association of caste with gender: The Table 7.8 describes the caste-wise distribution of respondents with respect to gender.

Table 7.8: Caste-wise distribution of respondents with respect to gender

<table>
<thead>
<tr>
<th>Caste</th>
<th>Gender</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>Jatt Sikh</td>
<td>73 (65.2%)</td>
<td>73 (61.9%)</td>
</tr>
<tr>
<td>Majhabi Sikh</td>
<td>32 (28.5%)</td>
<td>38 (32.2%)</td>
</tr>
<tr>
<td>Ramgarhia Sikh</td>
<td>7 (6.3%)</td>
<td>7 (5.9%)</td>
</tr>
<tr>
<td>Total</td>
<td>112 (100%)</td>
<td>118 (100%)</td>
</tr>
</tbody>
</table>

*Percentages in parenthesis

p = .836
It is clear from Table 7.8 that the caste distribution pattern followed males and females is similar to that followed by all respondents. There were no significant differences in caste-wise distribution of respondents with respect to gender.

7.1.4 Marital status of respondents

The marital status of the respondents in the present study was divided into unmarried, married and others including separated, widowed and widowers (Pie-chart 7.3).

**Pie-chart 7.3: Marital status of respondents**

A total of 87.8 per cent of the respondents were married in the present study while 3.5 per cent were unmarried and other 8.7 per cent constituted either separated, widowed or widowers.

7.1.4.1 Association of marital status with gender: The marital status of respondents with respect to gender is given in Table 7.9.
Table 7.9: Marital status of respondents with respect to gender

<table>
<thead>
<tr>
<th>Marital status</th>
<th>Gender</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>Unmarried</td>
<td>5 (4.5)</td>
<td>3 (2.5)</td>
</tr>
<tr>
<td>Married</td>
<td>101 (90.2)</td>
<td>101 (85.6)</td>
</tr>
<tr>
<td>Others</td>
<td>6 (5.3)</td>
<td>14 (11.9)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>112 (100)</td>
<td>118 (100)</td>
</tr>
</tbody>
</table>

p = .170
* Percentages in parentheses

It is clear from Table 7.9 that a majority (87.8 per cent) of respondents were married while other 8.7 per cent were either widowed or widowers and remaining 3.5 per cent were unmarried. There is no non-significant differences in marital status of respondents with respect to gender.

7.1.5 Educational status of respondents

The educational status of the respondents in the present study divided into illiterate, upto middle, upto senior secondary and, graduation and above (Pie-chart 7.4).

Pie-chart 7.4: Educational status of respondents
In the present study, a majority of respondents (45.6 per cent) were educated upto senior secondary followed by 30.0 per cent graduates and above, 15.7 per cent educated upto middle and remaining 8.7 per cent of the respondents were illiterates.

7.1.5.1 Association of educational status with gender: The Table 7.10 deals with the educational status of respondents with respect to gender.

**Table 7.10: Educational status of respondents with respect to gender**

<table>
<thead>
<tr>
<th>Education</th>
<th>Gender</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>Illiterate</td>
<td>8 (7.1)</td>
<td>12 (10.2)</td>
</tr>
<tr>
<td>Upto middle</td>
<td>23 (20.5)</td>
<td>13 (11.0)</td>
</tr>
<tr>
<td>Upto senior secondary</td>
<td>49 (43.8)</td>
<td>56 (47.4)</td>
</tr>
<tr>
<td>Graduation and above</td>
<td>32 (28.6)</td>
<td>37 (31.4)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>112 (100)</td>
<td>118 (100)</td>
</tr>
</tbody>
</table>

*p* = .235

* Percentages in parentheses

It is clear from Table 7.10 that the patterns in educational status among both males and females were found to be similar as followed by all respondents. Among males, the majority (43.8 per cent) were educated upto senior secondary followed by 28.6 per cent graduates and above, 20.5 per cent educated upto middle and only 7.1 per cent illiterates. Among females, the majority (47.4 per cent) were educated upto senior secondary followed by 31.4 per cent graduates and above, 11.0 per cent educated upto middle and only 10.2 per cent illiterates. There were non-significant differences in educational status of respondents with respect to gender.

7.1.6 Occupational status of respondents

Among the respondents, a majority were housewives (31.3 per cent) followed by 29.1 per cent labourers, 27.4 per cent farmers, 8.3 government employees and remaining 3.9 per cent in other occupations such as various private jobs.
7.1.6.1 Association of occupational status with gender: The Table 7.11 deals with the occupational status of respondents with respect to gender.

Table 7.11: Occupational status of respondents with respect to gender

<table>
<thead>
<tr>
<th>Occupation</th>
<th>Gender</th>
<th>Total</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
<td></td>
</tr>
<tr>
<td>Housewives</td>
<td>-</td>
<td>72 (61.0)</td>
<td>72 (31.3)</td>
</tr>
<tr>
<td>Farmers</td>
<td>63 (56.2)</td>
<td>-</td>
<td>63 (27.4)</td>
</tr>
<tr>
<td>Labourers</td>
<td>36 (32.1)</td>
<td>31 (26.3)</td>
<td>67 (29.1)</td>
</tr>
<tr>
<td>Government employees</td>
<td>8 (7.2)</td>
<td>11 (9.3)</td>
<td>19 (8.3)</td>
</tr>
<tr>
<td>Others</td>
<td>5 (4.5)</td>
<td>4 (3.4)</td>
<td>9 (3.9)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>112 (100)</td>
<td>118 (100)</td>
<td>230 (100)</td>
</tr>
</tbody>
</table>

*p* = <.001

* Percentages in parentheses

Table 7.11 shows that among males, the majority were farmers (56.2 per cent) followed by labourers (32.1 per cent), government employees (7.2 per cent) and 4.5 per cent in other professions. Among females, the majority were housewives (61.0 per cent) followed by labourers (26.3 per cent), government employees (9.3 per cent) and 3.4 per cent in other professions. There were highly significant differences in occupational status of respondents with respect to their gender.

7.2 BELIEFS AND PERCEPTIONS RELATED TO CANCER

Medical anthropologists and sociologists have come to understand and analyse disease and illness as two related but distinct phenomenon. According to this perspective, disease corresponds to some form of bio-psychological change in the body. Illness, on the other hand, is the social phenomenon of meaning and experience that surrounds disease. Angel and Thoits (1987) note that, “while the clinical characteristics of a disease are culturally invariant, the experience of illness of highly variable”. Thus, it is very important to understand the beliefs and perceptions of respondents regarding cancer.
A belief is a mental association between an object, concept or event to some attribute or quality (Glanz et al., 1990). The content of belief is the subjective judgement of the probability that the object-attribute relationship is true. These beliefs and perceptions about the illness are acquired through socialisation, socio-cultural factors and important life experiences. When individuals suffer from chronic disease, they develop their own formulations about the disease. They often hold a variety of beliefs about causes, consequences, control and outcomes of the illness (Awasthi et al., 2006). The prevalence of these beliefs and perceptions among patients regarding cancer is a reflection of the level of knowledge and awareness regarding the cancer among themselves and their community. Such beliefs influence the health-seeking behaviour of patients and may lead to delay in seeking medical care (Kishore et al., 2007). These also have great impact on the practices of a society for the prevention and diagnoses of a disease, decisions regarding its treatment, and care at the end-of-life (Kagawa-Singer, 2000). This section on beliefs and perceptions of patients about cancer is divided into four sub-sections namely description and the terminology used for cancer, symptoms of cancer, diagnosis of cancer, and attribution of causes to cancer.

7.2.1 Description and the terminology used for cancer

During the interviews, none of the respondents and their family members used the term ‘cancer’ as they believed that it is such a dreaded disease that using the term alone would cause cancer to them. They described cancer as a disease which spreads very fast as it develops its tentacles all over the vital organs of the human body and ultimately leads to death. The other terms like pinnā (rounded mass), gath/gand (dense mass), rasauli (tumour) and ulcer were also used to describe the disease. The respondents also described cancer as an incurable disease.

In the study, it was found that the names of cancer varied among the respondents. The widely prevalent names of cancer include marī bīmarī (bad disease), chandari bīmarī (dreaded disease), bhairī bīmarī (worst disease), oprī bīmarī (unknown disease), jar vala phora (rooted sore), mare karmā vāli bīmarī (disease caused due to bad karmā) and Bikaner vāli bīmarī (disease
treated at Bikaner). The Plate 7.1 shows the Bhog ceremony invitation of Sunny Brar, a politician from Punjab, portraying cancer as an unfortunate disease.

7.2.2 Symptoms of cancer

Symptoms refer to subjective assessment of their condition based on their experience of some unwanted conditions. A doctor may derive important ideas from patient's expression of symptoms but primarily tend to rely on medical diagnostic procedures but the medical anthropologists views expression of symptoms as a social construction (Winkelman, 2009). In the study, the respondents were asked about the symptoms which they first noticed and how did they react to those symptoms. The respondents expressed the appearance of a pinnâ (rounded mass), gathi/ gand (dense mass), rasauli (tumour) or ulcer with pain, continuous pain in any part of body, unusual bleeding either from mouth, anus or vagina/penis, constant indigestion, change in bowel habits (constipation or loose motions for a longer period), loss of appetite and sudden weight reduction as their first symptoms.

7.2.3 Diagnosis of cancer

Medical diagnosis is a labelling process whereby individuals are given disease labels that only partially encompass their experience of malady (Winkelman, 2009). Jutel (2009) argues that “diagnosis is a powerful social tool, with unique features and impacts which deserve their own specific analysis”. She observes that research into the social processes associated with diagnosis has explored the place of diagnosis in the institution of medicine, the social framing of disease definitions, the means by which diagnosis confers authority on medicine, and how that authority is challenged.

Anthropological analysis of diagnosis has achieved considerable influence in the last two decades, providing important insight into how one understands health, disease, and illness. It has also expanded how one views the social and cultural influences that shape our knowledge and practice on health and illness. This includes studies of diagnosis that have gone beyond
Plate 7.1: Bhog ceremony invitation portraying cancer as an u...
the interaction between doctor and patient, to take into account the larger social, structural, and temporal forces that shape diagnosis.

Social diagnosis is ‘social’ for two reasons: Firstly, it connects an illness or the act of diagnosing that illness to a set of political, economic, cultural and social conditions or factors. Secondly, social diagnosis is conducted by different social actors, and the actions of one group of stakeholders often spill over to affect the actions of other actors. Social diagnosis is done by anthropologists and sociologists who study diagnosis, as a way for researchers of social medicine and the social determinants of health to look at the process, outcomes, and consequences of diagnosis. It is also done by the lay public vis-à-vis social movements that expand what goes into the diagnosing process. In this more comprehensive, public version of uncovering the social determinants of health, a condition is diagnosed by a social group. The awareness of diagnosis with respect to gender is given in Table 7.12.

**Table 7.12: Awareness of diagnosis with respect to gender**

<table>
<thead>
<tr>
<th>Awareness of diagnosis</th>
<th>Gender</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>Aware</td>
<td>79 (70.5)</td>
<td>51 (43.2)</td>
</tr>
<tr>
<td>Unaware</td>
<td>33 (29.5)</td>
<td>67 (56.8)</td>
</tr>
<tr>
<td>Total</td>
<td>112 (100)</td>
<td>118 (100)</td>
</tr>
</tbody>
</table>

p = .001
* Percentages in parentheses

It is clear from Table 7.12 that a majority of cancer patients (56.5 per cent) were aware of their diagnosis. The awareness regarding diagnosis was more among males (70.5 per cent) than females (43.2 per cent). Among males, a majority (70.5 per cent) were aware and other 29.5 per cent were unaware of their diagnosis. Among females, a majority (56.8 per cent were unaware) and other 43.2 per cent were aware. There were highly significant differences in awareness of diagnosis with respect to gender.

The awareness of diagnosis with respect to age is given in Table 7.13.
Table 7.13: Awareness of diagnosis with respect to age

<table>
<thead>
<tr>
<th>Age group (in years)</th>
<th>Awareness of diagnosis</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Aware</td>
<td>Unaware</td>
</tr>
<tr>
<td>21-30</td>
<td>21 (16.2)</td>
<td>10 (10.0)</td>
</tr>
<tr>
<td>31-40</td>
<td>39 (30.0)</td>
<td>18 (18.0)</td>
</tr>
<tr>
<td>41-50</td>
<td>29 (22.3)</td>
<td>24 (24.0)</td>
</tr>
<tr>
<td>51-60</td>
<td>23 (17.7)</td>
<td>21 (21.0)</td>
</tr>
<tr>
<td>61-70</td>
<td>12 (9.2)</td>
<td>19 (19.0)</td>
</tr>
<tr>
<td>71-80</td>
<td>6 (4.6)</td>
<td>8 (8.0)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>130 (100)</strong></td>
<td><strong>100 (100)</strong></td>
</tr>
</tbody>
</table>

p = .066
* Percentages in parenthesis

The majority of respondents who were aware were in the age group 31-40 years and the minimum percentage of respondents who were aware were in the age group 71-80 years. There were non-significant differences in awareness of diagnosis with respect to age.

The awareness of diagnosis with respect to type of treatment is given in Table 7.14.

Table 7.14: Awareness of diagnosis with respect to type of treatment

<table>
<thead>
<tr>
<th>Awareness of diagnosis</th>
<th>Type of treatment</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Active treatment</td>
<td>Symptomatic treatment</td>
</tr>
<tr>
<td>Aware</td>
<td>120 (60.0)</td>
<td>10 (33.3)</td>
</tr>
<tr>
<td>Unaware</td>
<td>80 (40.0)</td>
<td>20 (66.7)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>200 (100)</strong></td>
<td><strong>30 (100)</strong></td>
</tr>
</tbody>
</table>

p = .006
* Percentages in parentheses
The Table 7.14 shows that the awareness of diagnosis is affected by the type of treatment received by the respondents. The 60 per cent of respondents who were receiving active treatment were aware as compared to only 33.3 per cent of respondents receiving symptomatic treatment. The level of unawareness was high among the patients receiving symptomatic treatment (66.7 per cent) as compared to 40 per cent among the respondents receiving active treatment. The differences between awareness of diagnosis with respect to type of treatment were found to be highly significant.

The Table 7.15 shows the awareness of diagnosis with respect to type of cancer.

**Table 7.15: Awareness of diagnosis with respect to type of cancer**

<table>
<thead>
<tr>
<th>Awareness of diagnosis</th>
<th>Gall bladder cancer</th>
<th>Oral cancer</th>
<th>Breast cancer</th>
<th>Cancer of cervix</th>
<th>Prostate cancer</th>
<th>Primary unknown with metastasis</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aware</td>
<td>31 (49.2)</td>
<td>47 (81.0)</td>
<td>22 (48.9)</td>
<td>17 (44.7)</td>
<td>10 (62.5)</td>
<td>3 (30.0)</td>
<td>130 (56.5)</td>
</tr>
<tr>
<td>Unaware</td>
<td>32 (50.8)</td>
<td>11 (19.0)</td>
<td>23 (51.1)</td>
<td>21 (55.3)</td>
<td>6 (37.5)</td>
<td>7 (70.0)</td>
<td>100 (43.5)</td>
</tr>
<tr>
<td>Total</td>
<td>63 (100)</td>
<td>58 (100)</td>
<td>45 (100)</td>
<td>38 (100)</td>
<td>16 (100)</td>
<td>10 (100)</td>
<td>230 (100)</td>
</tr>
</tbody>
</table>

p = <.001
* Percentages in parentheses

The differences in awareness of diagnosis with respect to type of cancer were found to be highly significant. The respondents with oral cancers were most aware about cancer while the respondents with cancer primary unknown with metastasis were least aware.
It is important to note that there were differences in description of diagnosis by the patients but doctors use the same objective criteria as guidelines to explain the diagnosis. Thus, from the perspective of patients, it is important to understand the ways in which diagnosis is described and lived (Helman, 2001). Some of the cases in relation to opinion of diagnosis are discussed in this section.

**Case 1:** A female respondent (aged 38 years, Jatt Sikh, completed her education upto graduation, housewife, suffering from cancer of cervix, village Sherewala, District Sri Muktsar Sahib) narrated:

"Mainu tan kade bukhār wī nahi chareyā sī, ainī wadī bīmaṛī kive bangāl, bas pani paindā sī"
(I never suffer even of fever, how such a big disease developed? Only watery fluid was discharged from vagina).

**Case 2:** A female respondent (aged 40 years, Majhabi Sikh, completed her primary education, agricultural labourer, suffering from breast cancer in post-operative stage, village Machaki Kalan, District Faridkot) told that her family members were shocked at the diagnosis but they all stood by each other and decided to carry forward her treatment. This provided her courage and her faith in God helped her immensely during the whole treatment process.

Here, both the social support of the family and faith in God helped the respondent during the diagnosis and later on during the process of treatment.

**Case 3:** A female respondent (aged 72 years, Jatt Sikh, illiterate, housewife, suffering from cancer primary unknown with bone metastasis, village Chandbaja, District Faridkot) mentioned that she did not accept for sometime that she is suffering from a *chandari bīmaṛī* (dreaded disease) such as cancer. She told that she used to read the stories of death and suffering of cancer patients in and around her village in newspapers but never ever imagined that she could also suffer the same way. At the time of
diagnosis, she instantly related herself to the suffering of those cancer patients and started feeling that her end is near but she told that her three sons and daughters-in-law provided her ample emotional and financial support that led her decide to carry forward her treatment.

**Case 4:** A male respondent (aged 70 years, Jatt Sikh, illiterate, farmer, suffering from cancer of tongue, village Machaki Kalan, District Faridkot) was aware about cancer beforehand as he has seen a number of cancer deaths in his family. So, on being diagnosed with cancer, he gathered courage and decided to carry forward his treatment as he did not want to die like his younger brother (who also died of cancer due to delay in treatment).

In this case awareness about cancer deaths that occurred due to delay in treatment led to respondent to be courageous and undergo proper treatment.

**Case 5:** A male respondent (aged 61 years, Jatt Sikh, completed his education upto senior secondary, farmer, suffering from cancer of tongue, village Machaki Kalan, District Faridkot) shared that his family did not tell him about the diagnosis of the disease but once he heard his son talking to the doctor about his surgery. He then decides to take treatment decisions for himself and told his family to take him to Acharya Tulsi Regional Cancer Institute and Research Centre, Bikaner (Rajasthan) for his treatment where the treatment is cheaper and success rate of treatment is high as compared to other hospitals in Punjab.

This case is an example of how a patient can be involved in the decision-making process by communicating the diagnosis of cancer. Thus, knowing about diagnosis and prognosis is very important to make the treatment process more effective. From the analysis of responses of respondents, the themes like shock and disbelief, gathering courage and role
in decision making emerged. The diagnosis with cancer gives rise to a variety of information needs.

The initial response of an individual diagnosed with cancer was found to be that of disbelief, a feeling of numbness. The next stage was that of anxiety and depression. The patients were preoccupied with the implications of the illness, thoughts about the future and sense of helplessness. As a result, re-adjustments and re-allocation of roles takes place, which again could prove to be successful, especially if members have started identifying with their newly assigned roles. This, re-adjustments does not just stop at the home front. The studies further mention that one of the most critical impact or concern of cancer is the acute psychological distress as the patient confronts the implications of cancer: lack of social support, possible death, anxiety, depression, dependence on others, disability, disfiguring changes in the body and loss of function. Kleinman (1980) presented the conceptualisation of illness and disease as socially constructed patterns of thought that provide answers to questions about health as etiology, symptoms, cause, course and treatment. Health, thus, is articulated within the context that embodies a web of social and cultural elements that gives meanings to the health issues.

Prognosis is forecast of the probable course and outcome of a disease. The awareness of the respondents regarding prognosis with respect to gender is given in Table 7.16.

<table>
<thead>
<tr>
<th>Awareness of prognosis</th>
<th>Gender</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>Aware</td>
<td>18 (16.1)</td>
<td>8 (6.8)</td>
</tr>
<tr>
<td>Unaware</td>
<td>94 (83.9)</td>
<td>110 (93.2)</td>
</tr>
<tr>
<td>Total</td>
<td>112 (100)</td>
<td>118 (100)</td>
</tr>
</tbody>
</table>

p = .026
* Percentages in parentheses

It is clear from Table 7.16 that a majority of cancer patients (88.7 per cent) were unaware of their prognosis and only 11.3 per cent were aware. The awareness regarding prognosis was low among both males and females but
males (16.1 per cent) have more awareness as compared to females (6.8 per cent). There were significant differences in awareness of prognosis with respect to gender.

The Table 7.17 shows the awareness of prognosis with respect to age.

**Table 7.17: Awareness of prognosis with respect to age**

<table>
<thead>
<tr>
<th>Age group (in years)</th>
<th>Awareness of diagnosis</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Aware</td>
<td>Unaware</td>
</tr>
<tr>
<td>21-30</td>
<td>8 (30.8)</td>
<td>23 (11.3)</td>
</tr>
<tr>
<td>31-40</td>
<td>11 (42.3)</td>
<td>46 (22.5)</td>
</tr>
<tr>
<td>41-50</td>
<td>5 (19.2)</td>
<td>48 (23.5)</td>
</tr>
<tr>
<td>51-60</td>
<td>2 (7.7)</td>
<td>42 (20.6)</td>
</tr>
<tr>
<td>61-70</td>
<td>-</td>
<td>31 (15.2)</td>
</tr>
<tr>
<td>71-80</td>
<td>-</td>
<td>14 (6.9)</td>
</tr>
<tr>
<td>Total</td>
<td>26 (100)</td>
<td>204 (100)</td>
</tr>
</tbody>
</table>

p = .003
* Percentages in parenthesis

It is clear from the Table 7.17 that the majority of respondents who were aware about their cancer prognosis were in the age groups from 31-50 years. The majority of respondents who were unaware about their cancer prognosis were in age group 71-80 years. There were highly significant differences in awareness of prognosis with respect to age.

The Table 7.18 deals with the awareness of prognosis with respect to type of treatment.

**Table 7.18: Awareness of prognosis with respect to type of treatment**

<table>
<thead>
<tr>
<th>Awareness of prognosis</th>
<th>Type of treatment</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Active treatment</td>
<td>Symptomatic treatment</td>
</tr>
<tr>
<td>Aware</td>
<td>22 (11.0)</td>
<td>4 (13.3)</td>
</tr>
<tr>
<td>Unaware</td>
<td>178 (89.0)</td>
<td>26 (86.7)</td>
</tr>
<tr>
<td>Total</td>
<td>200 (100)</td>
<td>30 (100)</td>
</tr>
</tbody>
</table>

p = .756
* Percentages in parentheses
The Table 7.18 shows that the awareness of prognosis was higher among the respondents receiving symptomatic treatment (13.3 per cent) as compared to respondents receiving active treatment (11.0 per cent). The reason for higher awareness of prognosis among respondents receiving the symptomatic treatment was that they understand that they are not receiving any kind of active treatment like chemotherapy, radiotherapy or surgery and are only given medication to reduce their symptom burden and suffering. A number of respondents who were not even told by their family members or doctors about their prognosis agreed that from their symptoms, their suffering and the kind of treatment they are receiving, they understand that the stage of their disease is advanced and they are left with a very less time. There were non-significant differences in awareness of prognosis with respect to type of treatment.

The Table 7.19 shows the awareness of prognosis with respect to type of cancer.

**Table 7.19: Awareness of prognosis with respect to type of cancer**

<table>
<thead>
<tr>
<th>Awareness of diagnosis</th>
<th>Type of cancer</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Gall bladder cancer</td>
<td>Oral cancer</td>
</tr>
<tr>
<td><strong>Aware</strong></td>
<td>10 (15.8)</td>
<td>9 (15.5)</td>
</tr>
<tr>
<td><strong>Unaware</strong></td>
<td>53 (84.2)</td>
<td>49 (84.5)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>63 (100)</td>
<td>58 (100)</td>
</tr>
</tbody>
</table>

p = .152
* Percentages in parentheses
The Table 7.19 shows that the majority of the respondents were unaware about their prognosis. In comparison to types of cancer, awareness of prognosis was more among gall bladder and oral cancer patients and least among the cancer of cervix patients. There were non-significant differences in awareness of prognosis with respect to type of cancer. The studies by Blackhall et al. (1995), and Carrese and Rhodes (1995) and Blackhall et al. (1995) support the findings of present study that majority of respondents were unaware of their cancer prognosis.

It is still a debate, whether a patient should be told about the cancer prognosis or not. Recent research challenges the ethical appropriateness of telling all cancer patients their prognosis (Blackhall et al., 1995). Critics contend that the prevailing model of informed consent in some circumstances may be culturally insensitive (Blackhall et al., 1995; Carrese and Rhodes, 1995) and indiscriminate disclosure may undermine patient autonomy by depriving patients of the choice to remain unaware of the truth of their condition (Blackhall et al., 1995).

The reason for not telling the patient about prognosis includes fear that the patient will lose hope and it will be difficult for patient to bear the news of cancer diagnosis. Cancer is highly prevalent in the field area and people consider it to be a common but chronic disease. There reasons why a patient is not told about cancer prognosis are as follows:

Firstly, it is the belief that the patient will not be able to bear the shock and he/she will be depressed, hopeless and social isolated.

Secondly, it is also feared that a patient may refuse treatment knowing that disease is not curable or in order to save the financial resources and efforts of the family.

7.2.3.1 Reasons for downplaying symptoms and late diagnosis: The making of symptoms is a complex activity involving individual cognitive processes and negotiations with oneself, caregivers and the health care professionals. The construction of symptoms as possible signs of cancer was
not always straightforward rather the respondents tried to downplay the symptoms. The social context played a very important role in naming and assigning meanings to the changes which the respondents recognised in their bodies. Some of the cases relating to downplaying symptoms and late diagnosis are as follows.

**Case 6:** A female respondent (aged 54 years, Jatt Sikh, completed her education up to matric, housewife, suffering from breast cancer, village Malkana, District Bathinda) was diagnosed with breast cancer in an advanced stage told that she ignored the ‘tikhī pīr’ (shooting pain) and ‘gath’ (lump) she experienced in her breast. She admitted thinking that it could be cancer but as a deeply religious woman she believed that cancer is caused due to bad *karmā* and she did not want to “believe it” and tried to “think it was something else”. She appeared to draw on her strong belief as a devout Sikh as well as a good person that she would be protected from serious diseases, such as cancer, and downplayed the possibility of cancer.

In this case, the respondent tried not to believe that her symptoms are due to cancer as she believed that diseases like cancer are caused due to bad *karmā* and as said earlier being a deeply religious women, she downplayed the symptoms.

**Case 7:** A female respondent (aged 44 years, Majhabi Sikh, illiterate, working as a domestic help, suffering from advanced breast cancer, village Bhagsar, District Sri Muktsar Sahib) was undergoing symptomatic treatment at Postgraduate Institute of Medical Education and Research, Chandigarh. She shared that it was her efforts to protect her family from worry and maintain family honour that she downplayed her symptoms. When she told her husband and mother-in-law about the symptoms, it was already too late and she was diagnosed with advanced cancer later on.
It can be summarised from the case that life of a woman is deeply integrated into family spheres. Thus, women sometimes try to hide symptoms in order to save their family from ‘chinta’ (worry).

Case 8: A male respondent (aged 56 years, husband of 52 years old advanced breast cancer patient from village Husnar, District Sri Muktsar Sahib) shared that it was seven years back, when his wife first noticed lump in her right breast. She shared this symptom with him and he immediately told her to visit a gynaecologist but she ignored. In the past seven years, she never complained about the lump or pain in the lump or whether it was increasing or decreasing. Suddenly in April 2011, she told only when she was not able to bear the lump in her right breast and the right arm. Her husband and her sons took her immediately to Guru Gobind Singh Medical College, Faridkot from where she was referred to PGIMER, Chandigarh for palliative care after confirmation of her advanced stage.

Sometimes the women are so much focussed to fulfill their gender roles that they tend to ignore their health problems and advice of their ‘significant others’. The above cited is such an example.

Case 9: A female respondent (aged 44 years, Jatt Sikh, completed her education upto matric, housewife, suffering from breast cancer, village Doda, District Sri Muktsar Sahib) was undergoing active treatment at Bikaner. She shared her experience of noticing lump in her breast as:

"Mai kise nu dasayā nahī, apne āp nū bahūt majbūt kittā, andro tan bahūt darī hō fī"  
(I did not tell anyone, made myself strong but I was scared from inside).

She hides the symptoms from her family till the time pain became unbearable for her. On asking about the reason why she did not share her symptoms with the family, she told that she is a woman, she has a whole family to take care of her and
if she would discuss her small problems with the family, life would be difficult for them. She explained that her role as a woman is to provide them good life and not to make their life worse.

It was found that a number of respondents tried to be strong so as to save their families from unnecessary worry and hide their symptoms from them. Especially, for the women, families are centre of their lives and women's roles, and responsibilities revolve around their family. The female respondents agreed that the family unit not only provide a sense of identity but also social, economic and emotional support.

Case 10: A female respondent (aged 36 years, Jatt Sikh, completed her education upto graduation, housewife, suffering from breast cancer with metastasis in bones, village Maur Mandi, District Bathinda) was undergoing symptomatic treatment at PGIMER, Chandigarh. She told that one day her father-in-law was reading a Punjabi newspaper and told her about the increase in breast cancer cases in Bathinda region. Her mother-in-law who was sitting close told her that any lump painful or painless could be dangerous and may lead to breast cancer. Then, she discussed with them about hard mass in her left breast which she did not reveal earlier as she considered it to be normal. Her mother-in-law took her to a gynaecologist in Faridkot who referred her to PGIMER, Chandigarh for further examination. They went to Department of Medicine where the medical examination confirmed cancer. Then she was referred to Department of Radiotherapy. Her left breast was removed and after the surgery, radiotherapy was given. After the treatment, her condition improved, she visited many desi healers (quacks) in Bathinda. At the time of interview, she had metastasis in bones and she was undergoing chemotherapy again at PGIMER, Chandigarh.
The findings suggest that female cancer patients were concerned about their health and their family members played an integral role in supporting prompt evaluation of cancer symptoms. The other source of information includes the mass media. In the above stated case, it is clear that mass media in the form of print media played an important role in cancer diagnosis.

A doctor (GGS Medical College, Faridkot) expressed that early diagnosis is very important in cancer and the key to early diagnosis is prior awareness of the disease. He mentioned, “what mind does not know we do not see”. The reason why most of the respondents did not seek medical help when they first experienced cancer symptoms especially in case of symptoms related to breast cancer is that the breast changes such as lumps in breast or shooting pain are normal. The respondents referred these changes as ‘common lumps’ or ‘milk lumps’ or related these to injury or muscle pain. Most of the women used the ‘wait and see’ approach. The other reason for downplaying symptoms is that women feel that breast and gynaecological issues are too personal to be shared. This also leads to delay in the treatment. The other important causes for late diagnosis include belief in karma, fear of cancer, belief that diagnosis with cancer would ruin the family honour and lead to inability to fulfill the gender roles. The influence of role expectations especially among the women also seems to hinder open discussion of cancer symptoms and delay in the treatment subsequently.

Interestingly, as the respondents reflected on their symptom experiences, almost all mentioned the need for more information and open communication between the patients, caregivers and health care providers.

7.2.3.2 Information-seeking after the diagnosis with cancer: Information is the communication or reception of knowledge or intelligence, concerned or related to a particular fact or circumstance; it can come from study, facts or data. A need is described as the patients expressed desire for information, or a lack of something requested (O'Leary et al., 2007). Any information is beneficial only when it corresponds to a need. “When put together, information needs are understood as a natural occurrence spurred on by a major life event, assisting the individual to cope” (Timmins, 2006). The information
needs have also been associated with patients' health and well-being, as it has been associated with decision-making, good adherence to recommended treatment and patient satisfaction (Kessels, 2003). Furthermore, it is well documented that openness in communication and access to information about aspects of diagnosis, prognosis, and treatment have been found to be beneficial upon patient outcomes such as satisfaction with communication, understanding and recall, emotional well-being, enhanced coping, and even functional adjustment.

A diagnosis of cancer is a stressful life experience. The nature of the disease requires patients to learn about the illness, make difficult decisions regarding the ensuing treatment, and cope with the consequences of the illness. It has been found that having relevant information not only helps patients to understand the disease but also facilitates patients' decision-making and coping (Cassileth et al., 1980; Iconomou et al., 2002). Providing cancer patients with adequate treatment information is important for patients' health, well-being and satisfaction. It is extremely important for cancer patients as they move through the illness trajectory (Ankem, 2006). Thus, it is vital for patients in overcoming cancer and making decisions about their treatment plans.

The information needs of cancer patients vary considerably across individuals. The cancer patients desire different types and amounts of information depending on their type of cancer, the extent of disease progression, and their unique personal life circumstances (Hack et al., 1994). Graydon et al. (1997) have postulated five categories for information needs among cancer patients as nature of disease, its process and prognosis; cancer treatments; investigative tests; restoration and maintenance of physical health; patient's or family's psychosocial concerns. Degner et al. (1997) developed nine categories of information needs among cancer patients such as spread of the disease; likelihood of cure; treatment options; side-effects of treatment; effect on family and friends; risk of disease to family; impact on work, daily activities, and social life; self-care issues; and sexual concerns.
This section of the present study is based on the observations made on the conversations between doctors and the patients, and is divided into two sub-sections namely information related to diagnosis and information related to prognosis.

(A) **Information related to diagnosis:** A patient suffering from a terminal illness like cancer undergoes the darkest days of life with realisation that the life is not easy. The diagnosis of cancer creates a crisis that requires the patients to adapt quickly to the catastrophic news. It changes his or her perspective and makes him or her to confront death. Acceptance of cancer involves the recognition of reality and initiation of strategy for coping with the challenge (Lala, 1999). Thus, the most important information need relate to the diagnosis of cancer. The following questions are frequently asked by the cancer patients relating to the diagnosis.

- What is the disease am I suffering from? (in case, diagnosis is not clear to the patient)
- What are the causes of this disease?
- What foods should be taken and what should be avoided?
- How this disease does spread?
- Does it spread from one person to the other?
- Is there any risk of other family members getting the disease?
- Is it hereditary? etc.

(i) **Treatment related information:** The initial diagnosis of cancer brings with it the possibility of death and the possibility may continue to be present throughout the therapy, remission and even following the pronouncement of the cure (Martin, 1982). Thus, the patients undergoing treatment ask questions related to their treatment from their doctor who broadly covers the treatment options, duration of treatment, side-effects of treatment, etc.

(ii) **Treatment options:** The respondents ask questions relating to treatment options available and the chances of cure. The other aspect of treatment options is the duration and cost of treatment. Both the patient and the family face a financial burden that may influence their decisions for carrying out their further treatment of the patient.
One of the respondents described the financial difficulties her family faced as a result of disease as:

“Eh bimar rab ohnu hi deve jehra ilâja karwâ sake”
(God should give this disease only to those who could afford its treatment).

Case11: Another female respondent (aged 40 years, Ramgarhia Sikh, completed her primary education, working as a domestic help, suffering from cancer of tongue, village Kauni, District Sri Muktsar Sahib) was undergoing active treatment at PGIMER, Chandigarh was diagnosed with cancer in September 2010 discussed about her financial difficulties and expressed:

“Hameshâ paise phad ke laike aunde ha kise na kise ton”
(Every time we borrow money from one or the other).

She also told that she is not able to meet expenses of her stay and travelling to Chandigarh. So, she always discusses her financial difficulties with her doctor who helps her as much as possible.

(iii) Duration of treatment: As the treatment of cancer runs over a long period of time, it leads to information-seeking regarding the duration of the treatment.

How long is the treatment?
Is there any alternate to the treatment which runs over a short period of time or can be taken at home?
What is the success rate of the treatment?
Does the successful completion of treatment assure the survival?
Do we need to undergo such treatment only once or is it required again and again?
If the disease recurs, does it mean the failure or inadequacy of treatment?
(iv) Side-effects of treatment: The other matter of concern regarding the treatment is the side-effects of the treatment. The female respondents inquire about the side-effects of the treatment, the ways of dealing with these side-effects and precautions to be taken during the treatment. Especially the female patients who are undergoing chemotherapy ask a variety of questions relating to the treatment such as:

- Will it lead to complete or partial hair loss?
- Is there any way to avoid the hair loss?
- How will I look?
- How long will hair take to regrow?

These questions give rise to identity issues such as loss of femininity which is often symbolised with hair and loss of religious identity among the Sikh women, the religion in which cutting of hair is a sin. The women attribute the disease and its side-effects to their past karmā, the wrong deeds which they committed in their past. Thus, hiding the hair loss becomes important for three reasons – to maintain the identity as a woman, to maintain identity as a Sikh woman, and to defy the belief that cancer is caused due to bure (bad) karmā.

(B) Information related to prognosis: Open communication in cancer care has gained increasing importance in recent years but there is significant variability in the sharing of prognostic information (Innes and Payne, 2009). The common practice of non-disclosure of prognosis and detailed disease-related information by health care professionals and the family leads to the questions in the minds of the patients such as:

- What is the stage of disease?
- How much has the disease spread?
- Are there chances of cure or survival?
- What will be future course of disease?
- What are the chances of the recurrence of disease? What are the symptoms of recurrence of disease?
In a clinical setting in India, such questions are often not answered to the patients but are answered to the caregiver.

It is observed that death is the persistent spectre for people who have cancer, and for their families. The cancer patients and their families also face time disruption and its appropriation in various ways. In the immediate term, cancer disrupts time and life, awareness of time increases, time is verbalised and reflected. The ideas of time, estimates of survival and life expectancy continue to shadow not only the end-of-life patients but also the survivors.

**Case 12:** A female (aged 40 years) told that when her family told her about diagnosis, she decided to visit the doctor to clear her queries about the disease. She told that doctor answered to all her queries and told:

“Jhorā nā kar, thīk ho jayegi”
(Do not worry, you will be fine).

She expressed that this assurance from the doctor gave her strength to complete her treatment.

Another respondent (female, aged 36 years, suffering from cancer of cervix) told:

“Parmatma to vadī chīz nahi par dactar rabb to utte hai
Dactar ne keha sī dil nā chadi, mai tān chadi bāthi sī”
(There is nothing greater than God but doctors are even greater. The doctor told me not to loose heart, as I lost hope initially).

Some of the respondents quoted the importance of doctor from some of the verses from Śrī Guru Granth Sahib. Some of them are quoted here.

Guru Angad Dev Ji (second Guru of Sikhs) also expounded upon the qualities of a perfect physician. He stated that:

*Rog dāru dōvai bujhai tā vaid sujān II* (SGGS, p. 148)
(If someone understands both the diseases and the medicine, only then he is a wise physician).
Vaidā vaid suvaid tu pehlā rog pehchhan, esa dārū lod lah jīt vanjhe rogā ghān, jīt dāru rog utheah tan sukh vase āe II
(SGGS, p. 1279)
(O physician, you are a competent physician, if you first
diagnose the disease. Prescribe such a remedy by which all
sorts of illnesses may be cured. Administer that medicine, which
will cure the disease, and allow peace to come and dwell in the
body).

One of the respondents (male, aged 49 years, suffering from cancer of
gall bladder) urged his doctor to tell him clearly about prognosis of his disease
as:

“Daṭṭar sāḥib sacho dasdeo, asi aiven nā dvāian te paise kharchī
djāye, māmā tan hai e ek din”
(Doctor tell us the truth, so that we do not waste our money on
medicines, one has to die one day).

It was found in the study that there are some reasons which lead to
lack of communication between doctor and the patient. The reasons for this
lack of communication are age and gender differences between doctor and
the patient, more focus on treatment rather than communication, and
inadequate rapport establishment by the doctor.

7.2.4 Attribution of causes to the cancer and search for meanings

The act of diagnosing an illness is important at multiple levels. It is
about an individual’s relationship to the illness or act of diagnosis, the
collectivity of people who suffer from an illness and the larger social structures
that influence the illness and its diagnosis. In other words, it is about locating
an individual and a group in relation to key social structures. The period
following a cancer diagnosis has been described as a time when concerns
about life and death predominate. However, little is understood about how
persons recently diagnosed with cancer deal with such issues as finding
meaning in their lives, their illness, and their impending death (O’ Connor et
al., 1990). The diagnosis with a chronic disease like cancer leads to the
attribution of causes to the disease and search for meanings behind the
disease. The causes of cancer with respect to gender are given in Table 7.20.
Table 7.20: Causes of cancer with respect to gender

<table>
<thead>
<tr>
<th>Causes of cancer</th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Karmā</td>
<td>44 (39.3)</td>
<td>79 (66.9)</td>
<td>123 (53.5)</td>
</tr>
<tr>
<td>Contamination of</td>
<td>39 (34.8)</td>
<td>9 (7.7)</td>
<td>48 (20.9)</td>
</tr>
<tr>
<td>underground water</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contagion</td>
<td>14 (12.5)</td>
<td>8 (6.8)</td>
<td>22 (9.6)</td>
</tr>
<tr>
<td>Hereditary</td>
<td>4 (3.6)</td>
<td>8 (6.8)</td>
<td>12 (5.2)</td>
</tr>
<tr>
<td>Stress</td>
<td>5 (4.5)</td>
<td>5 (4.2)</td>
<td>10 (4.3)</td>
</tr>
<tr>
<td>Kismat</td>
<td>3 (2.7)</td>
<td>6 (5.1)</td>
<td>9 (3.9)</td>
</tr>
<tr>
<td>Injury</td>
<td>1 (0.9)</td>
<td>1 (0.9)</td>
<td>2 (0.9)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>2 (1.7)</td>
<td>2 (1.6)</td>
<td>4 (1.7)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>112 (100)</td>
<td>118 (100)</td>
<td>230 (100)</td>
</tr>
</tbody>
</table>

* Percentages in parentheses

p = <.001

A majority (53.5 per cent; 39.3 per cent males and 66.9 per cent females) of the respondents believed *karmā* to be the cause of cancer followed by contamination of underground water 20.9 per cent (34.8 per cent males and 7.7 per cent females), contagion 9.6 per cent (12.5 per cent males and 6.8 per cent females), hereditary 5.2 per cent (3.6 per cent males and 6.8 per cent females), stress 4.3 per cent (4.5 per cent males and 4.2 per cent females), *kismat* 3.9 per cent (2.7 per cent males and 5.1 per cent females), injury 0.9 per cent (0.9 per cent males and 0.9 per cent females) and remaining 1.7 per cent of the respondents did not tell any cause of cancer. There were highly significant differences in causes of cancer mentioned by the respondents with respect to gender.

The causes of cancer with respect to type of treatment are given in Table 7.21.
Table 7.21: Causes of cancer with respect to type of treatment

<table>
<thead>
<tr>
<th>Causes of cancer</th>
<th>Type of treatment</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Active treatment</td>
<td>Symptomatic treatment</td>
</tr>
<tr>
<td><strong>Karmā</strong></td>
<td>96 (48.0)</td>
<td>27 (90.0)</td>
</tr>
<tr>
<td>Contamination of underground water</td>
<td>48 (24.0)</td>
<td>-</td>
</tr>
<tr>
<td>Contagion</td>
<td>22 (11.0)</td>
<td>-</td>
</tr>
<tr>
<td>Hereditary</td>
<td>12 (6.0)</td>
<td>-</td>
</tr>
<tr>
<td>Stress</td>
<td>9 (4.5)</td>
<td>1 (3.3)</td>
</tr>
<tr>
<td><strong>Kismat</strong></td>
<td>7 (3.5)</td>
<td>2 (6.7)</td>
</tr>
<tr>
<td>Injury</td>
<td>2 (1.0)</td>
<td>-</td>
</tr>
<tr>
<td>Don’t know</td>
<td>4 (2.0)</td>
<td>-</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>200 (100)</td>
<td>30 (100)</td>
</tr>
</tbody>
</table>

p= .003
* Percentages in parentheses

Among the respondents undergoing active treatment, 48.0 per cent mentioned karmā as a cause of cancer and a minimum percentage (1.0 per cent) mentioned injury as a cause of cancer. Among the respondents undergoing symptomatic treatment, 90.0 per cent mentioned karmā as a cause of cancer while a minimum percentage of respondents (3.3 per cent) mentioned stress as a cause of cancer. There were highly significant differences in causes of cancer mentioned by the respondents with respect to type of treatment received.

7.2.4.1 Karmā: A Sanskrit word from the root ‘Kri’, meaning ‘to do’, karmā literally means ‘that which is done’ or ‘action’, but is also a philosophical doctrine. In simple terms it is the law of cause and effect, the principle that ‘as you sow, so shall you reap’. Every action has a result, and good or bad fortunes is said to be the result of one’s own actions. The word also refers to
the totality of mankind's actions and their concomitant reactions in current and previous lives, all of which determines the future. One of the first and most dramatic illustrations of karma can be found in the “Bhagwad Gita”. Arjuna was preparing for battle when he realised that the enemy consists of members of his own family and decided not to fight. His charioteer, Krishna, explained to him the concept of one’s duty among other things and made him realise that it was his duty to fight. Krishna also specified moral duties and that detachment of one's actions from personal reward changes the quality of one's actions (Rangnekar, 2012).

The concept of karma is linked to the concept of reincarnation, in that the effect of actions can last through several lifetimes. Karma can be modified or changed through right action, and a state beyond the effects of karma is achieved through union with the divine. The karma is understood as that which causes the entire cycle of cause and effect originating in ancient India and treated in Hindu, Jain, Sikh and Buddhist philosophies. As a religious term, karma refers to intentional (usually moral) actions that affect one's fortunes in this life and the next. Karmā is a concept common to Hinduism, Buddhism and Jainism, but interpreted in different ways.

Within Sikhism, all living beings are described as being under the influence of three qualities of maya namely rājas (mode of passion), tāmas (mode of ignorance), and sātāv (mode of goodness). It is due to the influence of three modes of the nature of maya, jīvās (individual beings) perform activities under the control and purview of the eternal time. These activities are called karmā. The underlying principle is that karmā is the law that brings back the results of actions to the person performing them. This is the Gurbāni’s (Sri Guru Granth Sahib) law of karma. Like other Indian as well as oriental school of thoughts, the Gurbāni also accepts the doctrines of karmā and reincarnation as the facts of nature.

In the present study, a number of cancer patients attributed cancer causation to karmā. The respondents were asked whether they tried to search meaning behind the disease and their life. They were also asked to tell any teachings or verses from their religious texts which provide meaning to the
disease. The following verses were described by the respondents in relation to cancer causation and related suffering.

*Karm āvai kaprā nadṛī mokh duār II* (SGGS, p.2)
(By the Karmā of past actions, the robe of this physical body is obtained, by his grace, the gate of liberation is found).

*Jetī sīrath upāī vekhā vin karmā ke mlāī laī* II (SGGS, p.2)
(I gaze upon all the created beings, without the karmā of good actions, what are they going to receive).

*Ketī karam bhūmi mer kete kete dhū updes II* (SGGS, p.7)
(No many worlds and lands for working out karmā, so very many lessons to be learned).

*Karam khand ki bānī jor II* (SGGS, p.8)
(In the realm of karmā, the word is power).

*Jin kao nadar karam tin kār II* (SGGS, p.8)
(Such is the karmā of those upon whom he has cast his glance of grace).

*Ūtam se dar ūtam kahiāhi nich karam bahi roe II* (SGGS, p. 15)
(They alone are good, who are judged good at lord's door. Those with bad karmā can only sit and weep).

*Hukme karam kamāvne paiai kīrat firāo II* (SGGS, p. 66)
(According to the lord's command, people perform their actions, they wander around, driven by the karmā of their past actions).

*Karam dharte sarīr jug antar jo bovai so khāt II* (SGGS, p.78)
(The body is the field of karmā in this age, whatever you plant, you shall harvest).

*Kaun karam kaun nihkarmā kaun so kahai kahāči jī II* (SGGS, p.131)
(Who is subject to karmā, and who is beyond karmā? who chants the name, and inspires others to chant).

*Jehā bijāi so lunī karmā sandrakhet II* (SGGS, p.134)
(As he/she has planted, so does he/she harvest such is the field of karmā).

*Pūre gur ki kār karam kamāiāi II* (SGGS, p.144)
(By the karmā of good actions, some come to serve the perfect Guru).

*Karmā upar nibrai je lochai sakh koe II* (SGGS, p.176)
(According to the karmā of past actions, one's destiny unfolds).
With these verses, the respondents reflected their meanings of their illness. Some of the narratives and cases relating to karma as a cause of cancer are discussed as under:

**Case 13:** A male respondent (aged 31 years, Jatt Sikh, completed his education upto matric, farmer, suffering from cancer of gall bladder, village Jajjal, District Bathinda) told that every individual has to pay for his karma. Wrong deeds of previous birth, disobedience and non-conformance of one’s religion reflect ill effects on one’s present life. He believed that he has been suffering from this disease because he did an evil thing once in his life. On asking the same, he showed reluctance to tell but after sometimes, he narrated the incident.

He shared that at the time when his father distributed his property to himself and his brother, he demanded for the property share which was more fertile and left less fertile land for his brother. He attributed his disease causation to his past deeds which he is repaying as a disease.

**Case 14:** A male respondent (aged 70 years, Jatt Sikh, completed his primary education, farmer, suffering from cancer of gall bladder, village Malkana, District Bathinda) was undergoing treatment at GGS Medical College, Faridkot. He firmly believed in the karma theory. According to him, individual’s karma plays an important role in his/her life. Karma does affect the life of a person. He supported his viewpoint about the causes of the cancer by narrating his own story as follows.

He shared that he got his daughter married to an alcoholic and he was well aware of the fact before wedding of his daughter. His daughter died at an early age in an accident. The accident took place when his daughter’s husband was driving while he was drunk. Thus, he considers himself responsible for his
daughter’s death. He believed that he is repaying for his past wrong deeds.

After the diagnosis with cancer, the cancer patients tried to search meanings behind their cancer diagnosis and attributed causes to cancer. In the above mentioned two cases, the cancer patients mentioned cancer as repayment of their past deeds.

In the present study a total of 53.5 per cent of all respondents attributed cancer causation to karma (Table 7.20). The attribution of cancer to karma by the respondents and search for meaning behind the disease may be termed as “religious purification” which means confession of sins and asking for forgiveness. In their study, Pargament et al. (1988) also confirmed the role of karma in attribution of meanings to the disease.

7.2.4.2 Kismat: As the concept of kismat (fate) is somewhat related to karma, it is discussed here. 3.9 per cent of all respondents (2.7 per cent males and 5.1 per cent females) attributed cancer causation to karma (Table 7.20). Some of the cases related to kismat as a cause of cancer are discussed here.

Case 15: A female respondent (aged 62 years, Jatt Sikh, completed her education upto matric, housewife, suffering from breast cancer, village Kot Shameer, District Bathinda) attributed her disease to kismat and she told that after diagnosis with cancer, her faith in God has become more strong. She drew upon her religious beliefs and accepted the disease as kismat. She took comfort in the belief that God would protect her from the disease.

The narrative of kismat and a lesson from God appeared in some of the cases. In this narrative, the respondents asserted that cancer experience leads to the renewed and enhanced religious faith in God. The respondents drew strength from her religious belief that her kismat is in God’s hands.
Case16: A female respondent (aged 39 years, Jatt Sikh, completed her education up to graduation, housewife, suffering from breast cancer, village Machaki Kalan, District Faridkot) accepted her diagnosis with breast cancer as a part of her kismet and had faith that whatever would happen is in God's hands. With this belief, she underwent her treatment and considers her cancer experience as an important lesson from the God.

Case17: A female respondent (46 years, Majhabi Sikh, completed here education up to middle standard, agricultural labourer, suffering from breast cancer, village Deon, District Bathinda) attributed her breast cancer to her kismet and explained that her fate is in God's hands. She further told that she reassured her husband that she would be fine as she accepted the disease as her fate and believes that she could cure herself through sewa (service of God). She narrated:

"Jo honā oh hoke rehnā"
(Whatever is going to happen is going to happen).

Further, she explained that in Sikhism, pāth (individual prayer), going to Gurdwara (Sikh temple) for communal prayer and sewa are very important. Though her devotion for God and sewa, she could attract God's grace and seek God's protection.

It emerges from these cases that some respondents accepted cancer as their kismet and as a lesson from God. They also believed that their fate is in God's hands and through individual prayers, and service of God, the disease can be cured. Some of the verses from Sri Guru Granth Sahib in relation to kismet are given here.

Akhāra sir sanjog vakhān II (SGGS, p. 4)
(From the word, comes destiny written on one's forehead).

Visriā jinhā nām tinārā hāl kaun II (SGGS, p. 397)
(What shall be the fate of those who forget the nām).
Through a number of cases and narratives, the respondents attributed the cancer causation to their *kismat*.

**7.2.4.3 Contamination of underground water:** In 1950s to 1960s, India was importing food grains to feed its millions. Under drought conditions during 1964-65, India imported 13 million tonnes of food grains. This put a heavy strain on the foreign reserves of the country. Therefore, the country adopted the agricultural policies that promoted food grain production for National Food Security. As a result, 70 million rupees were spent on the development of agriculture in the states of Punjab, Andhra Pradesh, Tamil Nadu, Gujarat, etc., with the Punjab emerging as the forerunner. The hardworking and innovative farmers of Punjab were at the forefront of ushering in green revolution in the 1960s. Thus, Punjab became the hub of agricultural production. During the mid-sixties, the green revolution transformed the state’s agriculture and economy and contributed significantly in making the country self-reliant in food. Whereas the initial increase in production was mainly due to increase in the area under cultivation but a spectacular rise of 18.36 million tonnes in food grain production from the year 1971 to 2005 could be largely attributed to intensive use of inputs like fertilisers, pesticides, insecticides, herbicides, etc (Punjab State Council for Science and Technology, 2007).

Punjab is today battling with the environment-related health problems, including a noticeable rise in cancer cases, pre-mature ageing, kidney ailments and infertility as a result of large scale use of pesticides and fertilisers. The green revolution in Punjab not only led to environmental damage in the form of water contamination (Tirado, 2009) or decreased fertility of soil (Shiva, 1991), contamination of vegetables (Chattopadhyay, 1998; Chahal et al., 1999; Thakur et al., 2008), contamination of food crops (Joia et al., 1978), contamination of human milk (Kalra and Chawla, 1980), contamination of eggs (Aulakh et al., 2005) but also led to dangerous health outcomes like cancer (Dogra, 2007; Sharma, 2008a; Sandhu, 2009a), premature greying of hair (Halder, 2007; Dogra, 2007), reproductive health problems including infertility (Dogra, 2007; IANS, 2007; Sharma, 2008a), DNA damage (Misra, 2008), joint pains (Singh, 2008), asthma and skin diseases (Misra, 2008; Singh, 2008).
A total of 20.9 per cent respondents cited contamination of underground water as a cause of cancer. Among males, 34.8 per cent and among females, 7.7 per cent mentioned it as a cause of cancer (Table 7.20). The respondents also cited the contamination of underground water in Punjab as one of the reasons for cancer.

Case18: A female respondent (aged 40 years, wife of cancer patient who died of multiple myeloma, village Dhoorkot, District Faridkot) shared that the underground water in the District is contaminated and this is the major cause of cancer. That is why, she and her son go for regular check-ups for cancer at a private hospital in Ludhiana at a regular interval of six months after the death of her husband.

Case19: A male respondent (aged 33 years, Jatt Sikh, completed his education upto graduation, farmer, cancer of larynx, village Machaki Kalan, District Faridkot) was not affected by the diagnosis as he told that cancer is such a common disease in the region that anybody could get it. He narrated:

“Malwe ch Kainsar tan 'bukhār te jukhām' wāngu faiyā”
(Cancer has spread like ‘fever and cold’ in Malwa).

One of the cancer patients explained:

“Sab bimar ho rahe ne, sab di sehat kharāb ho rahe hai”
(Everyone is getting ill, everyone’s health is getting deteriorated).

Other expressed that:

“Hun raj ke khā dab ke wāh, Panjab de jimidāran layi sahi nai”
(Now the saying ‘eat to the fullest and till to the fullest’ does not hold true for the landlords of Punjab).

Yet another respondent explained:

“Kainsar bahūt wadi samasyā hai Panjab di”
(Cancer is a big problem of Punjab).

The cases and narratives cited above support the respondent’s attribution of cancer causation to contamination of underground water. The
Contamination of underground water in Punjab is described as a major problem by the respondents.

7.2.4.4 Contagion: Contagion means that cancer spreads from one person to another through direct or indirect contact. A total of 9.6 per cent respondents that contagion is a cause of cancer. These include 12.5 per cent males and 6.8 per cent females (Table 7.20). Some of the cases relating to this belief are discussed here.

Case20: A male respondent (husband of a cancer patient who died of advanced cancer of cervix, aged 33 years, housewife, village Doda, District Sri Muktsar Sahib) told that his wife was diagnosed with advanced cancer when she was pregnant. She was advised to undergo abortion but she did not take into consideration the advice given by doctor. After her pre-mature delivery in seventh month, her treatment was started at PGIMER, Chandigarh but it was already too late. She died after three months of her delivery.

After her death, her husband was worried about the health of child. He asked doctor:

"Mainu bahūt darr lag rehā, eh vi andar si; merā bachhā bahūt sohnā, ki parhez rakhān bachhe nu bachaun layi"  
(I am feeling very scared, the child was in womb, when his mother was suffering from cancer of cervix, my child is very beautiful, what precautions should I take to save the child from disease).

Case21: A female respondent (aged 26 years, Jatt Sikh, completed her education up to matric, housewife, cancer of gall bladder, advanced stage, village Bhagsar, District Sri Muktsar Sahib) told that she was three months pregnant when she was diagnosed with cancer. Her in-laws wanted her to give birth to the child and not to abort the foetus for her treatment. She continued with the pregnancy and at the time of interview she was seven months pregnant. She had some idea about her advanced disease as she could feel something spreading inside
her body. At this time, her only concern was life of her child. She feared that as the child is in her womb and she suffers from cancer which could lead to contagion to her child. She requested her doctor for a premature delivery so as to save the life of her child.

In these cases, the respondents believed that cancer is contagious and associated ‘risk’ with it. In the first case, the caregiver was worried about the health of the child whose mother died of cancer. In another case, the cancer patient was not worried about herself but her unborn child. Some of the respondents described the ways in which cancer can spread from one person to another. These include coming in contact of a cancer patient, sharing food, utensils, toilet, room and clothes with cancer patients.

Some of the cases relating to the ways in which cancer spread are given here.

**Case 22**: A female respondent (aged 43 years, Jatt Sikh, completed her education upto matric, housewife, suffering from cancer of cervix, village Mandwala, District Faridkot) told that she contracted cancer from her mother-in-law as she considered cancer as a contagious disease which can be spread by sharing food, utensils, toilet, room and clothes. For her, coming in contact with a cancer patient and sharing of any of the above mentioned things leads to its spread.

**Case 23**: Another female respondent (aged 40 years, Majhabi Sikh, completed her education upto middle standard, agricultural labourer, suffering from breast cancer, in post-operative stage, village Machaki Kalan, District Faridkot) told that after her diagnosis with cancer, she avoids eating among those who have a cancer patient in their family. She believes that she can again be affected with cancer by sharing food with other cancer patients.
In some cases, people distanced themselves from cancer patients in fear of contracting cancer from them. These cases not only relate to the belief that cancer is considered as a contagious disease but also to the fact that there is a wide-spread stigma associated with cancer.

**Case 24**: A female respondent (aged 55 years, Jatt Sikh, completed her education upto senior secondary, housewife, suffering from breast cancer, in post-operative stage, village Mandwala, District Faridkot) narrated her experience of cancer as:

“Bahar loh kehnde si ke ehda kapra lailea tän sānu hoju bimañ. Kamvāli ne vi aunā chad dittā”

(People used to say that if they would wear my clothes, they would also be afflicted by this disease. My servant also left working at my place due to fear of cancer contagion).

She also believed that cancer is contagious and during her course of treatment she did not allow her children to come near her. During this time, she confined herself to a room and never cooked or shared food with anyone. It was her sister-in-law who supported her during this time and told her not to think about what people say and how they behave with her.

**Case 25**: A female respondent (aged 42 years, Jatt Sikh, completed her education upto matric, cancer primary unknown with metastasis in liver, village Jajjal, District Bathinda) was in advanced stage of cancer. She told that she stays with her brother-in-law’s family whenever she comes to PGIMER, Chandigarh for her treatment. Her brother-in-law had a seven months grandson. Her brother-in-law and his wife clearly told her to stay away from the child but she did not listen to them. After few days of her stay, they told her to stay at some other place as they fear that their grandson would be afflicted by the disease. During her stay, food was given in utensils that were kept and washed separately. She was confined to a separate room where only the servant provides her food and other necessary things.
Due to fear that cancer spreads from one person to another led some of the cancer patients to worry about health of their family members. A case relating to this is given below.

**Case 26:** A female respondent (aged 38 years, Jatt Sikh, completed her education up to graduation, housewife, suffering from cancer of cervix, village Machaki Kalan, District Faridkot) was in advanced stage of cancer. She was undergoing her treatment at GGS Medical College, Faridkot. She shared that she did not allow her daughter to come close to her as she fear that she might be afflicted by the disease. On asking the reason, she replied that cancer is contagious. She narrated her fear as:

"Mainû darr lagda, meñ dhee nu nā hoje"
(I fear that my daughter might get afflicted).

The contagion appeared to be an important cause of cancer according the respondents. The researcher was asked by a key respondent about the reason why she was working on such a disease and this could also lead her to affliction with cancer.

7.2.4.5 Hereditary: Some of the respondents believed that cancer is hereditary and mentioned about their family members or other relatives who suffered from the same disease. A total of 5.2 per cent respondents believed that cancer is hereditary which includes 3.6 per cent males and 6.8 per cent females (Table 7.20). Some of the important cases relating to hereditary as a cause of cancer are mentioned below.

**Case 27:** A female respondent (aged 43 years, Majhabi Sikh, agricultural labourer, suffering from breast cancer in post-operative stage, village Chandbaja, District Faridkot) with family history of breast cancer argued that cancer is hereditary and she got the disease from her paternal aunt. Now, she fears that her daughters would also get the disease from her.

**Case 28:** A female respondent (aged 38 years, wife of a deceased cancer patient) told that her husband and mother-in-
law died due to cancer. His husband's nephew is also suffering from cancer. She argued that as cancer is in their family, she and her sons go to a private hospital in Ludhiana for regular check-ups so as to save their lives from *chandari bimari* (dreaded disease).

A number of cases support the view of respondents that cancer is a hereditary disease. The fact is that cancer is not a hereditary disease in general but the chances of certain type of cancer such as breast cancer increases with occurrence in more than one first-degree relative.

### 7.2.4.6 Stress

Stress has been defined as a particular relationship between a person and the environment that is appraised by the person as taxing or exceeding his/her resources and endangering his/her well-being (Man, 2008). In the present study, a total of 4.3 per cent including 4.5 per cent males and 4.2 per cent female respondents (Table 7.20) mentioned stress to be causative factor of cancer. Some of the important narratives related to stress as a cause of cancer are discussed here.

**Case**

A female respondent (aged 50 years, wife of cancer patients with primary unknown and metastasis in liver, village Dhoorkot, District Faridkot) told that they send their son to Australia for study after selling their land and her husband developed the disease because of the stress he faced after selling his land and sending his son at a distant place. He never told the family about what was he going through and the symptoms of the disease. By the time he went to the doctor, his disease was in its advanced stage. She narrated:

"*Bāhar kade pāp/dukh ni kadyā*"

(He never shared her worries with anyone).

Other narratives which emerged during discussions about causes of cancer are also discussed here. A caregiver of a patient suffering from cancer of cervix mentioned: "*Chintā chitā samān hai*" (Worry is equal to grave) meaning that thinking too much and worrying leads to an early death.
Another caregiver expressed:

“Soch nāl ban jandī hai eh bīmāri”
(This disease develops due to worry).

Thus, above mentioned narratives support the belief of respondents that cancer is caused due to stress. The terms like ‘soch’, ‘chintā’ and ‘fikar’ were used by the respondents to explain stress as a cause of cancer.

The perception regarding causation of cancer among cancer patients varied from karmā, contagion, contamination of underground water, hereditary, kismat and stress. A number of respondents described various verses from Sri Guru Granth Sahib in context of karmā (p. 2, 7, 8, 15, 66, 78, 134, 144, 176, 184) and kismat (p. 4, 394) as a cause of cancer.

7.2.5 Misconceptions regarding causes of cancer

Some of the causative factors of cancer mentioned by respondents are not the actual causes of cancer. They are the misconceptions regarding causes of cancer. It is also important to note that some of the causes of cancer mentioned earlier such as contagion is also misconception as cancer does not spread from one person to another. Some of the important misconceptions relating to cancer are:

- Cancer is a contagious disease.
- Cancer means death. It is incurable.
- Cancer grows faster after surgery or any attempt made to remove the cancerous mass. This makes it incurable.
- Cancer may develop on account of an injury that does not heal.
- Cancer recurs again and again in spite of regular treatment and medication.
- Occurrence of cancer reduces longevity of one's life.
- A mammogram or any other diagnostic test performed to detect cancer and its growth actually leads to its spread.
- Presence of lump in breast means that it is a breast cancer.
- Having a family history of cancer means that one will get it for sure.
Some of the cases relating to misconceptions regarding causes of cancer are given here.

**Case 30:** A male respondent (aged 26 years, Majhabi Sikh, student, village Deon, District Bathinda) was suffering from cancer of gall bladder with traces in chest as well. He was interviewed at GGS Medical College, Faridkot. He told that he was very fit and used to do weight training daily. On asking about the cause of cancer, he told that his disease developed on account of an injury while he was weightlifting at his place. One end of weight hit his chest as he lost control and the disease developed as a result.

**Case 31:** A female respondent (aged 34 years, Majhabi Sikh, completed her education upto matric, agricultural labourer, village Mandwala, District Faridkot) was suffering from cancer of cervix. She told that she never had any disease before but her husband hit her hard in stomach while he was drunk. The next day, she complained of severe pain in the same region to her family and was taken to a private clinic. She was advised to undergo certain medical tests which confirmed the cancer of cervix and her in-laws decided to take her to PGIMER, Chandigarh. At the time of interview, respondent visited PGIMER, Chandigarh for her treatment and she was interviewed there only.

**Case 32:** A female respondent (aged 65 years, Jatt Sikh, completed her education upto matric, housewife, village Husnar, District Sri Muktsar Sahib) was diagnosed with breast cancer in January 2010 and her breast was removed in August 2010. The respondent was interviewed at pain clinic, PGIMER, Chandigarh where she was accompanied by her son. Her son told that her cancer developed because her grandson (5 years old) hurt her on her breast while he was playing with her. This led to continuous pain in her breast and the medical examination revealed cancer.
Case3: A male respondent (aged 40 years, Jatt Sikh, completed his educated up to matric, farmer, primary unknown with bone metastasis, village Bhagsar, District Sri Muktsar Sahib) shared that one day he was watering his fields and was barefoot. Suddenly, a kanda (thorn) hurt his left foot and he started feeling pain in the same foot. Next day, he visited a private hospital and doctor gave him medicine but it did not work. The respondent then went to GGS Medical College, Faridkot where the medical examination revealed the presence of cancer. He expressed that cancer developed due to injury caused by the thorn.

Case34: A female respondent (aged 26 years, Jatt Sikh, student, cancer primary unknown with metastasis, village Deon, District Bathinda) explained that she developed cancer on account of a wrong surgery which she underwent on her right thigh for the removal of a mass at a private hospital in Bathinda. According to her, the mass again developed and much more than what was it before the surgery. This belief is common in the field area that cancer spreads at a faster rate after surgery. Then she went to PGIMER, Chandigarh for her treatment and at present she is registered with pain clinic for palliative care. Her misconception was due to the fact that she was not aware of her disease prognosis.

Thus, a number of misconceptions regarding causes of cancer appeared in the present study. The most frequently cited of these include contagion and injury.

By definition, chronic diseases are long-lasting, often life-long. Because of long-drawn nature of the disease, a person is required to integrate the disease into his/her daily life. The disease becomes a part of an individual's life. The meaning it acquires in a person's life largely depends on factors intrinsic to the disease, such as nature of disease, its severity and spread, as well as a number of intrinsic factors of a person – age, gender, caste, marital status, education, occupation and other socio-cultural factors that affect the belief system related to the disease. The affected person is required to
comprehend the significance of the disease in terms of nature of adjustments that he/she is expected to make to live with the disease. In this section, an attempt has been made to cover the description and the terminology used for cancer, symptoms of cancer, diagnosis of cancer, and attribution of causes to cancer.

7.3 HEALTH-SEEKING BEHAVIOUR OF THE RESPONDENTS

The way people interpret their illness and its treatment, or the meanings of these, has an impact on the way they deal with their illness and its treatment. These meanings further shape actions which are oriented towards illness management behaviour. The understanding of health and illness can vary across different contexts, environments, and cultures. MacLachlan (1997) described that the symptoms of a specific disease can be interpreted differently. What in one culture can be interpreted as illness does not have to be so in another culture, and a given disease can have different meanings in different cultures. He argues that symptoms of a disease can be ‘culture bound’. Helman (2001) argues that ‘both the meaning given to their symptoms, and their emotional response to them, are influenced by their own background and personality, as well as the cultural, social and economic context in which they appear. In other words, two individuals from different cultures or social backgrounds and in different contexts may interpret the same ‘disease’ or symptom in a completely different manner. Moreover, this will affect their subsequent behaviour and the sorts of treatment they will seek out.

As said earlier, perceptions of what constitutes illness, the meaning of a specific illness, and how illness is experienced, vary between cultures. The concept of explanatory models is very useful in exploring the meaning and experience of illness of the persons affected by it. Kleinman’s (1980) explanatory models are an attempt to understand health, illness, and healing in society as a cultural system. All people, when ill, have their own idea about their suffering; they all develop ‘explanatory models’ to understand this suffering. Explanatory models are sets of beliefs or understandings that specify for an illness episode, its cause, time and mode of onset of symptoms, pathophysiology, course of sickness, and treatment. Explanatory models are based on the general beliefs existing in a specific culture, but differ as to how
they are formed and employed to cope with a specific health problem. Thus, the meaning of an illness and its treatment will affect people’s coping strategies in dealing with their illness and its treatment, and consequently their health-seeking and adherence behaviour.

The health-seeking behaviour of any community is a result of knowledge, attitude and practice (KAP) prevalent in that community. The dimensions of KAP act as key determinants of any health-seeking behaviour and are mutually dependent and embedded in the social and cultural milieu of that particular community.

The illness behaviour of the respondents is aimed to understand people’s awareness level; the way they get concerned about it; what treatment strategies they follow; how and why they comply with these treatment strategies; and finally what influence do the socio-cultural factors and socio-economic factors have on these issues. In the context of the present research work, the illness behaviour of cancer patients has been grouped in six major categories.

- Appearance of symptoms
- Diagnosis of symptoms
- Consultation sought from a health care
- Treatment experience
- Outcome of the treatment
- Satisfaction with the treatment

Some of the important cases relating to health-seeking behaviour are as follows:

**Case 35:** A female respondent (aged 40 years, Majhabi Sikh, completed her education upto middle, suffering from breast cancer in post-operative stage, village Machaki Kalan, District Faridkot) did not used the term cancer during her two hour interview which last for two hours. Instead of using the term cancer, she preferred the terms *chandari bîmarî* and *mari bîmarî*. On asking, she revealed that cancer is caused due to
karmā and thus, by using such terms she tries to suppress her guilt feeling of having done something wrong in the past. She was aware about the disease beforehand but never thought that she could also be affected. She believed that it is a contagious disease and she never ate food cooked by a cancer patient or his/her family members but questions how she could get the disease. Even she did not have a family history of cancer. She argued that the cause of cancer is the karmā of the past. She narrated:

“Rabb te bharosā hai, karma karke hoyā te rabb hī thīk karugā” (I trust God, the disease is caused due to karmā and god will cure it).

She explained that a painful lump in the breast with swelling around it appeared as a first symptom. After noticing the lump, she went to a vaid (a traditional healer) named Najar Singh in Maur Mansa (District Bathinda, 7.8 Km from Maur town and 22 Km from Bathinda city). The vaid on examining her told that the lump is cancerous and gave her medicine for one and a half month. He charged her ₹ 1700 for the medicine. Even after consuming the medicine for more than a month, she did not feel any change in the lump. Then, she decided to visit GGS Medical College, Faridkot for her treatment. The doctors at Faridkot hospital suggested her some blood tests and mammography to confirm cancer. After confirmation of the disease, her breast was removed and she was given radiotherapy. She told that her mother offered chādar (green cloth offered at Dargāh) and dabbā (sweets) at a Dargāh (religious place of Muslims) at village Bhagta Bhai Ka (21 Km East from Jaito town in District Bathinda) for her successful treatment. She also send ₹ 1000 as charāwā (offering) for an unknown place in Gujarat where her brother's wife went to pray for her speedy recovery. She also visited her village Gurdwara continuously for 40 days and prayed for her health. She also heard of a traditional healer at
“Pahalwān da dhābā”, an eatery in Jagraon but never visited him. She believed that cancer cannot be cured permanently. At the time of interview, the respondent was in post-operative stage and was not able to do any household work such as cooking, etc. Earlier she was an agricultural labourer but she left her work for her treatment which led to financial constraints for her family.

In this case, the respondents believed that the cause of cancer is the karma and only God can cure the disease. She started her treatment from a traditional healer and moved to biomedicine as the previous medicine did not prove to be useful. During the course of her treatment, her family members and ‘significant others’ kept on praying for her good health.

Case36: A female respondent (aged 72 years, Jatt Sikh, illiterate, housewife, suffering from breast cancer bone metastasis, village Chandbaja, District Faridkot) used the term chandari bimari (dreaded disease) to describe cancer. She was aware of her disease diagnosis and prognosis. She explained about cancer as: “Eh sab to bhairī bimari hai” (this is worst of all illnesses). She explained that underground water contamination is the major cause of cancer in the region. She noticed a painful lump in right breast as the first symptom and then told her daughter-in-law about it. Her daughter-in-law immediately told the respondent's son to take her to a doctor. Her son took her to private hospital in Moga as he was a farmer and due to paucity of time, he chose private hospital over a government hospital. She was diagnosed with breast cancer in the year 2005 and underwent surgery at the same private hospital in Moga. As this hospital lacked radiation facilities, she was taken to a government hospital in Amritsar and finally at PGIMER, Chandigarh. She continued her follow-ups at PGIMER, Chandigarh. Later in 2010, the cancer again metastatised to bones.
Plate 7.2a: Packing cover of medicines provided by D.S. Research Centre, Varanasi

Plate 7.2b: Packing of medicines provided by D.S. Research Centre, Varanasi
She told that she is a mother of three sons and of these; two were not ready to take her responsibility. Her elder son was worried about what villagers would say if she is not treated well. Her son discussed his worry with his relatives and friends. On suggestion from a friend, he went to D.S. Research Centre in Varanasi (Uttar Pradesh) and brought medicine for her (Plates 7.2a and 7.2b shows the packing cover). From October 2010 onwards, she was regularly taking the medicines from this research institute. She explained that now she could sit properly on bed, take bath and help her daughter-in-law in household work while sitting on bed. She narrated:

“Sarā pind kehndā sī ke bachhdī nahi, par hun tān meri sehat thik hai”
(All villagers use to utter that I would not survive but now my health is fine).

The respondent was satisfied with the treatment because her physical presence of patient was not required by the research centre. They send the medicines on monthly basis through post after the patient submit the money in the account of the research centre (Appendix-XI).

The researcher also interviewed the women Sarpanch (village head) of the Chandbaja village. She told the researcher about the first case of cancer back in the 80s in their village when a woman died of cancer of cervix. She mentioned that cancer deaths are common now and she listed 21 names of the cancer patients who died in past five years in the same village.

In this case, the respondent started her treatment from a private hospital due to paucity of time to visit a government hospital but later on moved to PGIMER, Chandigarh as the private hospital lacked the necessary facilities for the treatment of cancer.

**Case37:** A male respondent (aged 33 years, Jatt Sikh, completed his education upto graduation, farmer, suffering from cancer of larynx, village Machaki Kalan, District Faridkot) was
interviewed at his place in village for two hours. She used the term *Bikaner vāli bīmarī* (disease which is treated at Bikaner) to describe cancer. Most of the people do not prefer to use the term cancer instead they used a code word Bikaner. Going to Bikaner is self explanatory to everyone in the region as their affordable respite for cancer treatment is found at Bikaner. The respondent was aware of his cancer diagnosis and prognosis. He belonged to a village with large number of cancer patients as well as cancer deaths in the past. So, he was aware of the places where this disease could be treated and also knew many of the traditional healers as he visited many of these with his relatives who suffered from the same disease. He considered cancer as a non-contagious disease and curable only at early stage. For him, the cancer is caused due to contamination of underground water in the Malwa region. He told that he had a very high fever for more than 15 days and diagnosed with typhoid. The further medical examination led to the confirmation of cancer. He was diagnosed with cancer at a private hospital in Ludhiana, where he was admitted for the treatment of typhoid in 2009. After diagnosis, he was admitted in the same hospital for three months for chemotherapy and the treatment for this time period cost him about ₹ 1,50,000. Later he decided to carry out the complete course of his treatment at Bikaner which spread over the time span of four months followed by follow-ups every six months. The treatment at Bikaner cost him about ₹ 85,000 apart from the train travel by Jammu Tavi express from Faridkot to Bikaner referred in native language as ‘cancer train’. During the course of treatment, he almost lost his voice and the doctors at Bikaner hospital told him to go abroad (U.S.A) for his treatment but he carried out his treatment at the same hospital but also consulted a large number of private practitioners in Faridkot city for the second opinion. On asking about the visit to any traditional healer, he agreed that he and his family visited a traditional healer in village Gaddarkheda for about seven times.
in forty days to complete the course of treatment. He told that healer also had cancer initially but later he got blessed with some miraculous powers to treat other cancer patients. The healer treats only those patients who have not undergone any kind of surgery for cancer; otherwise, treatment is not possible.

At the time of interview, he was in follow-up stage. The respondent chose both biomedical treatment as well as the traditional healing at parallel for his treatment. The reason for the parallel treatment was that he was the only son in the family and responsible for taking care of family land. His survival was a must for the whole family as nobody else in the family was earning. The respondent shared two cancer cases in his family which include his grandmother and father’s brother who also died of cancer.

Here the respondent started his treatment from a private hospital but due to financial constraints, he moved to Bikaner for treatment. According to the respondent, the treatment is more affordable at Bikaner. Along with the biomedical treatment, the respondent and his family also visited traditional healers.

Case38: A male respondent (aged 70 years, Jatt Sikh, completed his education upto matric, farmer, suffering from cancer of larynx, village Machaki Kalan, District Faridkot) was interviewed at his native village for four hours and he preferred the term *mari bimari* instead of cancer. The respondent told that cancer is non-contagious and curable only at early stages. The chances of long term survival for cancer patients are very less as the disease metastases in most of the cases. He explained that he suffered from a severe pain in his neck and chest region for almost two months. He visited a number of private practitioners in Faridkot but he did not get any relief from his pain. A family doctor suggested the patient to be taken to Rajindra Hospital, Patiala as he suspected cancer. It was way
back in the year 1999, when there was no government cancer hospital in the region. He was diagnosed with cancer of larynx and his family continued his treatment at the same hospital for more than six months but the respondent was not satisfied with the treatment as he talked to his fellow patient and felt that the survival rate was very less. He urged his family to take him to PGIMER, Chandigarh as he believed it to be a better place for treatment of cancer with good infrastructure. He carried out his treatment for more than one year (surgery and radiation) followed by follow-ups. In spite of the continuous treatment, the cancer metastasised to face in 2004. Then the family take him again to Rajindra Hospital, Patiala for treatment (radiation) and for the next two months his treatment continued there. The reason for shift again to the previous hospital was that stay at Chandigarh was costly as compared to Patiala but the treatment did not proved fruitful. As a result, family lost hope in biomedical system and decided to shift to another system of medicine. Thus, he and his family visited an ayurvedic doctor in Jagadari (Haryana) and a dhaulā healer in Moga for his treatment. The reason for this shift was failure of biomedicine in case of the respondent and the hope that other systems of medicine might cure the disease. The respondent mentioned that his brother who was a Punjab Roadways employee in Bathinda also died of cancer five years back in 2006.

In this case, on advice of a private doctor, the respondent visited a government hospital in Patiala as there was no cancer hospital in and around Faridkot. The respondent was not satisfied with the treatment and moved to PGIMER, Chandigarh but due to metastasis of disease and costly stay at Chandigarh, the respondent again moved to Patiala. Along with the treatment, a number of traditional healers were also visited.

**Case**39: A male respondent (aged 61 years, Jatt Sikh, completed his education upto matric, farmer, suffering from cancer of
larynx, village Machaki Kalan, District Faridkot) was interviewed at PGIMER, Chandigarh. At the time of interview, patient was in a follow-up stage and completely cured of cancer. He was living a normal life while performing all the daily activities. He mentioned that the symptoms of cancer first appeared in the year 2001 when he felt difficulties in swallowing food. He discussed his symptoms with his family and he was taken to Rajindra Hospital, Patiala where he was diagnosed with cancer. He shared that his family did not tell him about the diagnosis of the disease. They only told him that he needs to be operated immediately but once he overheard his son and nephew talking to doctor about the disease. He immediately refused to get operated as according to him operation lead to spread of cancer. Thus, he persuaded his family members to take him to Bikaner for his further treatment. He mentioned that he was satisfied with the treatment at Bikaner hospital and did not visit any other healer or religious place. On contrary, his wife added that she went to Gurdwara Dabar Sahib, Sri Muktsar Sahib consecutively for five maseya (new moon). This Gurdwara is a principal shrine at Sri Muktsar Sahib is on the western bank of the sarovar (holy bath) and was the earliest to be established by the first few Sikh families who had settled here around 1743. His son added that he got performed akhand path (recital of Guru Granth Sahib without any pauses or breaks) at his village Gurdwara after the doctor assured that the patient would be fine. His son-in-law added that he got performed an akhand path at his native village for his health.

The respondent also mentioned about his mother who died of breast cancer at the age of 70 years and his father’s sister who died of breast cancer at the age of 52 years. He told that in both the cases women preferred visiting traditional healers for their treatment. It was insufficient and improper treatment that led to their death.
As there was government hospital in the region, the respondent was taken to Rajindra Hospital, Patiala but after the diagnosis, he decided to take treatment decisions for himself and told his family to take him to Bikaner for further treatment. In this case, the family members visited a number of Gurdwaras and religious places to pray for health of the respondent.

Case 40: A male respondent (aged 50 years, Jatt Sikh, completed his education up to graduation, farmer, suffering from primary unknown with metastasis in lungs, village Sandhwan, District Faridkot) described cancer as a chandari bīmarī. He was aware of his diagnosis but not the stage of the disease. He told that it was only after his diagnosis that he became aware of cancer which he narrated as:

“Dukh hon to bād hi patā lageya”
(It was only after diagnosis that I came to know about the disease).

He explained that pain in leg appeared as the first symptom. With appearance of the first symptom, he went to a private orthopaedician in Faridkot city. On diagnosis in June 2009, he suggested his family to take him to PGIMER, Chandigarh. In spite of the suggestion, the family took the respondent to a desi healer (quack) in Lehragaga (District Sangrur). He gave desi davaī which gave relief in pain but the further medical examination indicated that the disease has spread further to lungs. Then, the family decided to take the respondent to PGIMER, Chandigarh and the reason for the shift from one medical system to the other was ineffectiveness of the previous system for the patient. The treatment was started from February 2010 onwards. The respondent was given chemotherapy and palliative radiotherapy but his body did not respond much to the treatment. At present, the respondent was in advanced stage of the disease and undergoing only symptomatic treatment at Pain Clinic, Department of Radiotherapy, PGIMER, Chandigarh. At
every step of the treatment, the patient's brother took decisions for him. The patient described his treatment experience as:

“Koshish tān karnī hi hai, ās tān bandā maran tak nī chad dā”
(One has to try, one cannot lose hope till one dies).

In this case, the respondent began his treatment from a private doctor who advised the family to take the patient to PGIMER, Chandigarh but the family took the patient to a traditional healer. The traditional healing did not prove to be useful for the patient and the disease spread further. This led the family to take the patient to PGIMER, Chandigarh.

**Case 41**: A female respondent (aged 28 years, Jatt Sikh, completed her education up to post-graduation, suffering from cancer of gall bladder, village Bhagta Bhai Ka, District Bathinda) explained that she is suffering from chandari bimari. She was aware of her cancer diagnosis and the exact stage of the disease. The pain in abdomen appeared as a first symptom. With appearance of pain in abdomen, her family take her to a private hospital in Ludhiana, where the doctor suggested a surgery to which her family readily agreed but the doctor operated her at wrong place. When the family questioned, the doctor assured that everything is fine with her. The girl got relief in pain after the surgery and the medication. On a subsequent visit, the doctor told the girl about her cancer diagnosis. The girl came back home and did not discussed the diagnosis with anybody. She was engaged at that time and she stopped talking to her fiancé and friends. Later, she also stopped talking to her family members as well. The worried family members take her to Civil Hospital, Faridkot where her medical examination revealed cancer in her gall bladder and the most shocking thing that came to light was that her right kidney was missing. The family wanted to sue the doctor at Ludhiana but her deteriorating condition did not give them much time. Then she was taken to a private hospital at Gurgaon (Haryana) where she was given
chemotherapy and radiation but of no use to her. Then the family decided to take her to their native village. While she was at home, her stomach started stretching (abdominal distension) and after two months of stretching, the stomach burst. A village doctor was called everyday for dressing of the wound and the injectables for pain and other medication was also given by village doctor only.

In this a number of hospital were visited for the treatment but it was too late and ultimately, the family decided to keep the respondent at her native place.

**Case 42:** A male respondent (aged 65 years, Jatt Sikh, completed his education upto graduation, farmer, suffering from cancer primary gall bladder with metastasis in liver, village Mandwala, District Faridkot) told that he suffered from problem of indigestion and his family take her to a large number of private practitioners in Faridkot and he also visited an ayurvedic practitioner in the city. He took the ayurvedic medicine for two months regulary but it did not work for him. In March 2011, the respondent's sister who stays at Mohali decided to take him to PGIMER, Chandigarh. He first visited the Department of Gastroenterology and later on he was referred to Department of Radiotherapy for further treatment after being diagnosed with cancer. The respondent reached at an advanced stage and he was registered for palliative care in pain clinic, PGIMER, Chandigarh. Apart from the regular treatment at PGIMER, Chandigarh, he also underwent treatment at Gracian Hospital, Mohali and Ivy Hospital, Mohali during medical emergencies. The family was asked about the reason why the respondent has not being told about the diagnosis and prognosis of the disease. His sister told that his will power is not strong and he would die much earlier than his destined end. Though the respondent was
illiterate and not aware about the diagnosis of cancer and its prognosis, he described the progression of disease as:

"Mere andar kuchh vadh rehâ, pinnâ jâ"

(Something is growing inside my body, something round in shape).

He told that his family is hiding something from him but he respects their decision as it would be difficult decision for them too.

The respondent started his treatment at a private hospital and also took ayurvedic medicine for sometime. Later on, the respondent moved to PGIMER, Chandigarh but PGIMER, Chandigarh does not provide the admission facilities to the cancer patients for long. They are not admitted for more than a day or so during emergency. The Chandigarh Hospice, which is a joint unit of Red Cross Chandigarh and PGIMER, Chandigarh provides admission facilities but lack the emergency facilities. Thus, in case of emergency, the patient was taken to a number of private hospitals.

**Case 43:** A female respondent (aged 36 years, Majhabi Sikh, completed her primary education, agricultural labourer, suffering from cancer of cervix in advanced stage, village Deon, District Bathinda) told that in early 2011, she faced the problem of pain and bleeding. In April 2011, her husband decided to take her to a private doctor in Faridkot and she was diagnosed with cancer of cervix. The doctor told her husband to take her to a private hospital in Ludhiana. Her husband took her to Ludhiana in early May and her treatment started there. She received three cycles of chemotherapy there but her condition deteriorated and she was referred to PGIMER, Chandigarh. In September 2011, she came to PGIMER, Chandigarh with complaint of severe lower backache and continuous bleeding. She reached PGIMER, Chandigarh in a very advanced stage and she was registered in the pain clinic and started on symptomatic treatment. She told that she did not visit any traditional healer as the course of disease was so rapid that she did not get time but she visited
Baba Farid Gurdwara, Faridkot on three consecutive Thursdays for her well-being. She told that this provided her courage to bear the pain and the suffering related to the disease.

In this case, the treatment of respondent was started at a private hospital but after the condition deteriorated, she was taken to PGIMER, Chandigarh. At the time of interview, she was undergoing symptomatic treatment. She also visited Gurdwara for her well-being.

A number of cases have been mentioned in this section and the various reasons such as ineffectiveness and dissatisfaction of the previous medical system, spread of disease, accessibility and affordability of previous health care services for shift from one medical system to the other are also discussed in detail. The Plates 7.3 and 7.4 shows a respondent in a follow-up stage and a breast cancer patient undergoing treatment respectively.

During the course of fieldwork, the researcher also asked from the respondents regarding the various types of treatment taken by them to cure cancer. The types of treatment taken by the respondents (gender-wise) are given in Table 7.22.

<table>
<thead>
<tr>
<th>Gender</th>
<th>Only biomedical treatment</th>
<th>Both biomedical and alternative treatment</th>
<th>Both biomedical and traditional treatment</th>
<th>Biomedical, alternative and traditional treatment</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>21 (52.5)</td>
<td>12 (80.0)</td>
<td>74 (44.6)</td>
<td>5 (55.6)</td>
<td>112</td>
</tr>
<tr>
<td>Female</td>
<td>19 (47.5)</td>
<td>3 (20.0)</td>
<td>92 (55.4)</td>
<td>4 (44.4)</td>
<td>118</td>
</tr>
<tr>
<td>Total</td>
<td>40 (100)</td>
<td>15 (100)</td>
<td>166 (100)</td>
<td>9 (100)</td>
<td>230</td>
</tr>
</tbody>
</table>

\( p = .060 \)

* Percentages in parenthesis
Plate 7.3: A respondent in a follow-up stage

Plate 7.4: A breast cancer patient undergoing treatment
It is clear from the Table 7.22 that both the majority of male (N=74) and female (N= 92) respondents used both biomedical and traditional treatment. There were non-significant differences in types of treatment taken by respondents with respect to their gender.

The types of treatment taken by respondents with respect to age are given in Table 7.23.

**Table 7.23: Types of treatment taken by respondents with respect to age**

<table>
<thead>
<tr>
<th>Age group (in years)</th>
<th>Only biomedical treatment</th>
<th>Both biomedical and alternative treatment</th>
<th>Both biomedical and traditional treatment</th>
<th>Biomedical, alternative and traditional treatment</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>21-30</td>
<td>10 (25.0)</td>
<td>6 (40.0)</td>
<td>12 (7.2)</td>
<td>3 (33.3)</td>
<td>31 (13.5)</td>
</tr>
<tr>
<td>31-40</td>
<td>6 (15.0)</td>
<td>7 (46.7)</td>
<td>42 (25.3)</td>
<td>2 (22.3)</td>
<td>57 (24.8)</td>
</tr>
<tr>
<td>41-50</td>
<td>14 (35.0)</td>
<td>0 (0)</td>
<td>38 (22.9)</td>
<td>1 (11.1)</td>
<td>53 (23.0)</td>
</tr>
<tr>
<td>51-60</td>
<td>3 (7.5)</td>
<td>2 (13.3)</td>
<td>38 (22.9)</td>
<td>1 (11.1)</td>
<td>44 (19.1)</td>
</tr>
<tr>
<td>61-70</td>
<td>4 (10.0)</td>
<td>0 (0)</td>
<td>26 (15.7)</td>
<td>1 (11.1)</td>
<td>31 (13.5)</td>
</tr>
<tr>
<td>71-80</td>
<td>3 (7.5)</td>
<td>0 (0)</td>
<td>10 (6.0)</td>
<td>1 (11.1)</td>
<td>14 (6.1)</td>
</tr>
<tr>
<td>Total</td>
<td>40 (100)</td>
<td>15 (100)</td>
<td>166 (100)</td>
<td>9 (100)</td>
<td>230 (100)</td>
</tr>
</tbody>
</table>

p=.001  
* Percentages in parenthesis

Among types of treatment taken by respondents, only biomedical treatment was used by the majority of respondents in age group 41-50 years (35.0 per cent). Both biomedical and alternative treatments were used by the majority of respondents in age group 31-40 years (46.7 per cent). Both biomedical and traditional treatments were used by the majority of respondents in age group 31-40 years (25.3 per cent). All the biomedical, alternative and traditional treatments were used by the majority of respondents in age group 21-30 years (33.3 per cent). There were highly
significant differences in types of treatment taken by respondents with respect to their age.

The Table 7.24 deals with the types of treatment taken by respondents with respect to their marital status.

**Table 7.24: Types of treatment taken by respondents with respect to their marital status**

<table>
<thead>
<tr>
<th>Marital status</th>
<th>Types of treatment</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Only biomedical treatment</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Both biomedical and alternative treatment</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Both biomedical and traditional treatment</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Biomedical, alternative and traditional treatment</td>
<td></td>
</tr>
<tr>
<td>Unmarried</td>
<td>1 (2.5)</td>
<td>1 (6.7)</td>
</tr>
<tr>
<td></td>
<td>1 (6.7)</td>
<td>4 (2.4)</td>
</tr>
<tr>
<td></td>
<td>2 (22.2)</td>
<td>8 (3.5)</td>
</tr>
<tr>
<td>Married</td>
<td>35 (87.5)</td>
<td>14 (93.3)</td>
</tr>
<tr>
<td></td>
<td>146 (88.0)</td>
<td>7 (77.8)</td>
</tr>
<tr>
<td></td>
<td>202 (87.8)</td>
<td></td>
</tr>
<tr>
<td>Others</td>
<td>4 (10.0)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>-</td>
<td>16 (9.6)</td>
</tr>
<tr>
<td></td>
<td>-</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>20 (8.7)</td>
</tr>
<tr>
<td>Total</td>
<td>40 (100)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>15 (100)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>166 (100)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>9 (100)</td>
<td>230 (100)</td>
</tr>
</tbody>
</table>

*p = .048

* Percentages in parenthesis

It is clear from the Table 7.24 that the only biomedical treatment was used by the majority of married respondents (87.5 per cent) and least used by unmarried respondents (2.5 per cent). Both biomedical and alternative treatment were also used by the majority of married respondents (93.3 per cent) and not used at all by other respondents (separated, widowed and widowers). Both biomedical and traditional treatments were used by the majority of married respondents (88 per cent) and least used by unmarried respondents (2.4 per cent). Similarly, all the biomedical, alternative and traditional treatment were used by the majority of married respondents (77.8
per cent) and not used at all by other respondents. There were significant
differences in types of treatment taken by respondents with respect to their
marital status.

The Table 7.25 deals with types of treatment taken by respondents with respect to their educational status.

Table 7.25: Types of treatment taken by respondents with respect to their educational status

<table>
<thead>
<tr>
<th>Education</th>
<th>Only biomedical treatment</th>
<th>Both biomedical and alternative treatment</th>
<th>Both biomedical and traditional treatment</th>
<th>Biomedical, alternative and traditional treatment</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Illiterate</td>
<td>3 (7.5)</td>
<td>1 (6.7)</td>
<td>15 (9.0)</td>
<td>1 (11.1)</td>
<td>20 (8.7)</td>
</tr>
<tr>
<td>Upto middle</td>
<td>7 (17.5)</td>
<td>3 (20.0)</td>
<td>25 (15.1)</td>
<td>1 (11.1)</td>
<td>36 (15.7)</td>
</tr>
<tr>
<td>Upto senior secondary</td>
<td>19 (47.5)</td>
<td>7 (46.6)</td>
<td>74 (44.6)</td>
<td>5 (55.6)</td>
<td>105 (45.6)</td>
</tr>
<tr>
<td>Graduation and above</td>
<td>11 (27.5)</td>
<td>4 (26.7)</td>
<td>52 (31.3)</td>
<td>2 (22.2)</td>
<td>69 (30.0)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>40 (100)</strong></td>
<td><strong>15 (100)</strong></td>
<td><strong>166 (100)</strong></td>
<td><strong>9 (100)</strong></td>
<td><strong>230 (100)</strong></td>
</tr>
</tbody>
</table>

p = .998
* Percentages in parenthesis

It is clear from Table 7.25 that only biomedical treatment was used by the majority of respondents educated upto senior secondary (47.5 per cent). Both biomedical and alternative treatments were also used by the majority of respondents educated upto secondary (46.6 per cent). Similarly both biomedical and traditional treatments and all the biomedical, alternative and traditional treatments were used by the majority of respondents educated upto
senior secondary (44.6 per cent and 55.6 per cent respectively). In each medical system used by the respondents, similar patterns were followed by the respondents based on their educational status. Thus, there were non-significant differences in types of treatment taken by respondents with respect to their educational status.

7.3.1 Factors affecting health-seeking behaviour of the respondents

The factors that are important in the decision making for health-seeking behaviour after the diagnosis are the extent of curability, influence of social group, availability of alternative and traditional healing, socio-economic factor and confidentiality.

7.3.1.1 Accessibility and affordability of health care services: Accessibility of health care services is a very important factor that determines the health-seeking behaviour. It has two aspects, mode of transport used and the distance travelled for the treatment. In the study area, there is only one government hospital i.e., GGS Medical College, Faridkot which has a department of radiotherapy with only three doctors established under the National Cancer Care Programme (NCCP) in 2009. The private hospitals include Adesh Charitable Cancer Hospital, Sri Muktsar Sahib which has facilities like Teletherapy Cobalt-60 Unit (Kirlosker Theratronics), high dose rate brachytherapy (Iridium-192 source), chemotherapy and cancer surgery facilities (Plate 7.5) and Max Superspecialty Hospital, Bathinda provides comprehensive cancer care (Plate 7.6). The facilities for detection of cancer such as X-Ray facilities are available at all community health centres, sub-divisional health centres and Government Medical College and Hospitals in Punjab. The ultrasound facilities are available at sub-divisional, District and Government Medical College and hospitals. The Computed Tomography (CT) scan facilities are available at all Government Medical College and Hospitals. Biopsy facilities are available at civil hospital, Jalandhar and Government Medical College and Hospitals. The mammography facilities are available at civil hospital, Bathinda, all Government Medical College and Hospitals and Mata Kaushalaya Hospital, Patiala. The laboratory facilities such as fine
Plate 7.5: Adesh Charitable Cancer Hospital, Sri Muktsar Sahib

Plate 7.6: Max Superspecialty Hospital, Bathinda
needle aspiration cytology, peripheral blood smear examination are available at District Hospitals and Government Medical College and Hospitals. The facilities for treatment of cancer such as surgery are available at sub-divisional, District and Government Medical College and Hospitals while the chemotherapy facilities are available at all Government Medical College and Hospitals. The radiotherapy facilities are available at Government Medical College and Hospitals at Patiala and Faridkot.

The GGS Medical College, Faridkot is at a distance of 31 kilometres from Sri Muktsar Sahib and at a distance of 66 kilometres from Bathinda. The regional cancer centre is at PGIMER, Chandigarh which is at the distance of 218 kilometres from Faridkot, 219 kilometres from Sri Muktsar Sahib and 223 kilometres from Bathinda. The Acharya Tulsi Regional Cancer Trust and Research Institute in Bikaner, one of India’s 19 regional cancer research centres, the nearest place where treatment is cheap is at the distance of 324 kilometres from Bathinda via Abohar-Jodhpur passenger train (Train No. 58703) which is commonly referred to as ‘cancer train’. The train travel costs ₹ 102 for sleeper and ₹ 43 for general and runs for all the seven days.

Cancer affects both the patient and the family such that they may faces a financial burden that may influence their decisions for carrying out their further treatment. At GGS Medical College, Faridkot and PGIMER, Chandigarh, the chemotherapy costs around ₹ 10,000 to ₹ 12,000 per cycle and the radiotherapy costs ₹ 1500 for a complete course. There is also provision for poor patients for free treatment at both the places but cost of medicines is still high. One of the respondents described the financial difficulties her family faced as a result of disease as:

“Garb de ilaj kroun vali bimari nai hai eh”
(This is not a disease which a poor man could afford).

The cancer creates financial problems and hardships for the patients and their families. In this case, financial difficulties made him stop the treatment but the pain and suffering relating to disease brought him back for treatment but that was too late.
Case 44: A female respondent (aged 40 years, Jatt Sikh, completed her education up to graduation, housewife, suffering from cancer of nasopharynx, undergoing active treatment, village Husnar, District Sri Muktsar Sahib) was diagnosed with cancer in September 2010 and discussed about her financial difficulties. She told that she is not able to meet expenses of her stay and travelling to Chandigarh. She was accompanied by her daughter who left her studies due to financial difficulties and to take care of her mother. Her daughter was hopeful that her mother would get well soon and she would resume her study.

Case 45: A male respondent (aged 45 years, Jatt Sikh, completed his education up to graduation, farmer, suffering from cancer of gall bladder, village Deon, District Bathinda) was diagnosed with cancer in July 2011. He explained that due to financial difficulties that followed the treatment led to rift in his family. He had three children, two sons and a daughter. His sons separated from him as they did not want to pay for his treatment expenses. Now, he was supported by his married daughter and her in-laws who stay close to him. The financial difficulties led to problems in the family relations and expressed:

“Sara ghar barbād kartā es bimārī ne”
(This disease ruined my whole family).

It is clear from the narrative that cancer is not considered as a disease of an individual but the whole family.

Similar expression has been made by son of a 68 years old breast cancer patient from Bathinda as:

“Cancer diān jārān tan pūre parivār nū khokhlā kar dindiān”
(The roots of cancer hollow the whole family) by which he meant both emotionally and financially.

Case 46: A male respondent (aged 34 years, Majhabi Sikh, illiterate, agricultural labourer, cancer of gall bladder survivor with persistent pain, village Machaki Kalan, District Faridkot) told
about his financial difficulties that due to pain and weakness as a result of disease, he is not able to work. His wife works as a maid servant in three households and earns ₹ 1500. With this meagre income, the family tries to meet their expenses. They have two sons (aged 5 years and 2 years) and the elder son goes to a government school for his education. Due to financial difficulties, he is not able to go for follow-ups and continue the pain medication. He described:

“Eh tan ek bande di nī, pūre parivār di bīmārī ā”
(This is not a disease of an individual but a whole family).

The notion of considering cancer as a disease of whole family was very common among the respondents.

Thus, accessibility and affordability of health care services are two very important factors that affect the health-seeking behaviour of the cancer patients. As not all the facilities of cancer detection and treatment are available in all the government hospitals, thus, the patients have to travel to access the health care facilities. This further leads to financial difficulties among cancer patients and their families. Some of the common problems that emerge from the cases cited include financial difficulties and burden on caregivers. The common theme that emerges from all the cases and narratives is that cancer is not considered as a disease that affect an individual but it is described as a disease that affect the whole family. Similarly, Kazak (1994) noted that the invasive treatment, distressing side-effects, uncertainty about survival, repeated hospitalisations that disrupt the normal family routines, and changes in usual roles and responsibility have implications not only for the patient but for the whole family system. Similar findings have also been made by Kristjanson and Ashcroft (1994) who recognised cancer as a phenomenon experienced by entire family, not just by the individual member diagnosed with the disease. Cancer in the family involves the management of changes in and disruptions to the daily life of the family members as well as the patient necessitating them to make role adjustments and life style adaptations, to meet the demands created by the
illness (Mor et al., 1994). The consequences that evoke from the diagnosis of cancer and its treatment do not merely include only physical health problems but also a wide range of potentially persistent social concerns (Knobf, 2007). The individual and his/her family attempts to maintain control and ‘normalise’ everyday activity by using certain coping strategies (Muzzin et al., 1994).

7.3.1.2 Religion: Research examining the relationships between religion and the health of individuals and populations has become increasingly visible in the social, behavioural, and health sciences. Systematic programs of research investigate religious phenomena within the context of coherent theoretical and conceptual frameworks that describe the causes and consequences of religious involvement for health outcomes. Recent research has validated the multidimensional aspects of religious involvement and investigated how religious factors operate through various biobehavioural and psychosocial constructs to affect health status through proposed mechanisms that link religion and health. As all the respondents in the present study are Sikhs, it is very important to understand the concept of health and disease in Sri Guru Granth Sahib in detail.

Guru Ram Das Ji (fourth Guru of Sikhs) maintained that, where health is an attribute for those who serve the Almighty God truthfully. Health is not just the attribute of the physically but that of mind as well.

*Mere rām har ārog bhae II* (SGGS, p. 735)
(O my Lord, the Lord’s humble servants become healthy).

At the same time he points out that till the time a person is healthy and enjoys a fulfilled life, he or she does not remember God, forgets His divine name. He stated:

*Jab lagjio pind hai sābat tab lag kichh na smāre II* (SGGS, p. 981)
(As long as his soul and body are healthy and strong, he does not remember the Lord at all).

At various points in the Holy Book, Guru Arjan Dev Ji (fifth Guru of Sikhs) has expounded about health as a gift of God attainable only through
divine name. He has referred to this in many of his verses as mentioned in the Holy Book. He stated:

As anit gurmukh mite nānak nām arog II (SGGS, p. 254).
(Hopes and desires for transitory things are erased for the gurmukh, O Nanak, the name alone brings true health).

Jih prasad arog kanchan dehl II (SGGS, p. 270)
(By His Grace, you have a healthy, golden body, attune yourself to that loving Lord).

Supporting this, he also mentioned that a person may have a healthy body, but is sick and diseased if he forgets to remember the name of divine God. He countered this by stating:

Ārogyan maha rogyan bisimrite karunā mayeh II (SGGS, p. 1356)
(The healthy person is very sick, if he does not remember the Lord, the embodiment of mercy).

The Guru presented a prayer to the Lord that whatever may be the condition, healthy or illness befalling him, let him not forget the name of the true Lord and remember him in sickness and health. He maintained:

Srīr sivasth khin same simrant
Nānak rām dāmodar mādhav II (SGGS, p. 1358)
(Whether his body is healthy or sick, Let Nanak mediate in remembrance on you, Lord).

All the verses are testimony that God's grace and his blessing could only be obtained through nām, the divine name. Healthy body, mind and soul are the blessings of God obtainable through his name. Should one forget to remember the divine Lord, his health is of no use as it is same as being sick and ill, because the person is away from God. His body may be healthy but his mind and soul are not. God's name is the only source of having and maintaining good health. The Sikh Gurus also pointed out that as long as, we human beings have the energy and the resources, we must not waste precious time in useless antics and must devote oneself to the service and name of God through his nām. The health is not just about the physical bodily entity but about mind and soul too.
In the Guru Granth Sahib, illness, sickness and disease have been projected in the context of disremembering nam and thereby, being detached from God. There are verses on what causes illness, sickness and diseases and how these could be healed. There is a frequent mention of the 'three fevers' in the Guru Granth Sahib (Talib, 1975). These refer to:

- Ādhi: Fever of mind or mental maladies.
- Biādhi: Fever of body or physical maladies.
- Upādhi: Fever arising from doubts (delusion) or psychic maladies.

The concept of fever is metaphorical, since it does not represent the clinical connotation of the word but the spiritual connotation that if a person is not involved in remembering nam, he suffers from the agony of separation from God and his mind, body and soul are diseased and ill. These fevers keep the soul attached in the cycle of birth and death. Some of the verses from Guru Granth Sahib, as written by various Sikh Gurus on these issues, have been cited below. Guru Arjan Dev Ji explicitly stated that forgetting the divine name opens the gates of pain and suffering including illness.

Kāea rog na chhidr kichh nā kichh kādā sog.  
Mi rat na āvī chit tisa henis bhoge bhog.  
Sabh kichh kton apnā jīne na sank dhareā.  
Chit na āeo pātbrahm jamkankar vas pree ī (SGGS, p.71).  
(You may have a body free of disease and deformity, and have no worries or grief at all; You may be unmindful of death, and night and day revel in pleasures; You may take everything as your own, and have no fear in your mind at all; But still, if you do not come to remember the Supreme Lord God, you shall fall under the power of the messenger of death).

A number of verses point towards the importance of remembering Guru and how through the nam of Guru, all the pain, suffering and diseases can be eliminated. Some of the verses are given below:

Manmukh rogī hai sansārā ī (SGGS, p. 118)  
(The self-willed individuals (manmukhs) are sick and diseased in the world).

Dūkh rog sog bisrai jāb nām ī (SGGS, p. 186)  
(Pain, disease and sorrow come when one forgets the nam, the name of Lord).

340
Har bisriai dukh rog ghanere II (SGGS, p. 197)
(Forgetting the Lord, all sorts of pains and diseases come).

Simar simar kāte sabh rog II (SGGS, p. 240)
(Remembering him in meditation, all diseases are healed).

Bin gur rog na tuti haumai pir na jae II (SGGS, p. 36)
(Without the Guru, the disease is not cured, and the pain of egotism is not removed).

Rog mitai har avkhadh lae II (SGGS, p. 228)
(The disease is cured only by giving the medicine of the Lord's name).

Nam japat maha sukh paio chintā rog bidari II (SGGS, p. 529)
(Chanting your name, I have obtained supreme peace, and my anxieties and diseases have been cast out).

Dūkh rog na bhao biapi jinhi har har dhiaa II (SGGS, p. 554)
(Pain, disease and fear do not cling to those meditate on the Lord).

Har ārādhe arog andai II (SGGS, p. 612)
(Worshipping the Lord in adoration, one becomes happy and free of disease).

Dukh dārū sukh rog bhaia ja sukh tām na hoi II (SGGS, p. 469)
(Suffering is the medicine, pleasure is the disease because where there is pleasure, there is no desire for God).

Mahā kilbikh kot dokh rogā parabh darisat tuhāri hāte II (SGGS, p. 530)
(The greatest sins, and millions of pains and diseases are destroyed by your gracious glance, O God).

Gurmukh samjhai rog nā hoi II (SGGS, p. 1038)
(The gurmukh understands and does not suffer).

Gurmukh bujheh rog gavāveh gur sabdī vicharā II (SGGS, p. 1130)
(The gurmukh understands, and is cured of the disease, contemplating the word of the Guru's shabad).

Har har aukhadh sādh kamāth II SGGS, p. 264)
(Har Har-the Lord's name is the healing medicine).
It can be concluded from the above mentioned important to remember God and when one forgets God, he pain and disease. In Sikhism, the concept of disease is not only physical body but also to the mind and soul. The Sikh Gurus defined the notions of illness, sickness and disease. They regard these problems in forgetting the divine name, which was committing a sin and being ill, and diseased. These notions are the moral grounds of righteous living, remembering the Gurus, His grace and blessings. Attachment with worldly pleasurable behaviour creates a wall between the individual and God and is the cause of all forms of sufferings and pain, all forms of illnesses of mind, body and soul.

In the present study, all the respondents were Sikhs, were asked whether they believe in existence of God. 98.7% respondents believed in God and only 1.3% did not believe (7.5%).

Pie-chart 7.5: Belief in God

Table 7.26.
Table 7.26: Belief in God with respect to gender

<table>
<thead>
<tr>
<th>Belief in God</th>
<th>Gender</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>Yes</td>
<td>110 (98.2)</td>
<td>117 (99.2)</td>
</tr>
<tr>
<td>No</td>
<td>2 (1.8)</td>
<td>1 (0.8)</td>
</tr>
<tr>
<td>Total</td>
<td>112 (100)</td>
<td>118 (100)</td>
</tr>
</tbody>
</table>

p = .614
* Percentages in parentheses

It is clear from Table 7.26 that more females (99.2 per cent) than males (98.2 per cent) believed in presence of God. There were non-significant differences in belief in God among respondents with respect to gender.

The belief in God with respect to type of treatment is given in Table 7.27.

Table 7.27: Belief in God with respect to type of treatment

<table>
<thead>
<tr>
<th>Belief in God</th>
<th>Type of treatment</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Active treatment</td>
<td>Symptomatic treatment</td>
</tr>
<tr>
<td>Yes</td>
<td>197 (98.5)</td>
<td>30 (100)</td>
</tr>
<tr>
<td>No</td>
<td>3 (1.5)</td>
<td>-</td>
</tr>
<tr>
<td>Total</td>
<td>200 (100)</td>
<td>30 (100)</td>
</tr>
</tbody>
</table>

p = 1.0
* Percentages in parentheses

It can be concluded from Table 7.27 that all the respondents undergoing symptomatic treatment believed in God while among the respondents undergoing active treatment, 98.5 per cent believed in God and other 1.5 per cent did not believe in God. There were non-significant differences in belief in God among respondents with respect to type of treatment.
One way in which religion may benefit people is through the attributions it provides. An important attribution is the selective incidence or 'why me'. It was found in the study that cancer patients usually question why they are chosen for such a disease by God. Some of the cases related to the phenomenon of selective incidence were found, where the respondents questioned themselves so as to why they got this disease.

**Case 47:** A male respondent (aged 52 years, Majhabi Sikh, completed his primary education, agricultural labourer, cancer primary unknown with metastasis in liver, advanced stage, village Machaki Kalan, Faridkot) told that as he belonged to a poor family and could not afford the treatment of cancer, he was shocked and questioned, "why God gave him this disease?" and told about his financial concerns as a result of the disease and how his wife and children works extra in order to pay expenses of his treatment.

**Case 48:** A female respondent (aged 60 years, Majhabi Sikh, completed her education upto middle standard, agricultural labourer, suffering from cancer of cervix, village Dhoorkot, District Faridkot) has three children, two sons (aged 35 years and 33 years respectively) and a daughter aged 29 years. She was interviewed at her native village. She was undergoing treatment at GGS Medical College, Faridkot. She was aware of her cancer diagnosis but not the prognosis. She expressed that she was shocked and had a feeling of disbelief on being diagnosed with cancer. She questioned, "why God gave me this disease, I never forgot God's name and always adhered to God's preaching".

**Case 49:** A male respondent (aged 52 years, Majhabi Sikh, illiterate, agricultural labourer, cancer primary unknown with metastasis in liver, village Machaki Kalan, District Faridkot) was staying with his wife at her parental village with his two children. After the diagnosis, he was not able to continue his treatment due to lack of financial resources for treatment. He always
questions himself and the God, “what have I done so wrong that I got this disease? He attributed the disease causation to his karma in the past. He told that he was an alcoholic in the past and used to beat his wife and children while he was drunk. It is his wrong deeds that led him to suffer from this disease.

The cases cited above relate to the phenomenon of selective incidence as the respondents question God to understand the reason for which they are being chosen for the illness. This helps them to attribute meanings to the illness and also to accept it as a will of God.

Cancer is a life-threatening encounter influenced by many factors including religion which is culturally shaped. In the present study, 54.3 per cent respondents accepted that cancer is caused by karma and 3.9 per cent accepted that it is caused as a part of pre-determined destiny i.e., kismat (Table 7.20). So, attribution of causes and meaning to the disease is an important coping strategy used by cancer patients.

Pargament et al. (1988) proposed three styles of religious coping. These include, (a) Deferring coping style; (b) Self-directing coping style; (c) Collaborative coping style. A collaborative relationship with God appears to provide the individual with a sense of empowerment in the face of a difficult life situation (Pargament and Park, 1995) while a deferring religious coping style appears to be associated with a reduced sense of personal competence in coping (Pargament, et al., 1988). The belief in God’s control is a factor that helps in coping with health related issues. However, it is important that an individual experiences a sense of ‘shared’ control with God that does not negate his or her own sense of responsibility and choice in coping with stress (Jackson and Coursey, 1988). And yet, the deferring style may be more adaptive as a response to uncontrollable, extreme situations (Pargament et al., 1988). A deferring-collaborative style was related to and may even be more important than social support to the psycho-social adjustment of cancer patients (Nairn and Merluzzi, 2003). Finally, the independent self-directing style has been shown to be a generally effective personal coping style.
(Pargament et al. 1988), which may only be disadvantageous under uncontrollable circumstances (Pargament, 1997).

In the study, the respondents were asked about the coping styles which they used to cope with their disease. In the present study, a majority of all respondents i.e., 62.6 per cent used deferring religious coping style followed by 33 per cent respondents who used collaborative religious coping style and other 4.3 per cent used self-directing religious coping style (Table 7.28).

Table 7.28: Religious coping styles used with respect to gender

<table>
<thead>
<tr>
<th>Religious coping style used</th>
<th>Gender</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>Collaborative</td>
<td>36</td>
<td>40</td>
</tr>
<tr>
<td></td>
<td>(32.2)</td>
<td>(33.9)</td>
</tr>
<tr>
<td>Deferring</td>
<td>71</td>
<td>73</td>
</tr>
<tr>
<td></td>
<td>(63.3)</td>
<td>(61.9)</td>
</tr>
<tr>
<td>Self-directing</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>(4.5)</td>
<td>(4.2)</td>
</tr>
<tr>
<td>Total</td>
<td>112</td>
<td>118</td>
</tr>
<tr>
<td></td>
<td>(100)</td>
<td>(100)</td>
</tr>
</tbody>
</table>

p = .960
* Percentages in parentheses

There were non-significant differences in religious coping styles used by the respondents with respect to gender. Both the males and females used similar kinds of religious coping styles. The most commonly used religious coping style in both the genders is deferring religious coping style (63.3 per cent for males and 61.9 for females) followed by collaborative religious coping style (32.2 per cent for males and 33.9 per cent for females) and self-directing religious coping style (4.5 per cent for males and 4.2 per cent for females).

The religious coping styles used by respondents with respect to age are given in Table 7.29.
Table 7.29: Religious coping styles used with respect to age

<table>
<thead>
<tr>
<th>Religious coping style used</th>
<th>Age group (in years)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>21-30</td>
<td>31-40</td>
</tr>
<tr>
<td>Collaborative</td>
<td>11 (35.5)</td>
<td>17 (29.8)</td>
</tr>
<tr>
<td>Deferring</td>
<td>19 (61.3)</td>
<td>36 (63.2)</td>
</tr>
<tr>
<td>Self-directing</td>
<td>1 (3.2)</td>
<td>4 (7.0)</td>
</tr>
<tr>
<td>Total</td>
<td>31 (100)</td>
<td>57 (100)</td>
</tr>
</tbody>
</table>

$p = .405$

* Percentages in parentheses

It is clear from Table 7.29 that in all age groups, deferring religious coping styles is the most common followed by collaborative religious coping styles and self-directing religious coping styles. There were non-significant differences in religious coping styles used by the respondents with respect to age.

The religious coping styles with respect to type of treatment are given in Table 7.30.

Table 7.30: Religious coping styles used with respect to type of treatment

<table>
<thead>
<tr>
<th>Religious coping style used</th>
<th>Type of treatment</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Active treatment</td>
<td>Symptomatic treatment</td>
</tr>
<tr>
<td>Collaborative</td>
<td>67 (33.5)</td>
<td>9 (30.0)</td>
</tr>
<tr>
<td>Deferring</td>
<td>123 (61.5)</td>
<td>21 (70.0)</td>
</tr>
<tr>
<td>Self-directing</td>
<td>10 (5.0)</td>
<td>-</td>
</tr>
<tr>
<td>Total</td>
<td>200 (100)</td>
<td>30 (100)</td>
</tr>
</tbody>
</table>

$p = .387$

* Percentages in parentheses
It can be concluded from the Table 7.30 that with respect to type of treatment, a majority of all respondents (62.7 per cent including 61.5 per cent undergoing active treatment and 70 per cent undergoing symptomatic treatment) used deferring religious coping style. Similar observations can be made while comparing the types of cancer with the religious coping style used.

Among all types of cancers, deferring religious coping style appeared to be most common followed by collaborative religious coping style and self-directing religious coping style (Table 7.31).

**Table 7.31: Religious coping styles used with respect to type of cancer**

<table>
<thead>
<tr>
<th>Religious coping style used</th>
<th>Gall bladder</th>
<th>Oral cancer</th>
<th>Breast cancer</th>
<th>Cancer of cervix</th>
<th>Primary unknown with metastasis</th>
<th>Prostate cancer</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Collaborative</td>
<td>24 (38.1)</td>
<td>17 (29.3)</td>
<td>14 (31.1)</td>
<td>12 (31.5)</td>
<td>6 (60.0)</td>
<td>3 (18.8)</td>
<td>76 (33.0)</td>
</tr>
<tr>
<td>Deferring</td>
<td>38 (60.3)</td>
<td>38 (65.5)</td>
<td>28 (62.2)</td>
<td>24 (63.2)</td>
<td>4 (40.0)</td>
<td>12 (75.0)</td>
<td>144 (62.7)</td>
</tr>
<tr>
<td>Self-directing</td>
<td>1 (1.6)</td>
<td>3 (5.2)</td>
<td>3 (6.7)</td>
<td>2 (5.3)</td>
<td>-</td>
<td>1 (6.2)</td>
<td>10 (4.3)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>63 (100)</strong></td>
<td><strong>58 (100)</strong></td>
<td><strong>45 (100)</strong></td>
<td><strong>38 (100)</strong></td>
<td><strong>10 (100)</strong></td>
<td><strong>16 (100)</strong></td>
<td><strong>230 (100)</strong></td>
</tr>
</tbody>
</table>

p = .655
* Percentages in parentheses

It is clear from Table 7.31 that among all types of cancers, the most commonly used religious coping style is deferring religious coping style followed by collaborative religious coping style. There were non-significant differences in religious coping styles used by the respondents with respect to type of cancer.
(A) Collaborative religious coping style: It refers to a style of religious coping which means a partnership between God and an individual in finding a solution to problems.

Case 50: A female respondent (aged 61 years, Majhabi Sikh, illiterate, agricultural labourer, suffering from breast cancer in post-operative stage, village Chandbaja, District Faridkot) described that she resort to **ardās** (prayer) as a coping strategy during course of her treatment. She visited the village Gurdwara for one month and seven days and prayed to God for her survival and well-being. Though she was suffering from the financial constraints as a result of her costly treatment, she made financial contributions to the village Gurdwara. She believed that she and her family are making efforts for her treatment but God's will is also very important to get cured.

A male respondent narrated:

"Je thik hona tan, apni koshish te rab di mehar jaruri hai"  
(If one wish to get cured, one's effort and God's will is necessary).

Another respondent expressed:

"Kade na tan kise da mara karo na mara socho  
Mai kade ni kita aiwen tan hi rabb ne bacha leya"  
(One should not do any bad to anybody nor think to do so, I followed this and because of this God saved my life).

It is clear that in collaborative coping styles, individuals wish not to be left alone in their difficult situations and they need some power, a religious one, to cope with their illness. In this coping style respondents used some religious power as a method of coping with their illness.

(B) Deferring religious coping style: It is used by those individuals who rely on divine intervention by God for relief from their problem.

Case 51: A male respondent (aged 48 years, Jatt Sikh, completed his education upto graduation, doing a government job, suffering
from cancer of gall bladder, advanced stage, village Chandbaja, District Faridkot) was diagnosed with cancer in October 2011 and the disease spread to brain and he lost his ability to understand. His son and brother told that they wanted to tell him about the prognosis of disease but before they could tell him, the cancer spread to his brain and he lost his ability to understand things. The family believes that it is his faith and devotion in God which saved him from emotional suffering which he would have faced otherwise. They explained his devotion to God as:

“Tātī vāo na laagai paar braham sarnāi chaugird hamare rām kār, dūkh lage na bhai”.
(I do not have fears as God is around me and I do not feel any worry).

A female respondent (aged 43 years, suffering from breast cancer in post-operative, follow-up stage) narrated her belief in God as:

“Parmātmā ne hath deke rakhe mainu”
(God saved my life).

Case 52: A female respondent (aged 68 years, Majhabi Sikh, illiterate, housewife, suffering from cancer of cervix, village Mandwala, District Faridkot) told that she is a believer of God since her childhood. After the diagnosis, all her family members decided to stop her treatment. Her daughter tried to continue her treatment for sometime but later on stopped it. At that time, she felt that all her family members have left her in the suffering. It is only with God that she could share her feelings and felt that God stood beside her and provide her support through her cancer journey. She told that she started reciting Sukhmani Sahib at the age of 13 years and continues the same even today. She believes in: "Sarab rog ka aukhad nām" (Sukhmani Sahib, Asthpadi 9/4) which means that the divine name is the medicine for all ailments). After diagnosis, she has also started doing Dukh Bhanjani Sahib path. She expressed the jist of Dukh Bhanjani Sahib as: “Dukh bhanjan tera nām” (Your name is
remedy for all misery). She always prays to God for an easy death. As her life is full of suffering as a result of pain and symptoms related to cancer (vomiting, constipation and abdominal distension) due to non-treatment of the disease. So, she asks God for an early, easy and painless death without any suffering. She narrated:

"Mamā tān sab ne hai, par saukhī maran"
(Everyone has to die one day, but I wish an easy death).

She tried to search meanings behind her illness. She questions herself as:

"Je changa nai kitā, mārā vi nai kitā, mainu eh bīmarī kyūn hoi?"
(If I have not done anything good, nor I did anything bad, why I got this disease).

It is clear from the above cited cases that a number of respondents used religion as a coping strategy. Some of them made individual prayers while for others their family members made prayers. Another respondent argued:

"Rabb te bharosa hai, karmā kārke hoya te rabb hi thik karuga"
(I trust God, the disease is as a result of karma and only god will cure it).

Case53: A male respondent (aged 52 years, Majhabi Sikh, agricultural labourer, cancer primary unknown with metastasis in liver, village Machaki Kalan, District Faridkot) was staying with his wife’s village with his two children. He was interviewed at his wife’s native village (Mehmuana, District Faridkot). He used the term bhairi bīmarī (bad disease) for cancer. He was diagnosed in an earlier stage but due to lack of treatment (due to financial constraints), the disease advanced. He believes in God and he expressed his belief as:

"Rabb hi sab kuchh hai"
(God is everything).
The diagnosis with cancer came as a shock to him and he also questioned himself and the God for disease causation. He told that his wife visits the village Gurdwara daily to pray for his health and well-being. She also reads the Sukhmani Sahib path for him. He expressed that Sukhmani Sahib is a miraculous scripture and listening to the path always reduces his pain and suffering. He expressed the relationship between health and Sukhmani Sahib with the following verse:

“Sarab rog ka aukhad nam” (Sukhmani Sahib, Asthpadi 9/4) which means that the divine name is the medicine for all ailments).

He prays to God to provide him strength to bear the pain and suffering related to the disease. His wife recites the Chaupai Sahib path at the sleeping time for him. He recited a verse from the path as:

Tumeh chadd koi avar nā dhiyaun, jo bar chahun so tum te paun (Benti Chaupai, line 14)
(I do not believe in anyone else but You, whatever I desire, I get from You).

The path like Sukhmani Sahib, Dukh Bhanjani Sahib and Chaupai Sahib are mentioned by the respondents to have miraculous powers to cure cancer.

(C) Self-directing religious coping style: It is used by those individuals who assume that God has given each person the agency to arrive at his/her own solution. Pargament (1997) argues that self-directing coping style is not religious as individual acts to solve problems without seeking the God’s help. Some of the narratives of respondents support the self-directing coping style.

A respondent narrated:

“Dekho chamatkar tan hoyuga nahi, aap hi koshish karni paini” (See, miracle will not happen; one has to try by himself/herself).
Another narrated:

"Dactar de gaye bina tan ilaaj nahi hunda"
(Treatment is not possible without visiting a doctor).

Here it means that individual effort is very important for treatment of disease.

The religion has emerged as an important aspect of health-seeking behaviour among the respondents. *Pāth, ardās* or visits to religious places formed an important aspect in the process of gaining normalcy. These practices have basis in the ingrained belief systems of the people. Religion was an essential aspect of life of the respondents. Practicing certain religious activities was a regular feature of a large number of respondents. Thus, it was likely that taking religious recourse for seeking help for healing and health was a common yet significant aspect of health-seeking behaviour of the respondents.

### 7.3.1.3 Social support and role of 'significant others':

Social support is a complex construct which has long been suggested to have direct and buffering effects on well-being and emotional adjustment in cancer (Northouse et al., 1995; Pistrang et al., 1997; Akechi et al., 1998; Hann et al., 2002; Kotkamp-Mothes et al., 2005; Schroevers et al., 2006; Walker et al., 2006; Nausheen and Kamal, 2007; Gass et al., 2007; Kinsinger et al., 2009; Julkunen et al., 2009; Choi et al., 2012). In the present study, social support and role of 'significant others' appeared to be important in health-seeking behaviour of respondents. Some of the respondents recalled consulting with their family members soon after they became aware of early symptoms and seek their advice in health-seeking behaviour.

**Case 54:** A female respondent (aged 48 years, Jatt Sikh, completed her education upto graduation, housewife, suffering from breast cancer, village Malkana, District Bathinda) told that she noticed a ‘sort of lump’ in her left breast which she first thought was not serious and did not pay much attention to it. Three weeks later when she experienced pain at the site of the lump she became more suspicious about her symptoms and told
family members who immediately took her to the doctor. Thus, women in this study depended on their immediate family members for input and advice about their symptoms, seeking medical help, and assistance when accessing the health care system.

**Case55**: A female respondent (aged 55 years, Jatt Sikh, completed her education up to matric, housewife, suffering from breast cancer in post-surgery stage, village Dhoolcot, District Faridkot) has undergone all her treatment at Dayanand Medical College, Ludhiana and now she visits the hospital every three months for follow-up. She stays with her only son (who was an undergraduate student at Faridkot) and her husband (who was a farmer) at her native village. She shared that as she is the only woman in the household, she needs to take care of everything and after diagnosis, she decided to stay at home and discontinue her treatment. It was her husband, who persuaded her that this is right time for her treatment otherwise she will not be able to fulfill any of her responsibility. Thus, social support provides her courage and hope to bear all the suffering related to the disease.

In this case social support played an important role in health-seeking behaviour. The social support is provided to the cancer patients in hope that their health can be restored and made able to fulfill their social roles again.

**Case56**: A female respondent (aged 42 years, Jatt Sikh, completed her education up to matric, housewife, suffering from cancer of cervix in advanced stage, village Husnar, District Faridkot) told that she got separated from her husband after a marital dispute and now she stays along with her 15 years daughter with her brother’s family in the village. The respondent was aware of her advanced stage of disease and want herself to be killed as she find it difficult to bear the pain and suffering related to the disease in absence of a social support. She told that her daughter is too young to understand her gynaecological
problems and her brother himself is going through the marital dispute. At the time of interview, she shared that now she always prays God for an easy death as there is nobody to take care of her.

This case clearly reveals that the patients do not want to be dependent on their families. This feeling of dependency makes them vulnerable to mental stress, emotional breakthrough and want for an easy death.

Case 57: A male respondent (aged 48 years, suffering from prostate cancer) told that his social support group comprise of his wife, his children and his parents who live together. Along with his family, his support group also comprise of his brother and his family. Though, there was a large support group to provide emotional support but the financial resources were separate for both the families. He was the only earning hand for his family but after diagnosis, he could not work. Now, his wife works as a domestic help and his two children also started working in the houses of landlords. The respondent was neither satisfied with the emotional support provided by his family nor by the financial support. As he was not receiving any regular treatment, he felt that his family is not making adequate efforts for his treatment.

Some of the respondent who felt that they do not receive the required amount of social support mentioned some of the verses from Sri Guru Granth Sahib mentioning that nobody is a real support and it is only God who is there to support individuals. Some of these verses are mentioned here:

\textit{Janan pita lok sut banita koe na kis ki dharia} \text{II} (SGGS, p. 10)  
(Mothers, fathers, friends, children and spouses, no one is the support of anyone else).

\textit{Pit suto sagal kaltar mata tere hoji na ant sakhaia} II (SGGS, p. 23)  
(Father, children, spouse, mother and all relatives- they shall not be your help in the end).
The gender of the cancer patient also determined the kind of support one receives. Some of the important cases relating to this are mentioned here.

**Case 58:** A female respondent was diagnosed with cancer of gall bladder when she was three months pregnant. It was in an ultrasound that a suspicious mass found further examination of which revealed presence of cancer. She was immediately referred to PGIMER, Chandigarh due to sensitive condition. At the time she reached PGIMER, Chandigarh, she was immediately advised to undergo an abortion and start her treatment for cancer. Instead of acting to the given advise, her family take her back to their village. The respondent was interviewed when she came back to PGIMER, Chandigarh again in seventh month of pregnancy. She was suffering from severe pain as by this time her disease has become locally advanced. It is to be noted that the family came to PGIMER, Chandigarh not in hope of her cancer treatment but to save the life of child as they believed that saving life of child is more important. They were completely ignorant about the disease. Her husband narrated:

“Asi kade sochea nahi si ki aiven hojų”.
(We never thought that this would happen).

He pointed out to his wife’s condition and showing his ignorance towards the disease. He stated that he thought that her treatment can be postponed till child delivery.

Her mother-in-law narrated:

“Sab kismat da khed hai”
(All is play of kismat).

As she was not ready to take responsibility for her deteriorating condition rather she scolded her kismat for all that happened. Now, the most important person in the whole situation is the respondent herself. She was asked why she supported decision of her husband and her mother-in-law. She narrated:
“Ehna de kehne to bahar kiven jà sakdi hàn”
(How can I go beyond what they say).

Here she pointed out to her role as a woman. She feels that it is important for a woman to be obedient to her husband and in-laws and to fulfill her responsibility as a woman especially responsibility of giving birth to a child but as the doctor told her that a very less time is left with her, she repent that this time, her decision to support her husband and in-laws went against her own life.

This case study is an important example of interrelationship between gender and health-seeking behaviour. In this case, treatment was postponed as her husband and her in-laws considered her role as a woman to give birth to a child as more important than her own life. She herself did not take any decision for herself and later on repented.

**Case 59:** A female respondent (aged 24 years, Majhabi Sikh, completed her primary education, housewife, suffering from cancer of gall bladder, village Sandwan, District Faridkot) suffered from indigestion from a long period of time. She along with her husband went to a large number of doctors in Faridkot but none of them was able to identify the disease. In September 2011, when she was three months pregnant, her ultrasound revealed a mass in her gall bladder. Finally, her husband decides her to take to PGIMER, Chandigarh for the opinion. They came to Department of Medicine first and then were referred to Department of Radiotherapy where she was told to abort her foetus so as to start her treatment. She left this decision to her husband. Her husband consulted his mother who did not agree to this and expressed her desire for the child and not for the life of her daughter-in-law. Finally, her foetus was not aborted and she was taken home. In January 2012, when her condition started deteriorating, she was again taken to PGIMER, Chandigarh. At this time, her disease was in advanced stage.
and she was seven months pregnant. The doctors at PGIMER, Chandigarh decided for a pre-mature delivery so that life of child could be saved. She delivered a pre-mature female child in the same month and the only treatment option left for her was symptomatic. At the time of interview, she was in advanced stage and regretted leaving her health decisions to her husband and in-laws which brought her to the verge of death. She told that every woman should take their health decision on their own. She also described the lack of support from her husband and in-laws as a major barrier in seeking the treatment.

In the analysis of data, it was found that age was an important factor that affected the health-seeking behaviour of the cancer patients and affects the decision-making of the family members.

**Case 60:** A female respondent (aged 60 years, Majhabi Sikh, illiterate, agricultural labourer, suffering from cancer of cervix, village Dhoorkot, District Faridkot) told that her social support group consisted of her two sons, their wives and their children but as her family has stopped her treatment. She narrated:

> “Rabb dā bharosā, nā putt dā, nā dhee dā, nā bande dā, bas malak dā bharosā”
> (I only trust God, neither my son, nor my daughter or husband, only trust God).

From her narrative, it is clear that she lacked the emotional support as well as the financial support from her family. She explained the behaviour of her family in her narrative:

> “Puranā koi len den hoyū, jehde karke bhugatanā pe rehā”
> (There must be some past give and take due to which I am suffering).

She explained that in her past life, she must have hurt people in her present family in some way that in this life they are not caring for her or continuing her treatment.

**Case 61:** A male respondent (aged 63 years, suffering from prostate cancer) told that his family stopped his treatment after
the cancer diagnosis. His son told him that he is old and have lived his life but he and his children have whole life in front of them. As his son believed that cancer is incurable and ultimate end of this disease is death. So, he decided to stop the respondent's treatment.

In these two cases, the caregivers of the respondents refused treatment to them based on their age. The caregivers believed that they have already lived their lives and their treatment is costly. Thus, it is difficult for them to afford their treatment. Therefore, age was an important factor that affects the health-seeking behaviour of an individual.

Social support and role of ‘significant others’ plays an important role in health-seeking behaviour of cancer patients. The respondents mentioned about their experiences of consulting their family members regarding their symptoms and taking their advice regarding treatment. The respondents further argued that social support provides them courage and hope to cope with cancer but in some cases, respondents mentioned that they do not want to be dependent on their families. The gender and age were found to be the two important factors that determine the kind of support one receives and affect the health-seeking behaviour.

7.3.1.4 Beliefs related to cancer: Cultural beliefs affect both the risk factors for cancer as well as meaning of disease by establishing norms of behaviour and providing guidance for its members to respond emotionally, cognitively and socially to this disease. These beliefs may also lay to delay in health-seeking behaviour and may prolong the interval between first appearance of symptoms and the first visit to the doctor (Kishore et al., 2007). In the present study, it was found that there are a number of beliefs related to cancer. The term cancer was not used by the respondents rather they used variety of other terms for cancer. There are also a number of misconceptions such as belief that cancer is contagious and it is caused on account of an injury. The other misconceptions include the cancer fatalism and belief that cancer becomes incurable after surgery.
(A) Cancer fatalism: Cancer fatalism is the belief that death is inevitable when cancer is present. Fatalism is traditionally conceived as the perception that events and or health issues are out of individual control. The fatalistic individual assumes that the outcome of the disease will be negative. It has been identified as a barrier in health-seeking behaviour of patients especially to participation in cancer screening, detection, and treatment. Fatalistic beliefs about cancer have been implicated in decision-making about cancer (Beekan et al., 2011). A number of studies report that cancer fatalism leads to delay in cancer treatment (Conrad, 1996; Mayo et al., 2001; Powe and Johnson, 1995; Phillips et al., 1999). Cancer fatalism is a multi-dimensional construct which is guided by a number of factors such as awareness, perceptions and beliefs about the disease. According to Powe and Johnson (1995), cancer fatalism is a "categorical surrender of human being to the external forces of life which destroy human personality, potential, hope and even life itself".

Some of the important narratives described by respondents in relation to cancer fatalism are:

"Es bīmārī da koi ilāj nahi"  
(This disease is not curable).

"Mainū tān maut dī sajā hogi"  
(I have got the death sentence).

"Cancer dā matlab maut hai"  
(Cancer means death).

In a number of narratives, cancer has been described as a disease which means death. As a result of this belief, a number of cancer patients desired death. The cases relating to this are discussed here. The desire for death among the cancer patients has been associated with depression, hopelessness, physical suffering, low social support, poor spiritual well-being, and low self-esteem in a number of studies of patients at the end-of-life. It may be affected by such factors as the fear of increasing dependency and the readiness for death (Rodin et al., 2007). The five respondents in the present study repeatedly talked about their desire of death. Some of the narratives of the respondents are given here.
“Mainu jehar deke mār deo”
(Kill me by giving poison).

“Es bimāri dā ilāj kraun nalo tān bandā mar hi jave”
(It is better to die than to get oneself treated for this disease).

(B) Cancer becomes incurable after surgery: One of the major barriers to seeking health care services was the belief that cancerous growth increases after the surgery and after the surgery, cancerous cells grows much faster than before. So, the surgery as the treatment of cancer is not considered as an ideal option. This is a common belief in the area under study and similar belief is held by the desi healers (quacks) in the area.

Case62: A male respondent suffering from gall bladder cancer told that he was diagnosed in an early stage at GGS Medical College, Faridkot and advised to undergo surgery but he refused surgery as he believed that cancer spreads much faster after the surgery. He argued that there is a healer in village Gaddarkheda, who claims that he can treat cancer patients only if patient has not undergone any kind of surgery which he describes as:

“Kainchī nahi lagi honī chahidi”
(No scissor should have been used).

The respondent’s brother-in-law suggested him to visit the healer. He told that he is visiting the healer for the past six months and he has got some relief in pain. He is not taking any medicine along with and has not undergone any kind of diagnostic tests in past six months.

The two important aspects emerged from the above stated case study are (a) belief that cancer becomes incurable after surgery or any kind of incision, (b) ‘significant others’ play an important role in health-seeking behaviour of an individual. Similar kind of belief was held by a number of respondents and some of the key respondents.
Case 63: A female respondent was suffering from cancer of cervix and diagnosed at Adesh hospital, Sri Muktsar Sahib at an earlier stage. She was advised to undergo a surgery to remove uterus and ovaries but she refused to undergo any kind of surgery due to prevalent belief that it is not possible to cure cancer after an attempt to remove/scrape cancerous cells. Due to this belief, she delayed her treatment and at the time of interview, she was in advanced stage of disease.

Some of the important narratives in relation to this belief are:

“No incision should be made in this disease.”

“I am very difficult to survive after incision.”

The doctors were also asked about the belief. They have another take on this belief. They explain that scapula is used to scrape the cancer cells during surgery and one scapula is used only once. If due to ignorance it is used for more than one time, it can also affect the normal cells and may aggravate the disease. So, they believe that surgery should take place in presence of an experienced surgeon.

Thus, beliefs related to cancer affect the health-seeking behaviour of cancer patients. Most important of these are cancer fatalism and belief that cancer becomes incurable after surgery.

Regarding factors affecting health-seeking behaviour of cancer patients, it can be concluded that a number of factors such as accessibility and affordability of health care services, religion, social support and role of ‘significant others’, and beliefs related to cancer such as cancer fatalism and belief that cancer becomes incurable after surgery affect health-seeking behaviour of cancer patients.

7.3.2 Role of NGOs

A number of Non-governmental organisations (NGOs) are working either directly or indirectly to address the issue of cancer in Punjab. The most
Plate 7.7: Roko Cancer awareness posters

Plate 7.8: Fully equipped Roko Cancer bus
important of these is ‘Roko cancer’. Roko cancer is a vision anchored in the future that was flagged off by Mr. Ajinder Pal Singh Chawla and family in memory of his beloved wife Mrs. Manjit Kaur Chawla, who lost her life to cancer at a very early age. An effort that voiced its appeal loud and clear “Roko Cancer” - It could happen to you. The movement gained momentum on 16th December 2005 when the trust launched the first fully equipped mobile breast cancer detection unit for the semi urban and rural areas of Punjab. As volunteers and cause driven partners joined hands globally, Roko Cancer’s clarion call started reaching out its buzzword of “awareness” to the far flung rural and semi urban areas of India at a fast and furious pace. The main objectives of Roko Cancer are:

- Awareness of cancer starting with Breast Cancer.
- Mass Campaign for Early Detection leading to treatment wherever possible.
- Referral to hospitals for treatment and care of cancer patients.
- Helping terminally ill patient to survive with comfort and die in peace and dignity.
- Support to the families of victims of this deadly disease.

The Plate 7.7 shows the Roko cancer awareness posters and Plate 7.8 shows the fully equipped Roko cancer bus. Some of the respondent’s experiences with Roko Cancer Campaign are discussed as under:

**Case 64:** A female respondent (breast cancer survivor from Faridkot, Punjab) was first diagnosed with a suspicious lesion in her right breast in 2005. As a result, a surgery was performed at GGS Medical College, Faridkot but unfortunately it was an incomplete and unsuccessful incision as the lesion appears again in her breast with tenderness. Then her free mammogram was done at Roko Cancer camp in Faridkot inside the mobile unit and it was found on mammogram film that the lesion is Birads 4, and then she again went to GGS Medical College, Faridkot where she was recommended chemotherapy and after some days her surgery was performed. Now, she was on regular follow-up.
Case65: A female respondent (aged 42 years, housewife and mother of two children) was diagnosed with breast cancer in her left breast in Roko Cancer camp held in her village Machaki Kalan, District Faridkot. She was aware earlier that she has a lump in her left breast but she went to a homeopathic doctor for medication but it did not work for her. And then she came to know about free Roko cancer camp in her native village. Her mammogram was conducted and further reports confirmed cancer and she was referred to GGS Medical College, Faridkot for further treatment. Now she was on regular visit to the hospital and undergoing chemotherapy, her lesion has decreased in size as a result of treatment.

Case66: A female respondent (62 years, housewife, village Husnar, District Sri Muktsar Sahib) was diagnosed with suspected breast lump in one of the Roko Cancer Camp (held on 3rd May 2010) in her village Chandbaja, District Faridkot, although the respondent had known it before the diagnosis that she got a lump in her breast but she never got the courage nor she had the awareness how to get it detected. The credit goes to the Roko Cancer team that they came to her village for the camp and her diagnosis was made possible through the mammogram. Now she was undergoing treatment at Bikaner.

Case67: A female respondent (aged 35 years, housewife, mother of a 12 years old son) was diagnosed with a lump in her breast during the camp held by Roko Cancer in her village Ubha, District Sri Muktsar Sahib. She was advised to undergo Fine Needle Aspiration Cytology (FNAC) test which came out to be positive. She started her treatment at a private hospital in Ludhiana and was undergoing radiation after her breast removal surgery. She believed that the support and efforts of Roko Cancer made her aware of this deadly disease.

Case68: A female respondent (aged 65 years, housewife and mother of two children) was diagnosed with a lesion in her left breast during the Roko Cancer Camp held in her native village Jhunir on 18th September 2009 and she was advised or FNAC
Plate 7.9: Print media coverage of Roko cancer c
'tour.
test. The FNAC report came out positive for cancer and she was referred to GGS Medical College, Faridkot where she underwent the breast removal surgery. Now, she was undergoing radiotherapy at the same place. After her diagnosis through the Roko cancer mobile unit, she underwent a mastectomy followed by radiotherapy. She expressed that since then, she is absolutely healthy.

**Case 69**: A female respondent (aged 60 years, housewife, mother of three sons and two daughters) was diagnosed with cancer lesion in her left breast in one of the Roko Cancer Camp held at her village. Following an examination after this diagnosis, she was operated in a private hospital near Bathinda called Bikaner Hospital. She was grateful to Roko Cancer for detecting cancer in the initial stages and she felt that if not detected early, treatment would have been much more expensive.

It is clear from the cases cited above that a number of respondents were detected with cancer during the Roko cancer camps. Thus, it can be concluded that NGOs can potentially play an important role in creating awareness about cancer, its symptoms, causes and treatment as there are a number of myths about cancer that are prevalent in the field areas. The print media coverage of Roko cancer camps is given in Plate 7.9.

The other NGOs working directly or indirectly on the health issues in Punjab include Kheti Virasat Mission, Baba Farid Centre for special children, Faridkot, Centre for Science and Environment, New Delhi and the Naandi foundation and Greenpeace India (Appendix-XII).

### 7.4 CONCERNS OF CANCER PATIENTS UNDERGOING TREATMENT

The active treatment is a type of treatment which aims at curing the disease and bringing back the patient to previous state of health. The active treatment for cancer includes chemotherapy, radiotherapy, surgery and follow-up. In this section, the concerns of cancer patients undergoing active treatment are divided into three sub-themes which include body image
concerns, stigma and social non-disclosure, and concerns at members. The body image concerns are also discussed themes such as hair loss or alopecia as a result of chemother concerns among breast cancer patients, body image concern patients with gynaecological cancers and body image concern cancer patients.

7.4.1 Body image concerns among cancer patients

Cancer and cancer treatment can have profound impa physical appearance. For the majority of patients, appear very distressing, and often even more difficult to cope than symptoms such as nausea and vomiting. Thus, in this section been made to understand body image concerns among . Among all the respondents, integrity of the body (73.0 per ce be the most important concern followed by identity (27.0 per image concerns of the respondents are given in Pie-chart 7.6.

Pie-chart 7.6: Body image concerns among cancer

The body image concerns with respect to gender of the under study are summarised in Table 7.32.
Table 7.32: Body image concerns with respect to gender

<table>
<thead>
<tr>
<th>Body image concerns</th>
<th>Gender</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>Identity</td>
<td>18 (16.1)</td>
<td>44 (37.3)</td>
</tr>
<tr>
<td>Integrity</td>
<td>94 (83.9)</td>
<td>74 (62.7)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>112 (100)</strong></td>
<td><strong>118 (100)</strong></td>
</tr>
</tbody>
</table>

p = .001  
* Percentages in parentheses

With respect to gender, both the males and females were more concerned about body integrity than body identity but if we compare the integrity issues among males and females, the integrity issues were more among males (83.9 per cent) than females (62.7 per cent) and the identity issues were more among females (37.3 per cent) as compared to males (16.1 per cent). There were highly significant differences in body image concerns with respect to gender.

The body image concerns with respect to type of treatment are given in Table 7.33.

Table 7.33: Body image concerns with respect to type of treatment

<table>
<thead>
<tr>
<th>Body image concerns</th>
<th>Type of treatment</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Active treatment</td>
<td>Symptomatic treatment</td>
</tr>
<tr>
<td>Identity</td>
<td>57 (28.5)</td>
<td>5 (16.7)</td>
</tr>
<tr>
<td>Integrity</td>
<td>143 (71.5)</td>
<td>25 (83.3)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>200 (100)</strong></td>
<td><strong>30 (100)</strong></td>
</tr>
</tbody>
</table>

p = .173  
* Percentages in parentheses
On comparing the body image concerns with respect to type of treatment received (Table 7.33), it can be concluded that the integrity remains the major concern (71.5 per cent for patients undergoing active treatment and 83.3 per cent for patients undergoing symptomatic treatment) than identity (28.5 per cent for patients undergoing active treatment and 16.7 per cent for patients undergoing symptomatic treatment). There were non-significant differences in body image concerns with respect to type of treatment.

The body image concerns with respect to type of cancer are given in Table 7.34.

<table>
<thead>
<tr>
<th>Body image concerns</th>
<th>Type of cancer</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Breast cancer</td>
<td>Oral cancer</td>
</tr>
<tr>
<td>Identity</td>
<td>28 (62.2)</td>
<td>16 (27.6)</td>
</tr>
<tr>
<td>Integrity</td>
<td>17 (37.8)</td>
<td>42 (72.4)</td>
</tr>
<tr>
<td>Total</td>
<td>45 (100)</td>
<td>58 (100)</td>
</tr>
</tbody>
</table>

p= <.001
* Percentages in parentheses

On comparing the body image concerns with respect to type of cancer, it can be concluded that there are some type of cancer such as breast cancer where the identity issues are higher (62.2 per cent) than the concerns regarding integrity (37.8 per cent). The reason for more identity issues among breast cancer patients is that the majority of these patients were in age groups i.e., 31-60 years (Table 7.7). The identity issues are lower among gall bladder cancer patients. None of the prostate cancer patients reported any identity issues. This may be because of the reason that majority of prostate cancer
patients are in age group 61-80 years (Table 7.7). There were highly significant differences in body image concerns with respect to type of cancer.

7.4.1.1 Hair loss (alopecia) as a result of chemotherapy: Hair are a physiological phenomenon but also a social one; a symbol of the self and group identity and an important mode of self-expression and communication (Douglas, 1973). Throughout the history, hair has universally been a powerful symbol of the relationship between the individuals and the society, denoting religious affiliation, and has acted as a symbol of social, cultural and political status quo (Ploug, 2007). They are a unique and complex symbol as it originates from the body, yet its symbolic significance is public rather than private. Hair has been associated with maturity, beauty, age and gender, and the absence of hair has been denoted as loss of individuality, sexuality and attractiveness (Batchelor, 2001).

The anthropology of hair calls attention to a close relationship between the physical body and the social body in the two aspects of gender and ideology. The early anthropologists have tried to explore the symbolic meanings of human body. Frazer (1935) conducted one of the earliest studies on hair customs and described hair as one of the strongest ritual symbol. Mauss (1936) also worked on symbolic meaning of human body. Mead (1949) differentiated between the symbolic meanings of gender. He pointed out that through our lives; our bodies learn how to be a male and how to be a female. Despite the work of Mauss (1936) and Mead (1949), mainstream anthropologists and sociologists until very recently have largely ignored the socio-cultural meanings of the body. Douglas (1973) suggested that the social body constraint the way the physical body is perceived. She explained that the physical experience of the body sustains a particular view of society. The other social scientists that focussed their research on symbolic meaning of body include Leach (1958), Firth (1973), Obeyesekere (1984), Sim (1990), Freedman (1994), Williams et al. (1999) and Batchelor (2001).

Alopecia is a significant and disturbing side effect of chemotherapy (Williams et al., 1999; Frith et al., 2007). It has been found that women face the problems such as refusing treatment (McGarvey et al., 2001), lower self-
esteem, poorer body image, and lower quality of life (QOL) as a result of hair loss (McGarvey et al., 2001). The various researchers have associated the chemotherapy-induced hair loss with a variety of factors such as changes in concept of self, diminished self (Freedman, 1994; Williams et al., 1999), loss of privacy, being a reminder of cancer (Freedman, 1994; Williams et al., 1999), effect on social life (Rosman, 2004), and body image concerns (Baxley et al., 1984). Understanding the full significance of the experience of alopecia in an individual's everyday life and personal identity is critical for providing support during the course of illness, and developing strategies to help the patients cope with the difficult changes that occur during cancer treatment (Williams et al., 1999).

Freedman (1994) found that alopecia can be harder to handle than the loss of a breast and that patients are often unprepared, and embarrassed by hair loss. Women with breast cancer who lose their hair have reported poorer body image than those who did not (Baxley et al., 1984). Rosman (2004) described female breast and lung cancer patients' experiences of chemotherapy induced alopecia in terms of the use of camouflage to hide the results, and its impact on identity, in particular feelings of being stigmatised. Rosman also found that the process of losing hair enhanced women's awareness that they had a life-threatening disease. Chemotherapy-induced hair loss is usually temporary and it has been suggested that its negative impact may be softened as hair starts to re-grow (Pendley et al., 1997). However, this often entails patients having to make further adjustment to an altered appearance as their hair may grow back with a texture and colour that is different to how it was before.

Health care professionals clearly have a sense that changes in appearance can be very difficult for their patients to handle, but they are often unsure of how best to support patients or how to meet their psycho-social needs in relation to an altered appearance (Clarke and Cooper, 2001). Randall and Ream (2005) found that nurses considered themselves to be a key in the management of alopecia but were typically unclear as to whether their efforts to help patients were effective. The discussions with oncology
staff, caring for people undergoing chemotherapy, revealed similar kind of uncertainties. To date, most existing research has not focused specifically on participants’ experiences of appearance changes, but rather on experiences of chemotherapy more generally.

The present study, therefore, set out to explore experiences of an altered appearance during chemotherapy treatment following diagnosis of cancer, with the aim of providing feedback and guidance to health care professionals responsible for the provision of care. The present research looks at the experiences of cancer patients undergoing chemotherapy in an anthropological context. It draws on ethnographic fieldwork and observation as research tools. The study of hair loss as a result of chemotherapy from an anthropological perspective is very important for three reasons. Firstly, chemotherapy-induced hair loss is considered to be the most important side-effects of chemotherapy and as hair holds a social significance, the anthropological dimension is very important. Secondly, it has been described as causing distress and as being traumatising. Thirdly, there might be an impact on body image. The following four themes emerged during the data analysis.

(A) Preparing for hair loss: A few qualitative studies have explored cancer patients’ (predominantly women) experiences of chemotherapy, including the meaning of hair loss (Gallagher, 1997); the social and cultural aspects of hair loss (Freedman, 1994); the experience of hair loss and re-growth (Williams et al., 1999); the meaning of chemotherapy treatment (Richer and Ezer, 2002; Rosman, 2004). Although not all of these studies focused specifically on hair loss as a process, collectively they have identified a number of key elements in the experience of chemotherapy-induced alopecia. These qualitative studies have been extremely useful for illuminating women’s experiences of hair loss. Despite the small sample sizes, there is some coherence between the themes being described across these studies. However, they rarely focus specifically on the process of preparing for hair loss. Where studies do address the anticipation or preparation for hair loss this is often one among many themes, and focus on this theme in detail is sacrificed in favour of
providing an overview of the chemotherapy experience (Gallagher, 1997; Williams et al., 1999). Consequently, despite the utility of these studies, researchers still know very little about how women prepare for the effects of chemotherapy treatment, and how this preparation might be supported by health care workers.

Some of the important observations and narratives that emerged during the discussions with the respondents are discussed as under:

“Tikeyan bāre sunde hi mai āpne āp nu taiyār kar leyā”
(I prepared myself soon after hearing about injections).

Here, the respondent referred chemotherapy to as 'injections'. She was already aware that these injections lead to hair loss and soon after knowing about the same treatment for her, she immediately prepared herself for the consequences.

“Haspatāl ch hor marījan nu wekhke samajh gal ke mere nal wi kuchh ajehā hi hoyu”
(In hospital, by looking at other patients, I got the idea that this would also happen to me).

It is clear from these two narratives that some of respondents knew that chemotherapy lead to hair loss and some observed other cancer patients to ascertain what actually will happen to them in course of treatment.

In the process of preparing oneself for hair loss, one of the important requirement is information-seeking. In a hospital setting, there can be three sources of information: Firstly, health care providers (doctors and nurses), secondly, other cancer patients undergoing treatment; and thirdly, information material in form of posters, pamphlets, etc. It was observed that talking and discussing with fellow patients was the most important source of information-seeking. This is known as social comparison. Social comparison helps to gain information about the treatment, side-effects, ways of coping, etc.

Research has shown that when confronted with serious health problems, people seem to relate their own situation to the situation of others. This process might be helpful when adapting to chronic diseases. Apart from
gaining the required information from the doctor, the other way by which cancer patients and their families gained information was through discussing and comparing themselves with other cancer patients. Van der Zee et al. (2000) pointed out that in cases of chronic illnesses like cancer; patients tend to compare themselves with those who are doing worse.

The respondents were asked whether they tried to contact or meet other cancer patients. 67.40 per cent respondents agreed that they contacted or met other cancer patients to compare their own condition and course of treatment with that of theirs, while 32.60 per cent respondents did not contact or met any other cancer patient. The respondents who contacted or met other cancer patients were inquired whether they made a upward comparison or a downward comparison.

The findings of the present study are in contrast with the findings of Van der Zee et al. (2000) as majority (53.54 per cent) of these patients tends to compare themselves with those who were doing better. The following questions are asked by the respondents in view of an upward comparison:

- Why he/she is improving better than me?
- Is he/she given better (costly) medication than me?
- Whether his/her treatment course is different from mine?
- Why the cost of my medication is different from others?
- Is that the doctor prescribe the cheaper medicine to the poor patients and costly medicine to those who are rich?
- Does the cost of medicine affect the outcome?
- Why the outcome from the same treatment is different for different patients?
- Why do some patients recover faster than the others?
- Why similar kind of treatment given to similar kind of cases does gives different side-effects and results?

The reason for the upward comparison is that cancer is considered as a dreaded disease and equated to death. When the cancer patients and their families sees other cancer patients getting well, they compare themselves
with these patients and this comparison brings hope for them. They try to believe that disease would also be cured in their case.

It was further observed that female cancer patient undergoing chemotherapy asks a variety of questions relating to the treatment from their doctor such as:

- Will it lead to complete or partial hair loss?
- Is there any way to avoid the hair loss?
- How will I look?
- How long will hair take to regrow?

Gaining information from different sources helps cancer patients to prepare themselves for the treatment and its side-effects.

(B) Experiencing hair falling out: Experiencing hair falling out is an important phase in the life of cancer patient in which he/she faces whatever he/she learns from others about the disease. Some of the interesting narratives are described in this section.

“Mai suneyā si ke fikeyan nāl vāl jharde ne, mere nāl wi ēh sach ho gyā”
(I had heard that injections leads to hair loss, similarly, it happened with me). The respondents generally denoted chemotherapy as 'tike' (injections).

“Kade vālan nu kainchī wi nahi lagaī sī”
(I never used scissor on my hair before).

“Mainu darr lagdā sī āpne āp to”
(I feel scared of myself).

“Mainu sāre vekhke andekhā kar dinde sī”
(When people saw me, they would ignore me).

“Āpne parivār wichh prâyā jā lagdā sī mainu”
(I felt like a stranger in my own family).

These narratives express a varied amount of concerns which includes religious concerns. It is clear from the narratives that hair loss leads to loss of dual identity, one as a man or woman and second, as a Sikh man or woman.
In order to understand the religious concerns of Sikh cancer patients regarding hair loss, the various published literature on Sri Guru Granth Sahib and importance of hair was researched and following observations are made.

The Kesh or hair are an indispensable main essential of the Sikh faith as enunciated by Tenth Sikh Guru Gobind Singh Ji at the time of institution of the Sikh baptismal ceremony in 1699. The Sikhism hair as an integral part of human body created by God and calls for its preservation and maintainence as any other part thereof. It is enjoined upon every Sikh at the time of his baptism to preserve the hair of his head, beard and other parts of body uncut and unshorn. With the removal of his hair, a Sikh becomes a patit (apostate). In Sikhism, there are certain fundamental essentials and donots which are to be followed to maintain the Sikh discipline. The intact preservation of hair is the first kurahit (donots) of the Sikh faith.

Individuals have various affiliation and associations and through those they may develop many different social identities. In social sciences, the term identity could be extended to encompass social identity, cultural identity, ethnic identity, religious identity and the like. Each term refers to identification of the self or the group with respect to a specific social position. All the respondents in the present study belonged to Sikh religion. In order to understand the body image concerns of Sikh cancer patients, it is important to understand Sikh identity. The respondents shared the Sikh philosophy and few verses from Guru Granth Sahib which states the importance of hair in lives of Sikhs.

Nirhari kesav nirvaira II (SGGS p. 981)
(He does not need to eat.
His hair are long and beautiful.
He is free of hate).

In Sikhism, the God is described as having long hair and the human body is considered as a mediator between God and the human soul. The verses which explain the importance of human hair are:
Gurmukh rom rom har dhayawe II (SGGS p. 941)
(The gurmukh mediates with the lord with every hair of his/her body).

Rom rom meh baseh murar II (SGGS, p. 344)
(And on each and every hair, the Lord abides).

Rome rom rom rome mai gurmukh rám dhiae rám II
(SGGS, p. 443)
(With each and every hair, with each and every hair, as gurmukh, I meditate with the Lord).

Thus, hair are described as an important medium between human beings and the God. The individuals who pluck their hair are described as drinking filthy water and eating garbage.

Sir khohae pīah malvānī jūthā mang mang jhahi (SGGS, p. 149)
(They pluck the hair out of their heads, and drink in filthy water, they beg endlessly and eat the garbage which others have thrown away).

The other concept of Sabat Surat Sikh meaning keep the God-given form intact also highlights the importance of hair. In Sikhism, discipline means following the rehat maryada (code of conduct). This rehat maryada include following the 5 Ks which include Kesh (hair), Kangā (small comb), Karā (steel/iron bracelet), Kashera (undergarment made up of cloth) and Kirpān (sword). A case which explains that cutting of hair is considered as a bad karmā is given below.

Case: A male (aged 85 years, Jatt Sikh, completed his education upto middle standard, farmer, suffering from cancer of larynx, village Jajjal, District Bathinda) was a Sikh, wore turban for whole of his life and never cut his beard or moustaches. He expressed that due to oral cancer his doctor required him to cut his beard but he narrated:

"Maharaj nu ki kahunga ke mere vāl kyun kat dite"
(What would I tell God so as to why my hair were cut).

For him, hair are a part of Sikh identity and loss of these would made him guilty in front of God after his death.
Here, three important concepts of hair as a religious identity, cutting of hair as a bad karmâ and believe in afterlife emerged.

(C) Realising the altered sense of self: Studies that focus on the meaning of hair loss suggest that this can represent a visible reminder of the illness, women look like a ‘cancer patient' and can be recognised as such by others (Freedman, 1994; Richer and Ezer, 2002; Rosman, 2004; Williams et al., 1999). Hair loss can also create a loss of self identity, as the person in the mirror no longer looks or feels like ‘me as I normally am' (Freedman, 1994; Williams et al., 1999). However, for some women hair loss is accepted as an inevitable consequence of treatment – part of the “price one pays for having treatment” – a temporary and manageable aspect of treatment which one just has to get through, and which can be taken as evidence of the effectiveness or strength of the treatment (Rosman, 2004).

The narratives of the women in the present study were in accordance with the findings of Freedman (1994) and Williams et al. (1999). The women considered hair as a symbol of womanhood, loss of which leads to the realisation that some important part of identity as a woman is lost. Some of the narratives are:

“Vāl tan aurat hon dī nishāni ne”
(Hair are a symbol of womanhood).

“Mainu kuchh kho gayā ja lāgdā si”
(I felt that something is lost).

“Main oh nāhī rahī pehān vāll”
(I am not what I used to be).

“Mainu aurat hon dā ehsās jā khatm hogāyā lāgdā si”
(It felt like that I lost the realisation of being a woman).

“Mainu mān si āpne suhhapan te, par...aś bīmarī ne kho leyā mere to”
(I was proud of my beauty but this illness has robbed me off it).

In all the narratives, hair are described as an important part of identity of a woman and loss of which leads to the loss of realisation of being a woman. The respondents also described that the hair loss leads them to
believe that they are not the same anymore. Furthermore, it was found that loss of hair leads the women to vulnerability of realising an altered sense of self, which they do not accept themselves. This is clear from the narrative

“अपे अप टो दार्र जा लगदा”
(I used to feel scared of myself).

The female cancer patients undergoing chemotherapy also felt that others around them especially their spouses will not accept their changed identity. This is clear from the narrative given below.

“मेरा घरवाला देखदा नाहि सी मेरे वाल”
(My husband did not look at me).

This feeling of an altered sense of self leads the women to think that they are burden on their families. This is evident from the narrative.

“मैं बोझ बंगाई परिवार ते”
(I have become a burden on my family).

**Case 7:** A female respondent (aged 24 years, Jatt Sikh, completed her education upto graduation, housewife, suffering from cancer of gall bladder, village Kot Shameer, District Bathinda) was undergoing treatment at PGIMER, Chandigarh told that her husband deserted her complaining that she is not attractive anymore (due to hair fall as a result of chemotherapy) and sexually of no use to him due to her disease. She accepted what her husband complained but questioned “if is this the only duty of a woman?”.

**(D) Minimising effects:** In order to manage or cope with alopecia, patients disguise or camouflage hair loss through the use of wigs, hats, and scarves. Rosman (2004) describes how some women engage in total camouflage where a wig is worn “always and everywhere” and partial camouflage when they decide not to wear a wig in the presence of some people (usually when at home). Looking ‘normal’ is something that takes effort, and is done for the benefit of self and the protection of others (Williams et al., 1999; Rosman, 2004). Some studies describe the problems associated with wig use, such as
finding them uncomfortable, as signalling a denial of the disease, and perpetuating a feeling of being abnormal, and some women were relieved when these efforts could be abandoned and the wig discarded (Williams et al., 1999).

In the study, only one female respondent was found to use the hair wig to hide her hair loss during the chemotherapy. Others were found to cover their head with a black coloured cloth (dupattā). It is not only women who covered their heads with dupattā but men also covered their heads either with a turban (the cloth length is 5.5 metre) or a sāfa (smaller than the turban, the cloth length is 2.5 metre) even if they do not wear turban normally and cut their hair. On asking, the male respondents expressed that keeping hair (cut or uncut), beard and moustaches are a part of their religious identity as well as an identity as Punjabis. The chemotherapy leads to loss of hair from all over the body. The male respondent explained that they try to minimise the loss of hair by covering their heads with either turban or sāfa as there is a sudden realisation of loss of one’s identity.

**Case 72:** A female respondent (aged 40 years, Jatt Sikh, completed her education upto graduation, housewife, cancer of gall bladder, village Dhorkot, District Faridkot) told that she started covering her head with a black cloth after her hair fall due to chemotherapy. She shared that everybody knows that hair loss occurs due to cancer only and anybody could make out that she is suffering from the disease. Moreover, she explained that she is a woman and does not want to lose her identity.

While comparatively little research has focused specifically on the personal impact of an altered appearance during chemotherapy treatment, the cases cited here offers an original insight into this aspect of cancer patient's experiences of cancer diagnosis and treatment. Previous research into the psychological impact of chemotherapy has reported patients ranking hair loss as the second most severe side-effect of treatment (Carelle et al., 2002). The present study supports the findings made by Rosman (2004) in demonstrating that it is the outward changes that publicly identified patients as having cancer.
and as a consequence, presented them with an additional array of potential stress. In essence their appearance acts as a visible indicator of their disease status to both themselves and others, including those who may have previously been unaware of it. Hair loss is seen as a confirmation of identity as a cancer patient. Previous research (Freedman, 1994; Richer and Ezer, 2002; Rosman, 2004) has reported that people undergoing chemotherapy meet the stereotypical appearance of a ‘cancer patient’ and can be recognised as such by other people.

7.4.1.2 Body image concerns among breast cancer patients: One population of interest among researchers in relation to body image is the breast cancer population. Since breast cancer directly affects an individual’s physical self, the disease may also affect body image. Breast cancer changes a woman’s body in several ways including surgical scars and loss of a part of the body, tactile changes, sensory changes, swelling in their limbs and hair loss. There may also be changes in physical abilities, weight gain and/or swelling, fatigue, night sweats, early menopause and functionality of body parts (Price, 1993; Pelusi, 2006).

In the study, women’s stories were anchored in descriptions about their experience in becoming aware of overt changes in their breasts or perceptions that their breasts did not “feel right.” A variety of changes were reported, including small lumps, pain, breast fullness, unusual softness, and small marks on their skin. Varying levels of pain intensity were described, including ‘fikhi pir’ (shooting pain), ‘chubhan vála ďard’ (pinching pain) and needle like pain “aiven lagda koi suyian chabho reha hove” (It feels as if some one is pinching needles). Similarly, descriptions of breast lumps varied from “Kuch aijb ja” (“something odd)” to more detailed images of lumps with the use of terms like “gath”, “gand” (dense mass) Not all of the women consistently linked their breast changes to breast cancer. For example, for some women, breast pain was attributed to muscle pain, whereas for others, it was viewed as an early sign of breast cancer. Similarly, although breast lumps, especially those without any pain, were viewed by some of the women
as “milk lumps” or normal lumps, other women immediately associated a lump with breast cancer.

The breast changes were plausibly associated with other factors such as menstrual cycle phase, injury, or muscle strain. Some women considered these alternatives first and either sought ways to deal with the symptom or adopted a ‘wait-and-see approach’ (thinking the symptom could resolve itself). Some women seemed to conceal their concerns about the possibility of breast cancer to protect their family from worry. This view can be supported by the work of Howard et al. (2007).

The diagnosis of breast cancer encompasses not only physical, but also social and psychological implications because of the importance of the breast in a woman’s body image, sexuality, and motherhood. Women may experience a range of concerns and fears including physical appearance and disfigurement, the uncertainty about recurrence and the fear of death (Mahapatro and Parkar, 2005). There are only a few Indian studies on this subject. The present study includes a significant number of patients with breast cancer. In Punjab, the women wear salwār kamīj and the women residing in the villages usually cover their head with dupattā wrapping it around their upper body. This type of dressing saves them from being noticed but this does not mean that they do not have body image concerns. The case studies relating to body image concerns of respondents suffering from breast cancer are discussed here.

Case 73: A female respondent (aged 34 years, Jatt Sikh, completed her education up to post-graduation, doing a government job, village Bura Gujjar, District Sri Muktsar Sahib) in a post-operative stage shared that her family is very supportive especially her husband but she feels as if she has lost an important part of her body. Moreover, the scars of surgery remind her of her loss (loss of her breast). She told that this loss is irreparable and she will have to live with this loss whole of her life. The female relatives who visit her ask questions such as:
How much part of breast is removed?
Is it possible to do something to hide the loss of breast in terms of surgery?
How you cover the surgically removed portion?
She explained that she finds it difficult to answer such kind of questions and she feels:

“Koi pardā nahi rehā”
(There is no privacy anymore).

She means that she has lost her privacy in family, among relatives and among health care providers. These difficulties make her to hide the breast with a dupattā spread all around for most of the time. The Plates 7.10 and 7.11 shows the breast cancer patients covering their breast with dupattā.

Case74: A female respondent (aged 40 years, Majhabi Sikh, completed her primary education, agricultural labourer, village Machaki Kalan, District Faridkot) in a post-operative stage told that soon after her diagnosis with breast cancer, her husband and in-laws told her parents to take her to their place as they were not ready to support her treatment. Her husband told her that he is not ready to accept her with changes in her body post surgery (removal of breast). Now she was staying with her parents who are paying for her treatment and supporting her in every possible way.

Case75: A female respondent (aged 46 years, Jatt Sikh, completed her education upto matric, suffering from breast cancer, post-surgery, follow-up stage, village Mandwala, District Faridkot) told that her husband never tried to be intimate with her post-surgery and he has become much more supportive towards her than before. This makes her feel that something is wrong with her and she is not the same person anymore. This feeling makes her think that as she has lost the most important characteristic of being a woman and that’s why her husband has become indifferent towards her.
Plate 7.10: A breast cancer patient with her family

Plate 7.11: A breast cancer patient with her mother-in-law
The breast cancer patients described the changes that they felt in their breasts in detail but they also reported ‘wait-and-see approach’ that they initially followed which lead to delay in their diagnosis. The women considered loss of breast as loss of womanhood and an intrusion in privacy. In some cases, they also reported separation from their husbands as a result of bodily changes that followed cancer. Furthermore, the breast cancer patients also mentioned that people have become indifferent towards them after their cancer diagnosis. One important aspect that adds to the body image concerns among breast cancer patients is that their health care providers do not pay attention to social consequences of biological changes due to cancer. One important study conducted by Thomas-MacLean (2004) investigates the subjective experiences of women diagnosed with breast cancer in an attempt to understand the social context in which breast cancer occurs. Through exploring women’s experiences of embodiment, this phenomenological study focused on the long-term changes to embodiment. As explained in Thomas-MacLean’s (2004) study, embodiment is the idea that:

...we do not simply have bodies, but that we are our bodies. It has been suggested that the body has various dimensions, including one’s physical being and the ‘sociological body’, which exists as “dialectic between the subject and society”.

The above mentioned narratives can also be analysed in this context which distinguishes between a social body and a physical body. It was found that social body is very important for the cancer patients but their socio-cultural perceptions are not fully understood by their doctors which leads to a number of body image concerns among them. These body image concerns of the respondents are not addressed.

### 7.4.1.3 Body image concerns among cancer patients with gynaecological cancers:

A diagnosis of cancer immediately threatens body image (Burt, 1995). The treatment of cancer such as surgery, chemotherapy and radiotherapy typically forces the patients to cope with the concerns such as self image, sexual identity and sexual functioning. The impaired body function or altered body image, or the psychological distress that follow the
diagnosis and treatment may affect the sexuality and sexual functioning. The term body image pertains to the individual's perception of what his/her body is like. In contrast the phrase “body image concern” pertains to how much the body image matters to the individual. Sexuality among cancer patients is an important concern but is often ignored. When referring to sexuality, a distinction should be made between the terms sexuality and sexual functioning. “Sexuality is a personal expression of one’s self and one’s relationship with others” (Pelusi, 2006). “Sexuality encompasses feelings about one’s own body, the need for touch, interest in sexual activities, communication of one’s needs to a partner, and the ability to engage in satisfying sexual activities” (Henson, 2002). In contrast, sexual functioning refers to areas of functioning such as vaginal lubrication, frequency of sexual activity and breast sensitivity (Baucom et al., 2006). For the purpose of this study, participants were asked their views of sexuality and not specifically about sexual activity or functioning per se. While the “body image is a component of one’s self-concept and refers to a mental picture of the physical self, including attitudes and perceptions regarding one’s physical appearance, state of health, skills, and sexuality” (Pikler and Winterowd, 2003). For the purpose of this study, body image and sexuality were considered separate yet related constructs.

The cancer patients and the survivours are at a high risk of developing altered sexuality (Krychman et al., 2006). Unlike other physiological side-effects of cancer which diminish over time, altered sexuality can persist for many years into survivorship (Tierney, 2008). The many physical changes which occur as a result of cancer and its treatment including weight loss, hair loss and scarring, all have the ability to negatively affect a woman’s body image. Other studies have also shown that women experience a disruption of their body image following diagnosis and treatment for gynaecological cancer (Kullmer et al., 1999; Green et al., 2000; Burns et al., 2007; Bukovic et al., 2008) and may feel sexually unattractive (Matulonis et al., 2008).

In the present study, an attempt has been made to gather information by means of qualitative data collection on the experience of women diagnosed
with cancer with regards to body image and sexuality. It is important to use both quantitative and qualitative research methods in order to learn as much as possible about a persons' experience. Using a mixed methods design allows the researcher: firstly, to gather more information to create an overall, deeper understanding of the phenomena being studied and secondly, it also enriches the ability to draw conclusions and broaden the scope to acquire a more complete picture of what is being studied.

The patients with gynaecological cancers report lower levels of sexual desirability, face difficulty in resuming sex after the treatment and often lack interest in sex (Andersen and Jochimsen, 1985). In the patients with gynaecological cancers, due to the delicate nature of the cancer site, treating this cancer typically affects sexual functioning and body image adversely, making it critical to identify the concerns of these patients.

Body image has also been linked to feelings of femininity and attractiveness (Kraus, 1999). Femininity is an important part of sexual identity and thus, have an important influence on a woman's body image. Loss of femininity has been reported by gynaecological cancer patients in both quantitative (Chan et al., 2001; Tornatta et al., 2009) and qualitative studies (Juraskova et al., 2003). A case relating to this is given here.

**Case 76:** A female respondent (aged 30 years, Jatt Sikh, completed her education up to graduation, teacher, suffering from cancer of cervix, village Jajjal, District Bathinda) was a mother of two children (son aged 6 years and daughter aged 4 years). She was told to undergo a uterus removal surgery but she narrated:

"Mai hijrā nai bannā"  
(I do not want to be a transgender).

As she considered uterus as a symbol of womanhood and removal of which leads to loss of identity. She related this loss of identity to transgender whose sexually identity is not defined and clear in the society.
Another female respondent expressed:

“Mai aurat hi maran chahundi han”
(I want to die as a woman).

She expressed this when her doctor suggested the surgery for removal of her uterus.

The case studies depicting the interrelatedness of body image concerns, sexuality and gender roles are discussed here.

Case 77: A female respondent (aged 49 years, Jatt Sikh, completed her education up to matric, suffering from cancer of cervix in post-surgery and radiation, village Jajjal, District Bathinda) shared her concern regarding the resuming sex after surgery. She further shared that she is worried about her health as she believes that sexual intercourse may lead to further development and consequent recurrence of the disease. Though her husband repeatedly tried to persuade her on the issue and she considers that it is her duty as a wife. She suffers from severe pain and sometimes bleeds during the sexual intercourse.

Case 78: A female respondent (aged 48 years, Jatt Sikh, completed her education up to matric, housewife, cancer of cervix, post-surgery and radiation, village Malkana, District Bathinda) told that she and her husband were sexually active during her treatment and after 2 months of her surgery, they became sexually active again. During treatment, the pain during sexual intercourse was much severe along with continuous bleeding for hours. After surgery, the pain reduced a bit but she feels uncomfortable, uneasy and the fear of recurrence of the disease still haunts her.

In both the above cited cases, the obligation to fulfill the role as a woman and as a wife leads these women to indulge themselves into the sexual activity inspite of pain, suffering and constant fear. The women also
fear that if they will say “no” to their partners, this may lead them to think that she has lost her femininity and sexually of no use which may also lead them to be deserted by their husbands. The submissiveness of women appears in these cases as these women assume that demand of their husbands to have sex is completely natural and legitimate, and it is their duty to oblige them.

A diagnosis of cancer typically results in patients experiencing uncertainty about and loss of control over their situation, which in turn has a negative influence on their health outcomes. Cancer treatment further disrupts patients’ QOL. Throughout their cancer journey patients often rely on their doctors to provide them with social/ interpersonal, informational, and decisional support. The treatment a patient receives can be greatly affected by what the patient chooses to disclose to his or her doctor. Barriers to disclosure include patients’ thinking that certain information is not important; feelings of anxiety, stigma, and embarrassment; and doctors not enquiring about certain issues. The sexual concerns among gynaecological cancer patients are because of two reasons given below:

(A) Lack of communication between the doctor and the patients on the sexual concerns: Gynaecological cancer has been shown to affect women’s sexual functioning, yet the evidence suggests that sexual concerns have long been neglected in health care (Stead et al., 2003). Herson et al. (1999) identified the barriers to providing sexuality information as lack of time, lack of knowledge, person’s attitudes about sexuality and patient’s lack of readiness. Stead et al. (2003) argued that the reasons for not discussing sexual issues between doctors and gynaecological cancer patients include the attitude that ‘it is not my responsibility’, embarrassment, lack of knowledge and experience, and lack of resources to provide support if needed. Lindau et al. (2011) believed that though the health care professionals believe sexual concerns to be important but they rarely discuss them.

Similarly during medical encounters, the patients may directly verbalise that they have concerns, or even fearful about their condition but may not be ready to ask questions. The fact that women asked few questions or asked none, does not necessarily mean that they had no questions. The respondents were asked about the questions which they liked to ask but did not ask. The majority of questions relate to sexual dysfunction and fear of
resuming sex after the treatment but it was found that they do not consult their doctors for the same because of lack of communication between doctor and the patient due to time constraints, age and gender differences between patient and doctor, feeling among the patients whether the issues are relevant or not. Under the theme on lack of communication between the doctor and the patients on the sexual issues, the following sub-themes emerged.

(i) **Time constraints and focus on treatment rather on the communication:** The communication between a doctor and a patient is very important for patient’s quality of life and well-being. In the present study, it was found that the major barrier in communication and seeking information regarding sexual concerns is the time constraint. The doctor usually does not spend extra time with their patients to establish a rapport with their female patients so that they could freely ask about their sexual concerns. Communication between doctor and female cancer patients is, thus, a major barrier.

(ii) **Age and gender differences between patient and doctor:** The age and gender of the doctor are other important factors that affect the communication process between the doctor and the patient. The female patients do not feel comfortable discussing their sexual issues with the male doctors.

**Case 79:** A female respondent (aged 56 years, Jatt Sikh, completed her education upto graduation, housewife, cancer of cervix, post-surgery and radiation, follow-up stage, village Mandwala, District Faridkot) shared that her husband told her to ask the doctor about when to become sexually active after treatment but she did not ask the doctor. On asking the reason, she told that the doctor was a male and she felt uncomfortable asking him about her sexual concerns.

**Case 80:** A female respondent (aged 62 years, Jatt Sikh, completed her education upto matric, housewife, suffering from cancer of cervix, village Mandwala, District Faridkot) continuously bleed for three days but did not visit her doctor till her condition become worrisome as she was aware from her...
previous experiences that to stop the bleeding, packing is done. She felt uncomfortable with the process and was not ready to get it done from a male doctor. But on the fourth day, she visited her doctor and get it done. She shared that the doctor is of the age of his son and she expressed:

"Narak lagda mainu"
(I feel life hell).

According to respondent, the procedure of packing by a younger male doctor makes her feel uncomfortable and she equated the experience to hell.

**Case81**: A female respondent (62 years, Jatt Sikh, completed her education upto matric, housewife, suffering from cancer of cervix, undergoing treatment, village Doda, District Sri Muktsar Sahib) shared that her husband told her to ask her doctor about whether to be sexually active during the course of treatment but she did not asked the doctor because of the reason that the doctor was a male and she felt uncomfortable and immoral to discuss such an issue.

(iii) **Lack of rapport establishment**: The patients do not understand whether the discussion of sexual issues is relevant or not and expect the doctor to answer all their queries before they actually ask. This happens due to lack of rapport establishment by the doctor with the patients.

**Case82**: A respondent (aged 36 years, Jatt Sikh, completed her education upto graduation, housewife, suffering from cancer of cervix, village Dhoorkot, District Faridkot) in a follow-up stage wanted to know about whether to resume sex or not and if yes, when to resume and whether it would affect the disease status or not or it would be painful. On asking, if she asked the doctor, she narrated as:

"Mainu lageā āp hi dasānge dactar sāhab"
(I expected that he will tell me by himself).
Thus, a communication gap as well as gender difference between cancer patients and doctor is a major gap.

(iv) Cultural insensitivity: Anthropological contributions to medicine are based on conveying an understanding of patient's cultural backgrounds, their illness beliefs, and health-seeking behaviour and motivation which can play an important role in understandings their complaints and the care they want. This enables providers to incorporate the patient into overall treatment plan that addresses not only disease but illness and sickness as well. Cultural understanding that can enhance clinical relations by addressing factors affecting access to and presentation to biomedical treatment include features such as meaning of symptoms; factors affecting the recognition of symptoms and disease; concepts of disease and illness, and theories of its causes and cures; conceptions of body and bodily functions, and their meanings; expressions of pain and sick-role behaviour; emotional reactions to illness, sickness, disease and symptoms; social networks for managing sickness; contributions of culture, family and community to causation of disorders; impacts of sickness on social life, roles, behaviour, work and family relations; descriptive data on how culture and social organisation affect health, etc (Winkelman, 2009). A conversation between a doctor and his female patient in this context was observed. The doctor told the patient:

“Bībī ehnā dhāge tavītān ne tere kām nahi aunā, Davāīān chanīgar tarah khā́”
(Lady, these sacred threads will not work, take your medicine properly and regularly).

The doctor made this statement referring to the black thread worn by the respondent around her neck. She did not talk or replied doctor in this context but later on during her interview, she complained that her doctor is insensitive and does not understand what a cancer patient goes through during treatment. She told that her mother brought her the sacred thread from a healer in Bathinda and she respects feeling of her mother. That is why she worn the thread.
She argued:

“Fāyda nahi tan nuksān wi koi nahi”
(If not useful, it will not be harmful).

This comment of a doctor can be analysed in the context that there are cultural differences, differences in beliefs and perceptions, and in description of disease between doctor and a patient. The doctors think they are actually discovering a disease rather than coming up with a culturally relevant classification. Consequently, there is little consideration of what diagnosis involves or actually means because it would involve questioning of whole enterprise of medicine (Winkelman, 2009). Here, health care providers need to be knowledgeable of the relationship of culture to health as culture is the foundation of everybody’s health concerns and practices. Thus, in order to improve health care services, it is important to bring attention towards cultural influences on health concerns, conditions, beliefs and practices. As medical anthropology is primary discipline addressing the interface of medicine, culture and health behaviour and incorporates cultural perceptive into clinical settings and public health programmes. The cultural perspectives of medical anthropology are essential for providing competent care, effective community, health programmes, and patient education. The concept of culture is fundamental to understanding health and medicine because personal health behaviours and professional practices of medicine are deeply influenced by culture. Thus, health care providers need to be culturally aware, sensitive, responsive, competent and proficient in order to deliver effective health care services.

(B) Fear of painful sexual intercourse and further spread of disease or recurrence of disease: Due to lack of communication with the doctor as a result of above mentioned reasons, the female patients with gynaecological cancers face the problem of fear of sexual intercourse and also fear that the sexual intercourse may lead to further spread of disease or recurrence of disease if already treated.

Case 83: A female respondent (aged 35 years, Jatt Sikh, completed her education upto post-graduation, housewife,
suffering from cancer of cervix, post-treatment, follow-up stage, village Malkana, District Bathinda) shared that she has completed her treatment 4 months back but as her doctor have not told her anything about whether to be sexually active or not and when. She fears that sexual intercourse would be painful and may lead to recurrence of disease. Her fear has created problems between her and her husband but she feels that her children are very young and she has to fulfill her responsibilities towards them. For this, she needs to be healthy and disease free which she shared is not possible otherwise.

The gynaecological cancer patients reported a number of body image concerns and sexual concerns but there were a number of factors that affected the communication between doctor and female cancer patients on sexual issues. These included time constraints, focus on treatment rather than on communication, age and gender differences between patients and the doctors, lack of rapport establishment and cultural insensitivity. It has also been suggested that health care professional’s knowledge about sexual concerns is not adequate (Stead et al., 2001) and they need training to help them communicate more comfortably about sexual issues (Stead et al., 2002).

7.4.1.4 Body image concerns among oral cancer patients: Body image is also recognised as a critical psycho-social issue for individuals with oral cancer, as the disease and its treatment can have devastating consequences involving disfigurement and functional impairment. There are enormous social implications for the body image changes experienced by these patients due to the visible nature of the facial region and its association with identity, communication abilities, and interpersonal functioning (Fingeret et al., 2010).

Fingeret et al. (2010) pointed out that such patients feel embarrassed due to the bodily changes as a result of treatment and cancerous growth which bursts and takes the form of wounds. In the study, it was found that such patients tend to cover the wounds by wearing high collared kurtas or formal collared shirts. The respondents also tend to hide the cancerous masses and wounds by covering them with cloth or a handkerchief. The oral cancers are generally associated with tobacco consumption and smoking.
The respondents in the present study are from Punjab and Sikhs by religion (the religion which prohibits the consumption of tobacco). Thus, the respondent felt stigmatised especially in the hospital setting where the first question asked to patients with oral cancer is “do you smoke or consume tobacco?” Thus, the respondents with oral cancers felt equated to the tobacco consumers and bidi smokers.

Case 84: A male respondent (aged 65 years, Jatt Sikh, completed his education upto senior secondary, farmer, cancer of larynx, village Machaki Kalan, District Faridkot) shared that one of his son take him to Bikaner for his treatment. As he was an amritdhari Sikh (baptised Sikh), he had a long beard. The doctor at the Bikaner hospital told him to cut his beard before the surgery as he was suffering from oral cancer but he refused to do so. The reason behind the refusal was his identity as a baptised Sikh which he did not want to loose. His son found a way out and he tied his beard tight so that doctor could clearly see the region to be operated. Only then he continued his treatment.

Case 85: A female respondent (aged 42 years, Majhabi Sikh, illiterate, agricultural labourer, suffering from cancer of nasopharynx, village Machaki Kalan, District Faridkot) told that after her diagnosis husband and her in-laws have deserted her due to the facial changes which have occurred as a result of disease. Her only support are her children. She shared that she always covers her face in front of her children and anybody else as she feels uncomfortable due to her changed identity. She told that she also avoids looking at herself in mirror and shared that she did so once and got so scared. For her, she has lost her femininity and beauty to this disease.

It is clear from the cases that patients with oral cancers can experience profound changes to fundamental and visible aspects of life that are often present as a cluster of symptoms and endure throughout the illness trajectory.
It is clear from the analysis that body image concerns in cancer patients are apparent for reasons like loss of gender identity, loss of religious identity, new identity of a ‘cancer patient’ and fear of stigma. With the loss of few identities (gender and religious) and gain of a new identity (of a cancer patient), it becomes difficult for cancer patients to cope with the disease.

7.4.2 Stigma and non-disclosure of cancer

It has long been recognised that various types of illnesses are associated with stigma or membership in a social category that results in a spoiled identity setting the individual apart from others (Goffman, 1963). A number of researchers have pointed out that cancer is a stigmatised disease (Fife and Wright, 2000; Chappelle et al., 2004; Rosman, 2004, Lebel et al., 2006; Ploug, 2007; Frith et al., 2007; Lebel and Devins, 2008). In the present study, a wide-spread stigma was found to be associated with cancer. It was further found that families tend to hide the diagnosis of cancer from others outside the family for five reasons: firstly, it is believed that cancer is caused due to karmā and kismat; secondly, cancer is considered as a contagious disease; thirdly, to save the patient from stigma; fourthly, cancer is considered incurable and is equated to death; and lastly, to save the patient from empathy of others. Some of the cases relating to stigma are given here.

Case 86: A male respondent (aged 61 years, Majhabi Sikh, illiterate, agricultural labourer, suffering from cancer of tongue, village Jajjal, District Bathinda) reported that he feels stigmatised when people ask him about his disease. They look down upon him in an unusual way. He believes that most of the people in his village had fears and myths about cancer as they believe that cancer is spread from one person to other by contact and that it can also afflict them. So, everybody in the village keeps distance from him and even if somebody visits him, they generally cover their face with some cloth leaving only the eyes uncovered. As they feel that they may also get afflicted with the disease.
Case 87: A female respondent (aged 43 years, Majhabi Sikh, illiterate, agricultural labourer, cancer of naso-pharynx, village Sherewala, District Sri Muktsar Sahib) told that her husband died five years back and she was diagnosed with cancer in December 2010. When she was diagnosed with cancer, her in-laws told her to stay somewhere else and not with them as they feared cancer affliction. They deserted her and her children. She told that it was her husband's cousin who helped her financially but told her not to come near her as he also feared of cancer affliction. At the time of interview, she was staying at Chandigarh Hospice.

Case 88: A female respondent (aged 27 years, Majhabi Sikh, completed her primary education, agricultural labourer, cancer of cervix, village Husnar, District Sri Muktsar Sahib) told that her husband and in-laws deserted her and her three years old son after diagnosis with cancer. Her in-laws feared that their son would get the disease, if he stays with her. So, they persuaded him to desert her. Now, she stays with her parents who also think that cancer is contagious and covers their face whenever they come close to her.

Case 89: A female respondent (aged 52 years, Jatt Sikh, completed her education upto matric, housewife, suffering from cancer of cervix in advanced stage, village Machaki Kalan, District Faridkot) told that she has a continuous discharge from her vagina which smells very foul and because of this smell, most of the people avoid coming close to her. Most of the time, the young females and children are advised not to go near her as it is believed that these two categories are more prone to infections. Further, it is believed that the older men and women have already lived most of their lives and do not catch the infections much easily.

Case 90: A female respondent (aged 33 years, Majhabi Sikh, completed her primary education, suffering from breast cancer, undergoing treatment, village Bhagta Bhai Ka, District Faridkot) told that she stays with her brother's family while she goes to
PGIMER, Chandigarh for her chemotherapy. She told that she is given food in separate utensils, her utensils are washed separately and kept at a separate place after washing. She is also told to sit and sleep separately from her brother's family. The respondent feels isolated and secluded because of the disease.

On enquiring about this seclusion, the respondent's brother told that they have secluded the respondent so as to save other family members from the same disease and its suffering.

It was found that the people try to distance themselves from those who are suffering from cancer as they believe that cancer is contagious. A caregiver shared that they wash the patient's clothes separately and keep them at a separate place as they believe that cancer is contagious. She shared:

"Bahut darr lagda mainu"
(I feel very scared).

Another caregiver shared that taking the name of cancer is bad and it is due to this reason that the people prefer to use other terms for cancer. He feels that one should not use the term cancer never ever in life, otherwise one might be affected. The Plate 7.12 shows an advanced cancer patient secluded from his family.

In some of the cases, the stigma was due to belief that cancer is caused due to \textit{karmā} and as a result people distance from cancer patients as they feel that cancer is due to their past bad deeds. A case relating to this is given below.

\textbf{Case }11: A male respondent (aged 40 years, Ramgarhia Sikh, completed his education upto middle standard, agricultural labourer, suffering from cancer of larynx, village Mehmuan, District Faridkot) told that the village people looked upon at him with hatred which made him feel stigmatised. They had fears and strong prejudices regarding cancer. They considered cancer
Plate 7.12: An advanced cancer patient secluded from his family
as a disease of sin i.e. a person is afflicted with cancer because of karmā. He was afraid that the stigma towards his disease would prove bad, especially for his daughters. They might not get a good life partner because of the disease.

Case 92: A male respondent (aged 52 years, Majhabi Sikh, illiterate, agricultural labourer, cancer primary unknown with metastasis in liver, village Machaki Kalan, District Faridkot) was staying with his wife's village with his two children. He was interviewed at his wife's native village (Mehmuana, District Faridkot). The family disclosed about cancer only to the landlords from whom they get the financial help. They did not disclose about the diagnosis to anyone else. As they explained that cancer spreads from one person to other and nobody would visit them or share food with them after knowing of the diagnosis. It was also observed that the respondent's family have also secluded him as he is made to sleep on a bed outside the house close to the area where domestic animals are kept. His utensils and clothes are also separated. The separate toilet pit has been dug for him which means that he is not even allowed to use the toilet which other family members use. On enquiring about this, his family members explained that this disease is due to his wrong deeds and thus, he should suffer alone and not the whole family. They do not want to be afflicted by the disease as for them this disease is contagious and spreads from one person to another.

The primary focus of stigmatisation experienced by persons with cancer is social isolation resulting from the aversion of others towards cancer patients. Therefore, individuals with cancer have concerns about disclosure of their medical history for occupational and social reasons. Occupational stigmatising frequently occurs as a result of the myths that cancer is a death sentence, cancer survivours are unproductive and a drain on the economy and cancer is contagious (Mellette, 1985). Disclosure is also a problem for unmarried survivours as new relationships and the issues of sexuality and
sterility are contemplated. Therefore, it has been suggested that some degree of isolation is imposed by others. Given these circumstances, the stigma of cancer diagnosis sets survivors apart from others, results in perception of the self as being different in important ways, and increases of isolation and alienation.

Case 93: A female respondent (aged 24 years wife of a cancer patient aged 26 years from village Doda, District Sri Muktsar Sahib) told that she got married in October 2010 and she was not told about the disease status of her husband. After a month of their marriage, her in-laws told her to stay with her parents in Sri Muktsar Sahib for somedays and ensured that her husband would come after a week or so to take her back but this did not happen. For the next four months, there was no communication from her in-laws and their house was also locked. After four months, his father-in-law came to take her back but the respondent's father also accompanied his daughter to her in-laws place. To their surprise, the respondent's husband was all bald and weak. They both questioned the family and came to know he is suffering from cancer and his family took him to Tata Hospital, Mumbai for his treatment. The respondent told that she questioned her husband and his family so as to why they ruined her life. The family gave the reason that their son is in advanced stage of cancer and they got him married so that he has children and his name continues after his death.

In this case, the family tried to hide the cancer diagnosis of the patient not only outside the family unit but from his wife as well. Similar kind of findings has been noted elsewhere that stigma associated with cancer often preclude cancer patients from openly discussing their experiences with individuals outside their family units (Bottorff et al., 1998; Choudhry et al., 1998).

Case 94: One of the villagers expressed that he attended the pyre lighting ceremony of a cancer patient and saw that a big mass
of the body kept burning even till the third day. Then the family, took that piece of mass, wrapped it in a big cloth piece and placed it deep in the pit which they dug for the purpose. The rest of the ashes were thrown in the sacred Sutlej river at Gurdwara Shri Patalpuri Sahib but the family decided not to throw that piece of mass in water so as to avoid further infection. He told that cancer is contagious and it is better to stay away from such people and their families.

It is clear from the above cited cases that wide spread stigma related to cancer was prevalent in the areas under study. There are a number of ways in which stigma related to cancer is manifested. These include keeping the utensils and other things of necessity separately, washing utensils and clothes of the cancer patients separately, giving food to cancer patients separately, keeping the cancer patients at isolated places. It is also important to note that wide-spread manifestation of stigma leads to non-disclosure of cancer.

The Figure 7.1 shows the interrelationship between stigma, its manifestations, body image concerns and beliefs related to cancer and its treatment; which is based on data collected by the researcher during her first-hand fieldwork. It can be concluded that there are two main causes of stigma; firstly, bodily changes due to cancer and its treatment and secondly, beliefs related to cancer and its treatment. Regarding bodily changes due to cancer and its treatment, we may conclude that loss of hair, loss of breast, loss of sexuality and facial disfigurement as a result of cancer and its treatment leads to bodily changes which further leads to body image concerns. The body image concerns among cancer patients are because of two reasons; firstly, due to bodily changes and secondly due to stigma. The other causes of stigma are beliefs related to cancer and its treatment. Beliefs related to causes of cancer (*karmā, kismat and contagion*), and beliefs related to nature of disease (*cancer fatalism and incurability of cancer*) leads to manifestations of stigma in terms of preferable use of other terminology instead of cancer (*mari bīmarī, chandari bīmarī, bhairi bīmarī*, opri bīmarī, *jar vala phora, mare karmā valī bīmarī* and *Bikaner valī bīmarī*)**, non-disclosure of cancer and discrimination against cancer patients.
Discrimination against cancer patients
Non-disclosure of cancer
Preferable use of other terminology instead of cancer

Figure 7.1: Network of stigma related with cancer

Source: Prepared by researcher based on original fieldwork
7.4.3 Concerns about other family members

Diagnosis with cancer gives rise to uncertainty which further gives rise to concerns about the health of other family members. With their long-term treatment and symptom problems, the cancer patients get worried about their other family members. The first concern regarding the family members is their health. Some of the cases relating to this are given below.

Case 5: A female respondent (aged 54 years, Majhabi Sikh, completed her primary education, agricultural labourer, suffering from cancer of gall bladder, undergoing treatment at GGS Medical College, Faridkot, village Chandbaja, District Faridkot) had only two daughters and both of them were married. Though, the respondent was undergoing treatment and she was responding well to the treatment but she broke down on account of her worry relating to her husband. She explained that her daughters live far away from them and visit very rarely. So, her husband is alone and if anything happens to her, there will be no one to take care of him. In such a case life would be difficult for him.

Case 6: A male respondent (whose wife aged 35 years, cancer of cervix), was undergoing treatment at GGS Medical College, Faridkot and he was diagnosed with cancer in September 2010 at the same hospital. She was a mother of eight months old child. After death of his wife, he became uncertain about the life of his child. He asked the doctors about the survival of his child. He questioned will his child be able to survive? What will be the symptoms to recognise the cancer in child? At what age the physical examination of the child is done to rule out the possibility of cancer? These questions which he asked clearly points towards uncertainty in his mind towards the future of his child. To his queries, the doctor responded, “If there is no problem in growth and development of a newborn, then there is no need to worry and to undergo any tests as of now”. The
doctor also explained that growing of foetus in the body of mother who is a cancer patient does not mean that child would also be affected as cancer is not contagious disease and does not spread from one person to the other.

In these cases, cancer is considered as a disease which is and will be passed on from one generation to the other. This associates with it the notions of 'risk', 'uncertainty' and 'fear'. The disease is considered to be associated with the family through genes and inevitable. Similar observation have been made by Finkler (2000) who argued that family and kinship relations are medicalised through explanations of the inheritance of genetic diseases and related risk factor. The concerns about other family members not only include the health concerns but also other concerns such as marriage of their children or siblings. Some of the cases relating to this are given below.

Case97: A male respondent (aged 65 years, Jatt Sikh, completed her education upto matric, village Mandwala, District Faridkot) was suffering from the cancer of gall bladder. His wife aged 62 years was suffering from cancer of cervix. He told that they have a son who is married and a daughter who is of marriageable age. They told that after knowing about the parent's disease, no family comes with marriage proposal for their daughter as it is commonly believed that cancer is an incurable disease that spreads from one person to another. Thus, he felt that the disease is posing a threat to the prospects of their daughter's marriage.

Case98: A female respondent (aged 47 years, Jatt Sikh, completed her education upto graduation, housewife, suffering from cancer of cervix in advanced stage, village Bhagsar, District Sri Muktsar Sahib) told that her life is unpredictable with the disease like cancer. So, she wants to get her son married as soon as possible but she shared that a large number of people approaches her but they do not turn up after knowing about the diagnosis and prognosis of her disease. They fear that the
person who stays with her throughout the day have the great chances of getting the disease. So, they do not want to get their daughters married to her son. The other reason which she cited was that most of the people fear that if mother has cancer then the son may also develop the disease in future. These two reasons reduce the probability of marriage of cancer patients.

It is clear from the cases that people do not prefer to get their children married in the families with any of the cancer cases and thus, the concerns about the marriage prospects of their children and siblings are very important for the cancer patients.

It was found that cancer patients have two types of concerns about their family members. These include concerns regarding health of their family members and the other concerns include the marriage of their children or siblings. These concerns are due to belief that cancer is contagious and the stigma associated with cancer. The belief that cancer is contagious creates a fear within the family in relation to health of other family members. The stigma associated with cancer affects the social interaction of cancer patients and their families outside the family unit. This further affects the marriage prospects of those related to cancer patients.

7.5 CONCERNS AT END-OF-LIFE: PATIENT’S, CAREGIVER’S AND HEALTH CARE PROVIDER’S PERSPECTIVES

This theme is mainly divided into various sub-themes such as palliative care, patient’s concerns, caregiver’s concerns and health care provider’s concerns at end-of-life.

7.5.1 Palliative care

Palliative care is defined as the care and management of the patients with active, progressive, far-advanced disease for whom the treatment is limited and the focus of such a care is quality of life (QOL). It is the active total care of patients whose disease is not responsive to curative treatment.
Palliative care has evolved because of insights developed within the modern hospice setting, through listening to patients and paying attention to their needs. Since the 1960s, new treatment and new concepts of care are being developed which are relevant to current practice. It has extended its spectrum of responsibility from care for the dying to caring for patients with irreversible disease at any point in their illness. Although palliative care has focussed on the needs of patients with cancer, it is also available for non-cancer patients such as those suffering from AIDS, congestive cardiac failure and motor neuron diseases, etc. (Scottish Partnership for Palliative Care, 2007).

Palliative care can be defined as the total care of patients and their families by a multiprofessional team when the patient's illness is no longer responsive to curative treatment. The control of pain, of other symptoms, and of psychological, social, and spiritual problems is important aspect of palliative care. The other important goal is to palliative care is achievement of best possible QOL for patients and their families.

WHO (1990) further defines palliative care by its characteristic principles:

- Affirms life and regards dying as a normal process.
- Neither hastens nor postpones death.
- Provides relief from pain and other distressing symptoms.
- Integrates the psychological and spiritual aspect of patient care.
- Offers the support system to help patients live as actively as possible until death.
- Offers a support system to help the family cope during the patient's illness and in their own bereavement.

7.5.1.1 Hospice: Hospice is a type of care and a philosophy of care that focusses on the palliation of a terminally ill patient's symptoms. These symptoms can be physical, emotional, spiritual or social in nature. Hospice care focusses on bringing comfort, self-respect, and tranquillity to the dying patient. Patients' symptoms and pain are controlled to help reach these goals;
however, the focus is providing care, not curing. The concept of hospice has been evolving since the 11th century. Then, and for centuries thereafter, hospices were places of hospitality for the sick, wounded, or dying, as well as those for travellers and pilgrims. The modern concept of hospice includes palliative care for the incurably ill given in such institutions as hospitals or nursing homes but also care provided to those who would rather die in their own homes. It began to emerge in the 17th century, but many of the foundational principles by which modern hospice services operate were pioneered in the 1950s by Dame Cicely Saunders. Hospice care also involves assistance for patients’ families to help them cope with what is happening. Although the movement has met with some resistance, hospice has rapidly expanded through the United Kingdom, the United States and elsewhere. Hospice exists to reduce this stress and diminish the feelings of isolation that accompany the dying process. The goals of hospice include reducing suffering at the end-of-life by creating an environment supportive of open communication about patient’s wishes and concerns about dying and death.

The hospice model is an example of interdisciplinary end-of-life. It incorporates Eastern perspectives into end-of-life care in such a manner as to cater to patient's emotional and spiritual needs and not just their physical needs. Hospices do not believe in aggressive cure through invasive, highly technologised and curative treatments that often cause more pain and distress. They focus on providing gentle ‘care rather than cure’ to dying patients for whom there is not much hope of cure from the illness.

Banerjee (2009) described ‘hospitals’ as the dens of maintenance of the physical body but lacking the emotional, social and spiritual care of the individual. The hospital is the right place for treatment but may not he right place for palliative care. In contrast, hospice is a place which provides relief from pain and other distressing symptom, affirms life and regards dying as normal process. It intends neither to hasten nor to prolong death. It provides psychological as well as spiritual care to patients and support patients to live as actively as possible until death. It offers a support system to help the family
cope during the patient’s illness and in their own bereavement. Palliative Care enhances the quality of life and may positively influence the course of illness.

In India, families have traditionally taken on much of the responsibility for caring for ailing and dying people. However, with changing family structures and increasing mobility of families, patients and their families today face considerable difficulties in managing such care on their own. These factors have led to the growth of palliative care clinics and hospices in India.

7.5.1.2 Palliative care in India: The concept of palliative care is relatively new to India, having developed over the past 15 years. With inputs from WHO, Red Cross and Cancer Relief India (CRI), palliative care is being set up in India. CRI funded palliative care posts in India and in 1994 began four year pump-priming for the establishment of the pain and palliative care clinic in Calicut which is now a WHO recognised model of delivery of palliative care for South-East Asia. Between 1993 and 1995, CRI and Cancer Relief Macmillan Fund in collaboration with WHO facilitated the training of doctors and nurses in palliative care courses in the United Kingdom during a three year Indo-British Project, and similar efforts have also been made by Red Cross to train the doctors and nurses effectively for palliative care. The Indian Association of Palliative Care was also formed in 1994 in consultation with WHO and Government of India to promote palliative care in India. Inspite of the efforts made for establishing palliative care in India, there are a number of challenges. These include lack of a national policy on palliative care in India, lack of government commitment on the issue, difficulties in availability of medicines, difficulties in training of health care providers, lack of communication between doctors and patients (Seamark, 2000).

Significant progress with palliative care continues to be made in India with the integration of palliative care in major cancer centres and the offering of fellowships in palliative care. Therefore, it is important to reinforce the continuing need for this alternative approach to cancer care in India and assess whether palliative care teams improve better QOL outcomes. However, one of the barriers of ongoing palliative care development in India is
the adopting of Western palliative care models, which are often irrelevant to the Indian setting. One aspect of Western palliative care that is particularly difficult to implement in the Indian context is the health care ethical standards by which palliative care centres are expected to uphold.

7.5.1.3 Palliative care at PGIMER, Chandigarh: Palliative care and home care was started in February 2000 by Indian Red Cross Society, Chandigarh in collaboration with PGIMER, Chandigarh. Palliative care is provided at PGIMER, Chandigarh from Monday to Friday in the unit termed as 'pain clinic' from 9 am in the morning to 1 pm in the afternoon. The terminally ill cancer patients from tricity (Chandigarh, Mohali and Panchkula) are provided with the facility of home care in which patients are visited at least once in a week or earlier depending upon the needs of the patients. This includes providing nursing care, dressing of the wounds and counselling to the patients as well as their families. Even after the death of the patient, the family is visited by the palliative care team one or two times for bereavement and to provide support.

As an extension of the previous Palliative care and home care programme, Chandigarh hospice was established in January 14, 2003. It is a 20 bedded hospice for terminally ill cancer patients with 2 medical officers, 4 staff nurses and other employees who are professionally trained in understanding the hospice and home care philosophy, death and dying, and bereavement as well as developing communication and listening skills. The various services are provided at Chandigarh hospice includes medication, dressing, nursing care and food for the patient. These services are provided free of cost.

7.5.2 Patient’s concerns

All the respondents in advanced stage of cancer were interviewed at pain clinic, which is a palliative care unit of PGIMER, Chandigarh. To deal with the issue of concerns at the end-of-life, it is very important to take the patient's perspective, caregiver's perspective and the health care provider’s perspective into account.
In this section, data is collected from a total of 30 advanced cancer patients using EORTC QLQ-C30 instrument and an interview guide. The EORTC QLQ-C30 is a well-known instrument for measuring QOL in cancer patients and contains 30 items that measures five functional scales, global QOL and several cancer related symptoms. All these patients were interviewed at baseline assessment at their first visit to a palliative care unit in a tertiary care centre and the follow-up after 15 days. The demographic data (age, gender, caste, marital status, educational status and occupational status) were recorded at the patient's initial presentation. An informed consent from both the patient and the caregiver was obtained before interviewing the patient. The higher values indicate higher level of functioning and QOL where 0 is minimum and 100 is maximum (Table 7.35).

**Table 7.35: Level of functioning among advanced cancer patients**

<table>
<thead>
<tr>
<th>Functioning</th>
<th>Baseline assessment</th>
<th>Follow-up assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>Cognitive functioning</td>
<td>56.40 (21.95)</td>
<td>72.35 (14.00)</td>
</tr>
<tr>
<td>Social functioning</td>
<td>48.00 (32.32)</td>
<td>54.55 (15.11)</td>
</tr>
<tr>
<td>Role functioning</td>
<td>46.35 (45.00)</td>
<td>49.50 (19.31)</td>
</tr>
<tr>
<td>Emotional functioning</td>
<td>35.20 (20.73)</td>
<td>74.50 (8.21)</td>
</tr>
<tr>
<td>Physical functioning</td>
<td>19.55 (14.55)</td>
<td>60.30 (10.96)</td>
</tr>
</tbody>
</table>

* Standard deviance in parentheses

The physical functioning among advanced cancer patients was found to be lowest of all the functional scores at the baseline assessment. It showed a marked improvement of 40.75 points from first baseline assessment at 19.55 to follow-up at 60.30. The cognitive functioning is found to be highest at the first baseline assessment and increased from 56.40 to 72.35 points. The emotional functioning also showed a great improvement from 35.20 to 74.50 points. Both the role and emotional functioning showed little improvement with palliative care from 46.35 to 49.50 and 48.00 to 54.55 points respectively. The levels of symptom burden among advanced cancer patients are given in Table 7.36.
Table 7.36: Level of symptom burden among advanced cancer patients

<table>
<thead>
<tr>
<th>Functioning</th>
<th>Baseline assessment</th>
<th>Follow-up assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>Mean</td>
</tr>
<tr>
<td>Constipation</td>
<td>82.00 (34.40)</td>
<td>62.85 (30.25)</td>
</tr>
<tr>
<td>Dyspnoea</td>
<td>76.90 (32.50)</td>
<td>63.25 (33.50)</td>
</tr>
<tr>
<td>Insomnia</td>
<td>73.55 (23.80)</td>
<td>59.25 (12.6)</td>
</tr>
<tr>
<td>Nausea</td>
<td>69.40 (33.25)</td>
<td>52.05 (25.76)</td>
</tr>
<tr>
<td>Appetite loss</td>
<td>53.80 (21.88)</td>
<td>49.00 (15.12)</td>
</tr>
<tr>
<td>Fatigue</td>
<td>49.25 (21.25)</td>
<td>60.50 (29.35)</td>
</tr>
<tr>
<td>Pain</td>
<td>48.60 (42.87)</td>
<td>37.00 (19.25)</td>
</tr>
</tbody>
</table>

* Standard deviation in parentheses

In symptom scale, high score represents a high level of symptomatology or a problem where 0 is minimum and 100 is maximum. The fatigue did not show any improvement rather increased at the follow-up assessment. Nausea, pain, dyspnoea and appetite loss also showed improvement from 69.40 to 52.05 points, 48.60 points to 37.00 points, 76.90 to 63.25 points and 53.80 to 49.00 points respectively. Insomnia as a symptom showed the marked improvement from 73.55 to 59.25 points. Constipation among the patients also improved from 82.00 to 62.85 points.

These findings show that advanced cancer patients benefitted from the palliative care. Except for role functioning and social functioning, other items on functional scale showed marked improvement. However, sustained symptoms such as fatigue (thakāvat), nausea (ji kacchā honā), pain (dard), dyspnoea (sah chadnā) and appetite loss (bhukh nā lagnā) were found. The other symptoms like insomnia (neend nā aunā) and constipation (kabaj) showed a marked improvement. Thus, it can be concluded that palliative care plays a very crucial role in improving QOL among advanced cancer patients.

7.5.2.1 Talking about death as a taboo: Some scholars have questioned the presumed taboo surrounding the use of term 'death' and communicating
about death and contend that certain attitudes and behaviours signal a shift in modern day society’s willingness to make death and dying more visible (Walter, 1994). Medical technologies and some increased interests in death related topics mark a transformation of dying and death, but not necessarily one that indicates the removal of related taboos. Walter (1994) argues that death taboos include more nuances than many scholars describe and that the proscription surrounding death exists for certain groups (medical personnel and the media), the individuals (the dying and the bereaved) but not for society as a whole.

It was found that the death is considered an inevitable truth which is evident in a narrative of one of the respondents “Marnā sachh te jeona jhooth” (Death is truth and life is a lie). The caregivers considered death as a continuity of life and it was considered as a temporary phase, since it is eventually followed by liberation of the soul. It was also believed that death merely leads to the end of the body and not the soul. These views can be supported by the concept of reincarnation in Sikhism.

The concept of reincarnation is also discussed in Guru Granth Sahib:

*Lakhir chaurāṣi fer paīā mar jammāi hoe khuār* II (SGGS, 88)
(They go through the cycle of 84 lakh reincarnations and they are ruined through death and rebirth).

*Kar kirpā parabh bhēlā maran na āvan jāo* II (SGGS, 48)
(Granting His grace, God meets us, and we no longer die, or come or go in reincarnation).

*Jin gurmukh nām na būjhiā mar janmai āvai jāe* II (SGGS, 19)
(Those who do not become gurmukh do not understand the nām, they die, and continue coming and going in reincarnation).

Āvan jan na chuki mar janmai hoe khuār II (SGGS, p. 19)
(Their coming and going in reincarnation do not end, through death and rebirth, they are wasting away).

Āvan jānā jaman marānā manmukh pat gavāl II (SGGS, p. 31)
(Coming and going through birth and death, the self-willed manmukhs loose their honour).

Āvan javan mitai parabh sev II (SGGS, p. 288)
(Coming and going in reincarnation is ended by serving God).
It is clear from these verses that an individual goes through 84 lakh reincarnations as per belief in Sikhism and this circle of reincarnations can only be broken by the power of nam and service of God.

Some of the family members may be psychologically unprepared to hear the diagnosis or prognosis at a specific moment of time. Denial may be the natural consequence of not being able to recognise the explicit facts about the illness accompanied by responses of overwhelming grief, despair, or anger. In the present study, denial was found to be an important aspect of communication between patients and their caregivers. Some of the cases of denial and talking about death as a taboo are discussed below. If the patient talks about death or desire for death as a result of suffering, the caregivers react using the expressions such as, “eho jian gallan muho nā kado” (Do not say such things from your mouth) referring to the use of term maut (death) by the patient. In next sentence, the caregiver tries to motivate the patient by saying, “changian gallan sochea karo” (Think about good things) and gives assurance that “tuhānu kuchh nahi hundā” (Nothing will happen to you).

In another conversation, a caregiver (son) of a 60 years old breast cancer patient expressed, “jīhnu kainsar hove ohnu pichho yād nahi karde jādā, kehnde ne ke ehoji bīmarī nāl ātmā nu shāntī nahi mildī” (The one who dies with cancer is not remembered thereafter, it is believed that the soul does not rest in peace with this disease). Here the term death is not used directly but the caregiver referred to death and beliefs relating to it. Another expression refers to the same argument that death is considered as a taboo. A caregiver reacted, “Anāye te anchhāhe ant to bād, ātmā nu shāntī mīnī aukhī hai” (After untimely and unwanted death, it is difficult for soul to rest in peace). Here the term 'end' is used in place of death. It is believed that if a soul does not rest in peace, it keeps on wandering around those who keeps on remembering the deceased for too long. Thus, it is advised not to remember those who are not alive. It is further believed that this makes it easy for soul to liberate from the present birth and take another birth.

7.5.2.2 Gender roles and financial concerns: Cancer is often so pervasive that it has an impact in shaping the social images of the illness reality within
the family milieu. Families are catapulted into an unfamiliar environment where they have little or no time emotionally and psychologically to incorporate, absorb and integrate the illness within the average course of their lives. The families and patients construct their own personal illness narratives to apprehend the meaning of the illness experience (Baider, 2008). Suffering from a chronic illness impels people to reconsider and reshape their roles and responsibilities within familial and social groups. Some of the cases relating to social role fulfillment are discussed here.

Case 9: A female respondent (aged 34 years, Jatt Sikh, completed her education up to post-graduation, suffering from breast cancer with bone metastasis, village Husnar, District Sri Muktsar Sahib) was diagnosed with breast cancer three years back in 2009, she underwent breast removal surgery and radiation at PGIMER, Chandigarh but the disease metastatised again in 2011 in bones. The respondent is registered with pain clinic, PGIMER, Chandigarh for palliative care. She told that her mother-in-law is 70 years old and unable to do any household work. This situation left her with no choice and she has to do all the household work inspite of her advanced disease and severe pain. She narrated her experience as:

“Aurtan di zindagī bahut buri hai, maran tak jīmēwārī nibhānī painī hai”
(Life of women is very difficult; she has to fulfill all her responsibilities till the time she dies).

Parsons (1951) concept of sick role does not hold true for this case as the woman suffering from cancer is not exempted from her responsibilities and still expected to fulfill her roles and obligations in spite of her advanced stage of disease. This finding is in accordance with the findings of Winkelman (2009) who challenged the Parsons’s concept of sick role for not holding true for long term illnesses. In this case, the respondent was asked why is she not exempted from her social roles and responsibilities, she explained that her family believed that she herself is responsible for her disease as it is caused due to her past karma. Winkelman (2009) also explains that Parsons sick role
concept does not apply to those illnesses in which the individual is held responsible for its causation.

Case 100: A female respondent (aged 34 years, Jatt Sikh, completed his education up to postgraduation, suffering from cancer of gall bladder with spread to chest, village Middukhera, District Sri Muktsar Sahib) was diagnosed with cancer at a private hospital in Ludhiana in July 2011. She was diagnosed with cancer at a very advanced stage but the doctors at the hospital did not tell the respondent and her family about the prognosis. With three cycles of chemotherapy costing about one lakh rupees and no relief in pain, left the family with no choice but move to a government hospital. The respondent and her husband came to PGIMER, Chandigarh in late October 2011 and were registered in pain clinic for palliative care. The respondent cried and persuaded that she has two children aged 6 years and 4 years to look after and she wants to get well as early as possible. She narrated:

“Mainu bachålo, mere bachhe bahut chhote ne”
(Save my life, I have to look after my kids).

Here the respondent adhered to the Parsons point of view that an individual who is ill tries to regain or restore health. The respondent was not aware of her advanced stage of disease and she believed that her condition is temporary. Thus, she wanted to get well as early as possible to resume her responsibilities.

Case 101: A female respondent (aged 36 years, Jatt Sikh, completed her education up to graduation, housewife, suffering from cancer primary unknown with metastasis in liver in advanced stage, village Giana, District Bathinda) was worried about her son (aged 15 years) whom she adopted from her younger brother as she was not able to give birth to a child. Her husband also died of cancer seven years back in a private hospital in Delhi. She was concerned about the future of her
child after her death. So, she returned the child to his biological parents so as to secure his future.

The concern here was not that the child would also get the disease as she was totally unaware of her disease diagnosis or prognosis. The respondent was admitted to PGIMER, Chandigarh with complain of jaundice and she believed that something serious has happened to her. Her concern was the future education and care of the child. That is why, she decided to return the child to his parents so as to make his future secure.

Case 102: A female respondent (aged 65 years, Jatt Sikh, completed his education upto senior secondary, farmer, suffering from cancer primary unknown with metastasis in liver, village Bhuttiwala, District Sri Muktsar Sahib) was worried about her only daughter who was married for seven years and had no child. The respondent shared that she wants to live for few more years till her daughter gets treated for infertility and have a child. At the time of interview, the respondent was most concerned about her daughter and wanted to support her daughter all through her treatment as a mother. Her role as a mother was the central concern for her. She was also not aware of her diagnosis and prognosis. She had stomach distension which led to stretching of her stomach and she felt that it would burst someday. Even though she was unaware of her disease but her symptoms made her to think that her end was near.

Case 103: A female respondent (aged 66 years, Jatt Sikh, completed her education upto matric, housewife, cancer primary unknown with metastasis in bones, village Mehmuana, District Faridkot) shared that her younger daughter lost her husband in an accident and had a four year old son. The respondent wanted herself to be treated as soon as possible as she want to get her daughter re-married. She explained that nobody in her family even her daughter does not think about her daughter's re-marriage and her survival is very essential. She was also completely unaware of her diagnosis and prognosis.
Case_{104}: A female respondent (aged 78 years, Jatt Sikh, illiterate, housewife, suffering from cancer of cervix in advanced stage, village Husnar, District Sri Muktsar Sahib) had only one son (aged 32 years) and her husband left her while her son was four years old. From then onwards, she brought up her son as a single parent. Now, as she was close to her death, she shared that as she wants to live till the time her son gets married. The recurring questions such as, “who will take care of her son after her death?”, “will he be able to survive alone or will end his life as well?”, “will he be able to get a good life partner in absence of any elder at home?” “will his partner be genuine or someone who will dupe him of all his money?” These recurring thoughts bother her and she tries to prepare her son for the worst.

In this case, the respondent’s role and responsibility as a mother was bothering her the most as she wanted best for him before she dies.

Case_{105}: A female respondent (aged 75 years, Jatt Sikh, illiterate, housewife, suffering from cancer of pharynx, village Deon, District Bathinda) stays with her husband, son, daughter-in-law and their children. Her son suffered from depression after he came to know about his mother’s illness. She explained that her son’s wife was also not ready to take care of her initially. So, her husband clearly told her daughter-in-law that he would give his farmland, which is 8 acres, to all his three daughters and not to his son if she would not take care of the respondent. Only then, their daughter-in-law started taking care of her. The respondent expressed: “Sāde kol jāmin jā paisean di ŋī, bandean di ŋī” (We do not have dearth of land or money but we lack the manpower) pointing out to her disease status and problems in her family.

Being a woman, she wanted to keep her household intact which she found impossible after her death. Though the doctors at PGIMER, Chandigarh told her clearly that no active treatment is
possible for her but she requested to continue her treatment even if she dies during the treatment. She wanted to take this risk in hope that she might live for sometime till her son gets well.

**Case 106:** A female respondent (aged 42 years, Majhabi Sikh, completed her education up to matric, suffering from cancer of cervix in advanced stage, village Deon, District Bathinda) told that she brought up her daughter as a single parent after she separated from her husband after a marital conflict. Her daughter was in 10th standard at the time of her interview and she has sent her daughter to her elder sister who has agreed to legally adopt the child after knowing about the advanced stage of her disease. She shared that earlier she was worried about the future of her daughter but now she is free from all such worries as her daughter is in secure hands. She expressed:

"Maran da darr nī lagdā hun”
(Now I am not scared of death).

Gender roles refer to the set of social and behavioural norms that are considered to be socially appropriate for individuals of a specific sex in the context of a specific culture, which differ widely between cultures and over time. The gender roles appeared to be central to the life of women. The most significant roles include that of mother towards her children and that of a wife toward her husband. The respondents wanted to fulfill some of their pending responsibilities before their death. They may not be aware of the cancer diagnosis or prognosis but they were aware from their condition that their end is near but hope played a significant role in their lives and they were ready to take chance for their treatment even if they die during the treatment.

Other than concerns about social roles and responsibilities, the cancer patients also discussed the financial difficulties faced by their families.

**Case 107:** A male respondent (husband of 32 years old patients suffering from cancer primary unknown with metastasis in brain, Bhuttiwala village, District Sri Muktsar Sahib) had to sell 2.5 acre
of his ancestral land for the treatment of his wife. He told that he has already spent ₹ 10 lakh on her treatment and now he has to borrow money from relatives to continue her treatment at PGIMER, Chandigarh. But he questioned “for how long can I keep asking for help from relatives who will begin to think that I am only wasting their money”? He mentioned that his last hope is help from the government. The Bhuttiwala village falls in the Gidderbaha Assembly constituency of Punjab. Cancer, in the past 10 years, has already claimed 43 lives in the village with a population of about 4,500 and eight are still fighting the disease. Bhuttiwala has earned the distinction of having maximum cancer death percentage in the District Sri Muktsar Sahib. He further stated the case of a 27 years old male cancer patient stopped his treatment as the expenses that incurred on his treatment left the family penniless. His father had to sell a part of their house to pay for the treatment and explained that for his widow, who gave birth to her second child after her husband's death, life would not be easy.

He further stated a case of a family from his village whose three members (including the man, his wife and their son) died due to cancer over a span of seven years. The only remaining son of the family narrated:

"Kainsar dā darr mainu kade ni chhaddā"
(The fear of cancer never leaves me).

Due to financial constraints, some of the cancer patients who were diagnosed in initial stages of cancer stopped their treatment and revisit the health care providers only when it became difficult for them to bear pain and other symptoms or take advice of some locally available doctor. Some of the cases relating to financial constraints faced by the patients and their families are discussed below.

Case 107: A female respondent (aged 60 years, Majhabi Sikh, illiterate, agricultural labourer, suffering from cancer of cervix,
village Dhoorkot, District Faridkot) has three children, two sons 
(aged 35 years and 33 years respectively) and a daughter aged 
29 years. She was interviewed at her native village and used the 
term oprī bīmaṛī (unknown disease) for cancer. She was aware 
of her cancer diagnosis but not the prognosis. On asking about 
cancer, she explained that she only know that she has a cancer 
but not aware of disease at all. She mentioned that excessive 
bleeding was the first symptom of cancer which she observed 
and brought to the notice of her sons and daugthers-in-law. She 
narrated:
“Khūn pain nāl oprī bīmaṛī bangal” 
(Excessive bleeding led to development of an unknown disease).

As she was a post-menopausal women, the excessive bleeding 
became a matter of concern for everyone in the family. On 
noticing the first symptoms, her eldest son took her to GGS 
Medical College, Faridkot where she was diagnosed with cancer 
of uterus in December 2010. After knowing about her cancer 
diagnosis, her sons and daugthers-in-law refused to carry out 
her further treatment. Her daughter takes her to a desi doctor 
(quack) in village Manuke near Moga and carried out her 
treatment for around six months. The treatment gave her slight 
relief in pain but she continued to bleed. Later, her daughter also 
stopped her treatment due to financial constraints. At the time of 
interview, she was not undergoing any kind of treatment and 
whenever she feels pain or any other problem, village doctor is 
consulted. The belief that cancer is incurable and ultimate end of 
this disease is death and the financial constraints led her family 
to stop her treatment. The family members explained that she 
would die someday or the other, but they have children at home, 
who are to be educated and whole of their life is in front of them. 
So, their responsibility is more towards their children than their mother.
Case: A male respondent (aged 52 years, Majhabi Sikh, completed his education upto senior secondary, agricultural labourer, suffering from cancer primary unknown with metastasis in liver, village Machaki Kalan, District Faridkot) was staying with his wife's village with his two children. He was interviewed at his wife's native village (Mehmuana, District Faridkot). He used the term bhairī bimarī (bad disease) to refer to cancer. He was diagnosed in an earlier stage but due to lack of treatment (due to financial constraints), the disease advanced. Initially, he felt that his stomach region is coming out and it is very hard to touch. After sometime, it got stretched out so much that the respondent felt that it would burst someday. The respondent went to GGS Medical College, Faridkot with the symptoms of abdominal distension in March 2011. He was diagnosed with cancer but as he and his family believed that treatment of cancer is better at Bikaner. So, after diagnosis they went to Bikaner for his treatment. Due to inability to afford the cost of treatment and travelling charges, his family stopped his treatment. At the time of interview, he was not undertaking any kind of treatment due to financial constraints. Whenever he feels that his pain was unbearable, his family calls a village allopathic doctor for pain killer injection (voveran). He agreed that he and his family visited a dhaulā healer near the village Jaurian Chakian and in his village itself for his treatment. The reason for visit to traditional healers was that he could not afford the costly medical treatment and such traditional healers do not ask for money. It is up to the patient to give any amount of money which they afford. He questioned that government is not making any efforts to reach the cancer patients for treatment. His family was prepared that one day he would die and they have to live their life on their own. In order to make-up the loss of income due to his disease, his son (10 years) and daughter (8 years) also started working in the houses of landlords.
The above cited cases mention a number of concerns of advanced cancer patients including concerns about gender roles and financial concerns. The Plates 7.13 and 7.14 shows the advanced cancer patients interviewed at their native places.

7.5.2.3 Contrary body image concerns: In relation to body image concerns, 83.3 per cent respondents, undergoing symptomatic treatment were worried about integrity of body and only 16.7 per cent were worried about the identity. In contrary to the body image concerns among the cancer patients undergoing treatment, some of the respondents themselves wanted to bring alterations in their body so as to get rid of severe pain and suffering. In the context of advancing cancer, the desire for life and a life without symptom burden becomes important. Thus, advanced cancer patients showed less body image concerns than the patients who were undergoing treatment. Some of the cases are discussed as under:

Case110: A male respondent (aged 55 years, cancer primary unknown with metastasis in bones) had severe pain in his left hand and after three months of suffering from pain, he asked his doctor if the hand can be amputated as he was not able to bear pain but the doctor told him that it is not only his hand which is affected but disease has spread to other bones also. His doctor also made it clear to him that amputation is not a solution in such a case.

Case111: A female respondent (aged 64 years, Jatt Sikh, completed his education upto matric, farmer, suffering from cancer primary in knee with bone metastasis, village Malkana, District Bathinda) was completely bed-ridden and not able to walk or sit. She had a severe pain in her right leg which was primary site for cancer. Earlier she was advised amputation of right leg in a private hospital but she refused. Later but due to her inability to bear pain, she agreed for amputation. Even after amputation, she did not get much relief as the ends of amputated leg also suffer shooting pain.
Plate 7.13: An advanced cancer patient with her husband

Plate 7.14: An advanced cancer patient at her place
Case\textsubscript{112}: A male respondent (aged 15 years, Jatt Sikh, completed his education upto ninth standard, student, suffering from cancer primary unknown with bone metastasis, village Wada Draka, District Faridkot) with right leg amputation told that after amputation, he feels severe pain at the ends of the amputated leg. He shared that after amputation he is not a normal child anymore as he will not be able to play with his friend. Though, he was hopeful that with the help of artificial leg, he will be able to walk properly.

Case\textsubscript{113}: A female respondent (aged 24 years, Jatt Sikh, completed her education upto graduation, student, suffering from sarcoma, village Mandwala, Faridkot) shared that she is bed-ridden and moves only for urination or stool. She told that her friends have distanced from her and none of their parents have allowed them to visit her after her diagnosis. Her body image concerns were dual, one, relating to hair loss after chemotherapy and second, due to amputation and surgery scars which according to her reminds her of her suffering. She also shared that on her request, her parents have removed all the mirrors from her room as she feels scared when she looks herself in the mirror.

Case\textsubscript{114}: A male respondent (aged 36 years, father of a girl child suffering from cancer primary unknown with bone metastasis) requested the doctor to amputate left arm of her daughter as she suffers from a constant pain but doctor replied:

\textit{Ki ki kat dayiye?}  
(How much did we amputate?).

This means that amputation is not a treatment or a solution to pain from cancer. It is not possible for patients who have cancer spread to a wider areas. The cases of amputation were found in the respondents who were earlier undergoing active treatment but later entered into advanced stage. The amputation was provided to these patients only to provide them temporary relief and not as a long term solution.
7.5.2.4 Coping strategies used by the patients

The term coping has been used to denote the way of dealing with stress or the effort to master the conditions of harm threat or challenge, when a routine or automatic response is not readily available (Lazarus, 1974). Coping can thus have an effect on the three kinds of outcomes: social, psychological and physiological. The coping is more of psychological aspect but it depends on a large number of social aspects such as social support, religion, belief system, etc. Coping strategies generally refers to those efforts, both behavioural and psychological, that people facing a difficult situation employ to master, reduce or minimise stressful events. Coping strategies mediate evaluation of the significance of a stressor or threatening event as well as evaluation of the controllability of the stressor and the person's coping resources. The two general goals of coping strategies are recognised: to alter the relationship between the self and the environment and to reduce emotional pain and distress.

In the face of death, each individual copes in his or her unique way. People in the same environment with the same stressors may cope very differently. Thus, coping is a fluid and dynamic process and different individuals may use different coping strategies.

(A) Search for meanings and attributing causes to cancer: A diagnosis of a life-threatening illness can turn a person’s life upside down. Things that used to give a person meaning and purpose in life are questioned; religious or spiritual beliefs may be questioned and sometimes rejected. The patient may feel a perceived abandonment by God also. The specific questions that arose in this reflective time among the respondents include:

- Why me?
- Why now?
- Why do good people suffer?
- Did I do something wrong in my life?
- Am I not praying and remembering God?
May be I have not been a good person?

What gives my life meaning and purpose?

The respondents who were aware of their diagnosis tried to search meaning relating to their illness while those who were not aware tried to search meanings behind their suffering.

After the diagnosis with cancer, a number of respondents attributed various causes to the disease causation. The attribution of cancer causation was different for patients undergoing active treatment and for the patients diagnosed in advanced stage. A majority of respondents with advanced cancers attributed its causation to karma (90 per cent) and others attributed the cancer causation to kismat (6.7 per cent) and stress (3.3 per cent). Some of the narratives of the respondents are given here.

A female respondent (aged 64 years, Jatt Sikh, housewife, cancer of vault, advanced stage) expressed:

“Main rabb di marji to baharkuchh galat karta, tan hi eh bimarī hoi”
(I must have done some wrong things against the will of God that is why I got the disease).

Another female respondent (aged 36 years, Majhabi Sikh, housewife, cancer of cervix, advanced stage) expressed:

“Main hi kuchh māre karam kite honge”
(I must have performed some wrong deeds).

It is clear from the narratives that through attribution of causes to cancer, the respondents tried to meanings behind it which helps to accept it as will of God.

(B) Religion: A number of studies relate religiosity as a coping strategy to cancer. These include Heim et al., 1993, Krause, 1993, Jenkins and Pargament, 1995; Risberg et al., 1996; Cotton et al., 1998, McClain, 2003; Aukst-Margetic et al., 2005; Vachon, 2008; Razaei et al., 2008; Koffman et al.,
2008; Kernan and Lepore, 2009; Baldacchino et al., 2012; Jang et al., 2012; Nguyen et al., 2012, etc. In the present study, religiosity appeared to be an important coping style used by the respondents. At the end-of-life, the respondents believed that it is God alone that can cure their disease (70 per cent) while 30 per cent believed that efforts of both the individual and God are important and none of the respondents believed that they alone can make efforts to get cured. The respondents mentioned verses from Sri Guru Granth Sahib in relation to suffering and death. These verses were carefully noted and looked into Sri Guru Granth Sahib. A detailed concept of suffering and death along with the verses mentioned by the respondents are given here.

Sikhism is not a philosophy of suffering. Even so, human suffering and death are two themes running through the Sikh poetic traditions. The poet-philosophers of Sri Guru Granth Sahib repeatedly stress these twin facts of human life, not for highlighting them, but to encourage human beings to face them and to conquer them. In Sri Guru Granth Sahib, Guru Arjan Dev Ji expressed the formula of overcoming anguish and suffering in life which is:

\[
\text{Tišū sahib kī tek nānak manne māhī} \\
\text{Jīsu simrat sukhu hoi sagale dūkha jahi} \text{ II (SGGS, p. 517)}
\]

(\text{Let my mind bank upon the support of that Lord; Contemplating whom joy descends and all sufferings vanish}).

In \textit{Gurbāṇī}, the suffering is used in all its dimensions. Guru Nanak Dev Ji (first \textit{Guru} of Sikhs) describes three types of suffering as:

\[
\text{Dukhu wechhorā eku dukhu bhūkha} \\
\text{Eku dukhu sakawar jamdāta} \\
\text{Eku dukhu rogu lagai tani dhāi} \\
\text{Waid na bhole dārī lāi} \\
\text{Dardu howai dukhu rahai saṛī} \\
\text{Aisa dārī lagai na bir} \text{ II (SGGS, p. 1256)}
\]

(\text{The pain of separation - this is the hungry pain I feel; Another pain is the attack of the Messenger of Death; Another pain is the disease consuming my body; O foolish doctor, don't give me medicine; Your medicine has no effect on me}).

\[
\text{Nānak bolanu jhakhanā dukha chhadi mangiahi sukh} \\
\text{Sukhu dukhu dui dari kapare pahirahi jai manukh} \text{ II (SGGS 149)}
\]
(O Nanak, it is absurd to ask to be soared from pain by begging for comfort; Pleasure and pain are the two garments, to be worn in the court of the Lord).

Guru Nanak Dev Ji often quoted, “Nanak dukhiyā sabh sansār” (SGGS, p. 517), matches in its sweep by Sheikh Farid's saying:

Faridā mai janiā dukhu mujhakū dukhu sabāiye jagi
Uche charī kai dekhiā tān ghari ghari ehā agi II (SGGS, p. 1382).
(Farid, I thought that I was in trouble; the whole world is in trouble! When I climbed the hill and looked around, I saw this fire in each and every home).

A major strand in Sheikh Farid's writings is existential anguish illustrated in his couplet that speaks of the midwife snipping the umbilical cord at birth: “Better, if she would also press a little the throat, one would not have to face the affairs of life and to bear its sorrows” (cf. Singh, 1983). The root metaphor in Sheikh Farid's bānī is dukh. The Sri Guru Granth Sahib also contains certain verses in which a brighter aspect of dukh such as “Dukh daru sukh rog” (SGGS, p. 5). The concept of dukh and sukh appears frequently in Sri Guru Granth Sahib. In Japuji Sahib, Guru Nanak Dev Ji expresses:

Ketīā dukhi sikhi sad mār ehi bhi dáti teri dátar II (SGGS, p.5)
(Many endure distress, deprivation and constant abuse, even these are your gifts, O great giver).

Here even the torments are treated as the Lord's gifts. The concept of dukh is further elaborated by Sheikh Farid by the concept of birhā:

Birhā birhā ākhīye birhā tū sultānu
Faridā jītu tani birhā na tipājai so tanu janu manāsu II (SGGS, p. 1379)
(Many talk of pain and suffering of separation, O pain you are the ruler of all. Farid, that body within which love of the Lord does not well up- look upon that body as a cremation ground).

In Sri Guru Granth Sahib, it is advised that in a situation of inevitable suffering; accept it with a sense of resignation to the Divine will. The only alternative is to engage oneself in prayer for the alienation of suffering, not only from one's own life, but from the life of humanity at large.
Jagatu jalanda rakhi lai āpnī kirpā dhārij
Jitu duārī uprai titai laihu ubārī
Satiguru sukhu wekhāliā sachhā sadhu bichari
Nānak awaru na sujhāi hari binu bakhasaṇhāru II (SGGS, p. 853)
(The world is going up in flames - shower it with Your Mercy, and save it; Save it, and deliver it, by whatever method it takes; The True Guru has shown the way to peace, contemplating the true word of the shabad; Nanak knows no other than the Lord, the Forgiving Lord).

In Sri Guru Granth Sahib, the self-willed manmukhs are described to suffer and that they depart in disgrace.

Andin dukh kamavde nit johe jam jale II (SGGS, p. 30)
(Night and day, they suffer in pain; they see the noose of death always hovering above them).
Manmukh andh na chethi dub mue bin pani II (SGGS, p. 31)
(The blind, self-willed manmukhs do not ever think of the Lord; they are drowned to death without water).

Manmukh maile malie mue jasan pat gavāe II (SGGS, 39)
(The filthy self-willed manmukhs die in filth, and they depart in disgrace).

Bhai winu jiwai bahutu bahutu khusī khusī kamāi
Nanak bhai winu je marai muhi kālai uthi II (SGGS 149)
(Without the fear of God, you may live very long, and savour the most enjoyable pleasures. O Nanak, if you die without the fear of God, you will arise and depart with blackened face).

As we see the concept of suffering and death are discussed in detail in Sri Guru Granth Sahib. Death is described as inevitable and described as an event which happens to every individual who is born. It is further described that the time and means of death are secret and the death is in hands of God. The others concepts that are discussed in Sri Guru Granth Sahib in relation to death are concepts of ‘reincarnation’ and ‘death while alive’.

The death and suffering are the two most fundamental aspects of human experience and also important to every religion. In Sri Guru Granth Sahib, especially in the writings of Sheikh Farid, death is described as a visible presence which is not to be ignored in course of the daily round of life. Talib (1975) quotes a verse of Sheikh Farid from Sri Guru Granth Sahib:
“Life is like a tree growing on the river's bank- how long may it last? How long may the unbaked pitcher retain water?”

In the writings of Sheikh Farid, death is figured as the bridegroom who must carry away on the appointed day his betrothed bride, loath to leave the parent's home like the typical Indian bride (Talib, 1975). Guru Nanak employed the metaphor of sister and the brother for depicting the relation of the body with the soul. The elements of inevitability and in determinacy associated with death constitute the major theme of verses dealing with human life in Sri Guru Granth Sahib. Some of the verses are as follows.

_Jivan marnā jāe kai ethai khājai kāl II (SGGS, p. 15)_  
(Life and death come to all who are born; Everything here gets devoured by death).

_Sabhanā maranā āīā wechhorā sabhnāh II (SGGS, p. 595)_  
(Death comes to all, and all must suffer separation).

_Gurmukh giān dori parabh pakhṛī_  
_Jin khinachai tin jāēai II (SGGS, 935)_  
(The _gurmukh_ knows that God holds the string; Whenever He pulls it, they must go).

_Nānak kis nu akheai_  
_Vin puchā hī laī jāye II (SGGS, p. 1412)_  
(O Nanak, unto whom should we complain? Death takes one's life away without anyone's consent).

Guru Arjan Dev Ji expressed that whosoever is born is sure to die.

_Jaise kirsānu bowai kirasāni_  
_Kāčā pākī badhi paranī_  
_Jo janamai so jānahu mūā_  
_Gowind bhagatu asthiru hai thīā II (SGGS, p. 375)_  
(Just like the farmer, He plants His crop; Whether it is ripe or unripe, He cuts it down; Just so, you must know this well, that whoever is born, shall die; Only the devotee of the Lord of the universe becomes stable and permanent).

Guru Tegh Bahadur Ji (ninth Guru of Sikhs), expressed his views on death as:

_Garabu karatu hai deh ko binsai chhina mai mīta_  
_Jīhi prānī harī jasu kahio nānak tihi jagū jītī II (SGGS, p. 1428)_.

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You are so proud of your body; it shall perish in an instant, my friend; That mortal who chants the praises of the Lord, O Nanak, conquers the world).

Sukha nai bahū sangī bhaye dukha mai sangi na koi
Kahu nānak hari bhaju manā anti sahai hoi II (SGGS, p. 1428)
(In good times, there are many companions around, but in bad times, there is no one at all; Says Nanak, vibrate, and meditate on the Lord; He shall be your only help and support in the end).

The moment of the actual death is secret though its inevitability is not.

Sheikh Farid talks of 'eagle' swooping unawares upon the crane, spoiling its fun and frolic. Here 'eagle' is used as a symbolic term for death.

Farīdā dāriāvāi kanai bagulā baithā kel kare
Kel karayday hānjh nu achinte bāj paye II (SGGS, 1383)
(Farid, the crane perches on the river bank, playing joyfully; When it is playing, an eagle suddenly pounces on it).

Guru Nanak Dev Ji speaks of the 'net' thrown to catch the fish, that is how death appears all too suddenly and one is not aware of mode of one's departure or how painful will it be (Singh, 1983). In the depiction of the life of a human being, Guru Nanak counts ten stages of life, beginning with the baby's love for the mother's milk followed by the various temptations and affections of death that reduces the body to ashes.

The Guru is the giver; the Guru is the house of ice. The Guru is the light of the three worlds; O Nanak, He is everlasting wealth. Place your mind's faith in Him, and you shall find peace; First, the baby loves mother's milk; Second, he learns of his mother and father; Third, his brothers, sisters-in-law and sisters; Fourth, the love of play awakens; Fifth, he runs after food and drink; Sixth, in his sexual desire, he does not respect social customs; Seventh, he gathers wealth and dwells in his house; Eighth, he becomes angry, and his body is consumed; Ninth, he turns grey,
and his breathing becomes laboured; Tenth, he is cremated, and turns to ashes).

It is also mentioned that nobody is satisfied with the amount of life lived and work completed in their lifetime. It is clear from the following verse:

*Raji na koi jivi pahuchi na chali ko I* (SGGS, p. 1412)
(No one lives long enough to accomplish all he wishes).

According to Sikh perspective, death is welcome, as it comes, but death is no better than life. Human life is considered as a serious affair. It is described as a valuable gift and a rare opportunity to identify and realise moral and spiritual objectives. This seems to be the *gurbani*'s main thrust. This view ensures that God is the pinnacle of all creation (Singh, 1983).

A verse of Guru Amar Das concludes:

*Kiia jann kiva marahagai kaisa maran hoi Je kari sahibu manahu na visarai ta sahil maran hoi Maranai te jagatu darai jivi lorai sabhu koi Gur parsadai jivatu marai hukamai buhai soi Nanaa aisi marani jo marai ta sad jiwanu hoi II* (SGGS, p. 555)
(What do I know? How will I die? What sort of death will it be? If I do not forget the Lord from my mind, then my death will be easy; The world is terrified of death; everyone longs to live; By Guru's grace, one who dies while yet alive, understands the Lord's will; O Nanak, one who dies such a death, lives forever).

The other verses which highlight the concept of death while alive are:

*Muija ghar jai tit jindi mar mar II* (SGGS, p. 21)
(To reach your true home after you die, you must conquer death while you are still alive).

*Gur parsadai apo chnai jivatia mareai II* (SGGS, 935)
(By Guru's grace, one comes to understand himself; in this way, he remains dead while alive).

*Kabir marata marata jagu mua mari bhi na jania koi Aise mame jo marai bahuri na marana hoi II* (SGGS, p. 1365)
(Kabir, dying, dying, the whole world has to die, and yet, none know how to die; Let those who die, die such a death, that they shall never have to die again).
To reach your true home after you die, you must conquer death while you are still alive.

Sheikh Farid argues that whereas everyone dies sooner or later, no one really knows how to die, if we know what it meant to die, we would not have to die again. The point is elaborated in Guru Nanak’s verse:

.Binding together water and air, He infused the breath of life into the body, and made the lamps of the sun and the moon; To die and to live, He gave us the earth, but we have forgotten these blessings.

The worldly delusions are described as 'delicious' by Guru Nanak Dev. He also referred symbolically to black buck:

Listen, O black deer: why are you so attached to the orchard of passion? The fruit of sin is sweet for only a few days, and then it grows hot and bitter; That fruit which intoxicated you has now become bitter and painful, without the name; It is temporary, like the waves on the sea, and the flash of lightning; Without the Lord, there is no other protector, but you have forgotten Him. Nanak speaks the Truth. Reflect upon it, O mind; you shall die, O black deer).

Some of the other verses in relation to death are:

(Farid, the shore of death looks like the river-bank, being eroded away).

(Farid, look upon pleasure and pain as the same; Eradicate corruption from your heart).
Malkal maut jā āvsi sabh darvāje bhann II (SGGS, 1383)
(When the messenger of death comes, it breaks down all the doors).

Kabir jis marne te jag darai mere mann ānand II (SGGS, 1383)
(Kabir, the world is afraid of death- that death fills my mind with bliss).

There are some verses in Sri Guru Granth Sahib in which God is described as the creator of all and by chanting His name, the fear of birth and death is eradicated.

Hukmī hovan ākār hukam na kahiā jāī II (SGGS, 1)
(By His command, bodies are created; His command cannot be described).

Ākhā jīvā visrai mar jāo II (SGGS, 9)
(Chanting it, I lives, forgetting it I die).

Satgur samī ālān bāhur nahi binās II (SGGS, 52)
(Entering the sanctuary of the true Guru, you shall never die again).

Har jan har har nāṁ samāne
Dukh janaṁ maran bhav khanda he II (SGGS, p. 13)
(The humble servants of the Lord, Har, Har; The pain of birth and the fear of death are eradicated).

Janam maran kā bhao gaia bhagat gopāl II (SGGS, 45)
(The fear of death and rebirth is removed by performing loving devotional service to the lord of the world).

The concept of suffering and death are discussed in detail in Sri Guru Granth Sahib. Death is described as inevitable and described as an event which happens to every individual who is born. It is further described that the time and means of death are secret and the death is in hands of God. The others concepts that are discussed in Sri Guru Granth Sahib in relation to death are concepts of ‘reincarnation’ and ‘death while alive’.

(C) Use of alternative and traditional systems of medicine: Traditional systems of medicine refer to local indigenous practices and belief systems that are used for health-related purposes. Alternative medicine is generally used to refer to a range of systems of medicine such as homeopathy,
naturopathy, herbalism, etc. Regarding the use of alternative and traditional systems of medicine, a caregiver (of a male cancer patient aged 75 years, village Waada Draaka, District Faridkot) expressed:

“Manndā koi nahi, par jandā har koi hai jado āpne sir te paindi hai”
(Nobody accepts but everybody goes to healers when it comes to them).

**Case:** A Jatt Sikh female respondent (aged 53 years, mother of three children aged 28 years, 25 years and 18 years) was a widow and belonged to village Mehbadhar, District Sri Muktsar Sahib. She told that she tried a large number of treatments including allopathic from Adesh hospital, Sri Muktsar Sahib and PGIMER, Chandigarh, and ayurvedic from a *vaid* in Jalandhar. She stated that she was diagnosed with cancer in 2007 in her right breast at Adesh hospital, Sri Muktsar Sahib where she underwent a breast removal surgery and later on followed by follow-ups but she again developed cancer in her left breast in 2009. This time her children decided to carry out her treatment at PGIMER, Chandigarh, where the medical facilities are much advanced according to them. As it was a case of recurrence, her children did not want to take risk regarding her life, so they also went to a *vaid* in Jalandhar and brought medicine for her. The ayurvedic medicine costed her around ₹ 10,000 for medicine of 15 days. She simultaneously took both allopathic and ayurvedic medicines but later on she stopped the ayurvedic medicine as she felt sleepy all the time after taking both the type of medicines together. She further shared that her children took her to a number of traditional healers who claim to treat cancer in Sri Muktsar Sahib and Sri Ganga Nagar (Rajasthan). These traditional healers gave a variety of medicines, ointments and *bhasma* (ash) as a part of treatment. She agreed that use of traditional systems of healing gave her and her family a psychological satisfaction but it did not benefit her at all. At the
time of her interview, she was in advanced stage of breast cancer.

It is clear from the case that the respondents not only undergo the biomedical treatment for cancer but also a variety of alternative and traditional systems of medicine.

(D) Communication: Open communication in cancer care has gained increasing importance in recent years but there is significant variability in the sharing of prognostic information (Innes and Payne, 2009). The common practice of non-disclosure of prognosis and detailed disease-related information by health care professionals and the family leads to the questions in the minds of the patients such as what is the disease am I suffering from? What is the stage of disease? How much has the disease spread? Are there chances of curability or survival? What will be future course of disease? What are the chances of the recurrence of disease and what are its symptoms? In a clinical setting in India, such questions are often not answered to the patients but are answered only to the caregiver.

Communication with health care provider is a critical aspect of end-of-life care but it was found in the study the study that though the doctors believe that patient should be informed about prognosis but do not initiate such talks and waits for the caregiver and the patient to do so. A doctor dealing with advanced cancer patients argued:

"Main sirf oohnā de svālan dā jwāb dindā han"
(I only respond to their questions).

The doctor highlighted that conversation about the prognosis is not initiated by the doctor but by the caregivers or the patients. On asking what if a patient asks about prognosis, the doctor replied:

"Mai sirf marji de svāl da jwāb dindā hān,
je mareej sidhā puchh lave tan thorā dasnā hi payugā"
(I answer the questions of patients only, if patient asks directly then I am bound to tell little bit of it).
Another doctor from the palliative care unit adds:

“Agar mārij puchhe to hi batāte hai”
(We only respond, if the patient asks).

He further added:

“Ham āge se nahi puchhte ki āpko jannā hai ke āpko kyā biārī hai”
(We do not ask the patient ourselves whether they want to know about the disease from which they are suffering).

Among advanced cancer patients, search for meanings and attributing causes to cancer, religion, use of alternative and traditional system of medicine, and communication were found to be important coping strategies used by advanced cancer patients. It was found that cancer patients try to search meanings behind their illness and attribute causes to it. It was further found that cancer patients turn to religion to understand the religious context of their suffering and nearing death. The respondents also mentioned a number of verses from Sri Guru Granth Sahib regarding the concept of suffering and death. This concept was further developed by the researcher. Apart from seeking biomedical treatment, it was found that the respondents resort to alternative and traditional systems of medicines to ensure their survival from the disease. The other coping strategy used by advanced cancer patients was found to be communication. They try to get the information regarding their prognosis and future course of their disease from their health care providers but such information is not provided directly to the patients.

7.5.3 Caregiver’s concerns

Terminal cancer is an extremely heavy burden for relatives to carry. The process of grief begins upon learning about the diagnosis or the news of death. It has been shown in a number of studies that most relatives develop various physical and mental symptoms after the cancer diagnosis and the death of a close family member (Kristjanson and Ashcroft, 1994; Anderson and Dimond, 1995). The serious illness also changes the relatives’ everyday
life in various ways (Astedt-Kurki et al., 1997; Edwards and Ung, 2002). Health care professionals can help relatives adjust to the new life situation brought about by the patient’s illness or death (Patenaude and Last, 2001). The help received by a relative may be either direct or indirect. Direct help consists of informational and emotional support, as well as spiritual support. Indirect support involves participation in the patients’ care and the sense among relatives that the patient is receiving good care.

The caregivers expressed the advanced disease of the respondents as “Jwāb de dīta hai” meaning that there is no further treatment possible. Further they express the cancer progression as “Bīmarī dīaṅ jārāṅ bahūt failiān hoyān” (The roots of the disease has spread a lot). The advanced stage of cancer is described as: “Eh oh tāyam hāi jādo rabb aṅge hāth jānde ne” (This is the time when one’s hand gets folded in front of God) meaning that the survival of the patient is in the hands of God.

7.5.3.1 Importance of time: It is observed that death is the persistent spectre for people who have cancer, and for their families. The cancer patients and their families also face time disruption and its appropriation in various ways. In the immediate term, cancer disrupts time and life, awareness of time increases, time is verbalised and reflected. The caregivers of the respondents express their concern about time in the form of following questions such as “How much time does he/she have? Is this the time to tell the near and dear ones about the disease and its stage so that they could come and meet the patient or the patient could be taken to them? Is this the right time to take all the pending decisions for the patient?”

Even when the caregivers acknowledge the inevitable, there found to be coercion and conflict over the time needed for families to process this information. This leads to time disruption and its appropriation in various ways. In the immediate term, cancer disrupts time and life, awareness of time increases, time is verbalised and reflected. The caregivers of the respondents expressed their concern about time in form of following questions to their doctors:
How much time does he/she have (years/weeks or days)?
Is this the time to prepare the patient for the worst? (In case the patient is not aware of diagnosis and prognosis)
Is this is the time to tell the near and dear ones about the disease and its stage so that they could come and meet the patient or the patient could be taken to them?
Is this the right time to take all the pending decisions for the patient?
Is this the right time to distribute the wealth and the other resources to the heirs of the patient?

The ideas of time, estimates of survival and life expectancy continue to shadow not only the caregivers of end-of-life patients but also those of the survivours. The caregivers expressed their views regarding death. The husband of 65 years old woman with advanced cancer of right leg from Bathinda expressed:

“Māi tān būri tarah nāl tuṭ chukea”
(I have been broken badly).

Similarly, husband of a 62 years woman with advanced breast cancer from Sri Muktsar Sahib told that she had been a best life partner whom one could ever get and he shared all his feelings with her. Her near end led him express as:

“Ohdi maut meri zindagī wich nā purā hon vālā ghāta hoyu”
(Her death would be an unbearable loss in my life).

From the above cited narratives, it is clear that time is an important matter of concern for the caregivers of the patients. The important of time in lives of cancer patients and among caregivers has also been recognised by Lindqvist et al. (2008).

7.5.3.2 Concerns about suffering of the patient: It was found during the study that cancer is equated to hell and this expression is clear from the
narratives cited here. One of the caregiver expressed the suffering of cancer patients as:

“Oh tân kainsar nāl jūjh rahe ne”
(She is struggling with cancer).

Another caregiver expressed:

“Maut de muh ch ne oh”
(She is in the grips of death).

Some of the caregivers described cancer experience comparable to hell. Some of the cases relating to this are given below.

**Case 1:** A male respondent (son of a female cancer patient aged 62 years, Jatt Sikh, suffering from cancer of gall bladder, village Jajjal, District Bathinda who died in August 2011) is 42 years old and resides in Australia and came to attend last rites of his mother expressed:

“Oh tan chhut gaye, āzad hogye narak cho”
(She got free from agony of hell).

He told that his village Jajjal, situated in Malwa’s cotton belt, shot to fame in 2002 when the media brought out the story of a retired government teacher, Jarnail Singh, whose study of his village revealed the abnormally high incidences of cancer deaths in the village and some adjoining villages. Jajjal is a small village with 500 odd households and a population of about 3,500 people. Following this exposure, several experts and study teams from across the country visited the village in the last few years.

**Case 2:** A male respondent (son of a female cancer patient aged 42 years, Jatt Sikh, suffering from breast cancer, undergoing treatment, village Chandbaja, District Faridkot) is 22 years old and a student at Brajindra College, Faridkot expressed:
There can be number of reasons why cancer is considered as equal to hell, firstly, it is considered as a disease which means death; secondly, there is so much suffering associated with the disease; thirdly, cancer is a stigmatised disease (due to attribution of cancer causation to karma, kismat and contagion). From the above mentioned narratives, it is clear that cancer is considered as hell due to suffering and death associated with it.

7.5.4 Health care provider’s concerns

Medicine is the art of saving life, which accords with society’s longstanding moral and legal prohibition against the taking of life. However, what is also universally true is that death is inevitable for and intensive medicine cannot postpone the inevitable indefinitely. Technological developments are now making it possible to exercise greater control over the dying process. Some of the important narratives between caregivers and doctors are given here.

Conversation 7.1

Caregiver: “Kīnā tāyam rehgāyā?”
(How much time is left?).

Doctor: “Yeh sab Uske hāth mein hai, prarthanā karo, Uskā bulāwā ā jāne dō”
(All is in His hands, pray to God, let His invitation come).

This is the conversation between the doctor and the caregivers of a terminally ill cancer patient admitted in Chandigarh hospice. It was found that in a palliative care setting, the references to the God and God’s will are very common and caregivers are told to have faith in God as death and life are believed to be in Almighty’s hands.
Conversation 7.2

Caregiver: “Kinna k tāyam hai hor?” (How much time is left with the patient?).

Doctor: “Dekho zindagī já maut tan rabb de hāth hai. Na main nā tusi das sakde ho ke kinna tāyam hai. Bas hun sewā karo jado tak bulāwā ni aundā” (See, life or death is in the hands of God. Neither me nor you can tell about the time which is left. Now just take care of the patient till the time death comes).

Conversation 7.3

Doctor: “Dekho ehna di hālat changi nai. Merī jīmewārī hāi tuhānu dasnā. Kade wi kuchh vi ho sakdā hai. Tuhānu tāiyār rehnā payegā. Changā hovegā je tusī ehnu wi dasdeo. Āpne nāl ehnū wi tāiyār karlo” (See, her condition is not good. It is my responsibility to tell you. Anything can happen anytime. It would be better if you tell her about her condition. Prepare her along with you as well).

Caregiver: “Ehde to seh nai honā” (She will not be able to bear).

Doctor: “Kaho tān mai dasdeya” (If you permit, I can tell her).

Caregiver: “Nai docrtā sāhab. Rehan deo” (No doctor. Do not tell her).

From the analysis of conversations 7.2 and 7.3 between the caregiver and the doctor, the theme such as advanced stage of disease, uncertainty of life associated, importance of time, ethical responsibility of a doctor, truth telling to the patient, family collusion (a secret agreement made between health care providers and caregivers to hide the serious illness from a patient) and God’s role in life and death emerges. Here, the doctor tries to fulfill his ethical responsibility to tell the prognosis to the patient but the family collusion leads to non-disclosure of the stage of disease to the patient.

While discussing the issue of euthanasia or whether the cancer patients in advanced stage should be given euthanasia by the doctors treating them, one of the doctors immediately responded, even if it becomes legal, who will do it? Who will commit this sin (pāp)? My religion (Hinduism) does not allow me to do this. The other doctor explained that “death is a natural
phenomenon and nobody is greater than God to impart untimely death to anybody”. The perspectives of patient’s, caregiver’s and health care provider’s regarding the disclosure of the cancer prognosis are summarised in Table 7.37.

**Table 7.37: Disclosure of cancer prognosis to the patients (Patient’s, caregiver’s and health care provider’s perspectives)**

<table>
<thead>
<tr>
<th>Patient’s perspective (Patient should be told about prognosis)</th>
<th>Caregiver’s perspective (Patient should not be told about prognosis)</th>
<th>Health care provider’s perspective (Patient should be told about prognosis)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Helps to cope in a better way</td>
<td>The patient will not be able to bear the shock</td>
<td>Helps patient to accept the disease and come out of false hopes</td>
</tr>
<tr>
<td>Important to accept the fact that the disease is incurable</td>
<td>The patient will be depressed</td>
<td>Helps patient to get treated and die with dignity as the patient is able to take decisions for himself/herself</td>
</tr>
<tr>
<td>To take timely decisions regarding financial resources, distribution of wealth, etc.</td>
<td>The patient may refuse symptomatic treatment timely decisions</td>
<td>Helps them to cope in for family such as the treatment to save the better and easier way</td>
</tr>
<tr>
<td>To prepare the caregivers for the inevitable</td>
<td>The patient may loose hope for life and may symptomatic problems</td>
<td>Patients suffer from less symptomatic problems and have better QOL</td>
</tr>
<tr>
<td>To take timely decisions for family such as the marriage of children in financial resources and giving responsibility of children to someone if they are minor</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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It can be observed that both the patient and the health care providers believe that patient should be informed well about the disease diagnosis, though the reasons for this are different for both of them. On contrary, the caregivers believe that it is better to hide the disease prognosis from the patient.

7.6 CHARACTERISTICS OF ‘GOOD DEATH’, ‘BAD DEATH’ AND ‘DIGNIFIED DEATH’: PATIENT’S, CAREGIVER’S AND HEALTH CARE PROVIDER’S PERSPECTIVES

In its most basic form, a ‘good death’ is a death free of physical and spiritual pain. The ambiguity of the concept allows patients, family members, and hospice teams a great deal of flexibility to work towards this end. Translating the characteristics that define a ‘good death’ into practical guidance for clinicians proves more difficult. Smith (2000) outlines 12 principles of a ‘good death’, but does not address how to achieve these ideals. Generally, the characteristics of a ‘good death’ involve freedom from physical and spiritual pain through various medical and psycho-social interventions including medication, psychological counselling, spiritual consultations, prayer, physical therapy, massage, and music and art therapy. However, lack of economic resources, caregiving, and social support may require attention in order to help alleviate a patient’s pain. For example, dying people may become preoccupied with the financial well-being of the loved ones they will leave behind, which in turn causes the dying person psychological pain. The principles of a ‘good death’ given by Smith (2000) are:

- To know when death is coming, and to understand what can be expected
- To be able to retain control of what happens
- To be afforded dignity and privacy
- To have control over pain relief and other symptom control
- To have choice and control over where death occurs (at home or elsewhere)
• To have access to information and expertise of whatever kind is necessary
• To have access to spiritual or emotional support required
• To have access to hospice care in any location, not only in the hospital
• To have control over who ever is present and who share the end
• To be able to issue advance directives which ensure wishes are respected
• To have time to say goodbye, and control over other aspects of timing
• To be able to leave when it is time to go, and not have life prolonged pointlessly

Kellehear (1990) described the five features of a ‘good death’ differently by focussing on the internal (or personal) and external (or social) work of dying well, which include such factors as “[t]he social life of the dying person, identifying awareness of dying, social adjustments and personal preparations, public preparations, arrangements relating to work and farewells” (McNamara, et al., 1994). Although categorised differently, the characteristics of a ‘good death’ described by Kellehear correspond to the five dimensions of the QOL (Byock and Merriman, 1998). Scholars, however, recognise the importance of defining a ‘good death’ as a series of interactions that should begin months before a person dies (Emanuel and Emanuel, 1998), rather than a single event (McNamara, et al., 1994).

7.6.1 Characteristics of ‘good death’: Patient’s perspective

Death is the persistent spectre for people who have cancer, and for their families. The two concerns are very common among cancer patients and their families are cancer fatalism and death anxiety. Cancer fatalism is defined as “the belief that death is inevitable when cancer is present” (Powe, 1994). There is an anxiety related to cancer among the patients as well as their families which is referred to as death anxiety. Webster’s New World Dictionary defines anxiety as a state of being uneasy, apprehensive or worried about what may happen; concern about a possible future event. Human mortality and the dying experience can serve as a beginning and enter to any
anthropological investigation of health, illness and healing. The socio-cultural construction of death is very important issues that can be studied by medical anthropologists. In this study, an attempt has been made to analyse the construction of death by cancer patients and their families.

The various characteristics of ‘good death’ described by the cancer patients include death at home/native place and community participation in death rites, awareness of prognosis and nearing death, less symptom burden and suffering, less financial burden on family at the end-of-life, and less emotional burden on family.

7.6.1.1 Death at home/native place and community participation in death rites: The place of death is presumed to be an important parameter of the quality of end-of-life care. Several studies reveal that most of cancer patients prefer to die outside of the acute hospital setting (Patnaik et al., 1998; Leeb et al., 2005). Family perspectives indicate that patients dying in institutional settings have numerous unmet needs relating to symptom control, communication and emotional support (Teno et al., 2004). In this context of place of death, it is important to note about the preferences of cancer patients regarding their place of death and the factors affecting the same. Some of the cases relating to this are discussed below.

Case118: A male respondent (aged 68 years, Jatt Sikh, completed his education upto matric, retired government employee, village Kot Shameer, District Bathinda) suffered from indigestion and continuous vomiting for more than two months before he went to a Max Hospital, Bathinda where the doctors did not tell the family about the disease but told the family to take the respondent to PGIMER, Chandigarh for further treatment. His son took him to Department of Medicine, PGIMER, Chandigarh from where he was referred to Department of Radiotherapy after diagnosis with cancer. The time, he was diagnosed with cancer, his disease was already in an advanced stage. He was not aware of his cancer diagnosis or prognosis but he felt that his end was near. At the time of his
interview, he told that he understands that the disease from which he is suffering is incurable and he showed his desire to go back immediately to his native village. He wanted himself to die in the village in which he was born. As he understood that his end was near, he also showed his immense desire to meet all his siblings and childhood friends.

The desire to die at one's native village was found to be very common among cancer patients and their caregivers. The patients and their caregivers described it as a 'good death'. On contrary, the health care providers treating cancer patients believe that a 'dignified' death is one which occurs in midst of all medical facilities such that the patient is cared by the health care professionals and not by the family alone.

Case 119: A female respondent (aged 44 years, Majhabi Sikh, completed her education upto postgraduation, suffering from advanced breast cancer, on symptomatic treatment from PGIMER, Chandigarh, village Bhagsar, District Sri Muktsar Sahib) shared that it was her efforts to protect her family from worry and maintain family honour that she downplayed her symptoms. She shared that when she first felt a gilti (small lump) in her breast, she had fear that it could be cancer. She did not tell about the lump till it became too large and painful. Then, she told her husband who showed his unawareness about the reason behind the lump. She then, told her mother-in-law about the symptoms. Her mother-in-law cited the case of her sister who had similar painful lump in her breast and later on, she was diagnosed with breast cancer. Her mother-in-law and her husband took her immediately to GGS Medical College, Faridkot where she was diagnosed with advanced cancer with metastasis in bones. She was refused treatment in the same hospital due to advanced stage disease but her husband decided to take her to PGIMER, Chandigarh to look for further possibility of treatment. She was started with symptomatic treatment and was
admitted in Chandigarh Hospice. Her husband was clearly told about the advanced stage of her disease and he took her back after one week of stay at hospice. The reason for taking her back to her village was that at the time of death, a person should be at his/her native place.

Dying in an institutional setting is a western idea of a 'good death'. Hospices are projected as sites for 'healthy living', moral order and ultimate individualism (Seale, 1998; Walter, 1994). Yet the individuals for whom biological death is followed by a social death, and for whom dying is frequently without reflexivity, lie outside the 'good death' cultural ideal (Kaufman, 2004). So for the respondents, social death is much more important aspect, death at home or their native place was the preference.

Another important aspect of death that appeared during the interviews was that 'good death' is one in which all community members take place in last rites. As cancer is a stigmatised disease, the patients described community participation in their last rites as an important characteristic of 'good death'. Some of the cases relating to cancer stigma and lack of community participation in last rites of cancer patients are given below:

**Case**: A female respondent (aged 50 years, Jatt Sikh, completed her education upto matric, housewife, suffering from breast cancer patient post-operative stage, village Chandbaja, District Faridkot) shared her experience of a burial ceremony of a woman who died of uterus cancer at the age of 50. Most of the women from the village and close relatives chose to stay away from the last bathing ceremony of the deceased in the fear of contracting cancer. Only two to three persons actually participated in her last rites while others maintained a distance. She was worried about her future, if she dies, nobody would actually participate in her death rites and she would never be able to salvage in peace.

**Case**: A female respondent (aged 42 years, Jatt Sikh, housewife, completed her education upto graduation, suffering
Another respondent narrated:

“Mukti nahi mildi, je sare antim wele nál ná hon” (One does not get salvation, if all are not with the person during his/her end time). Here all means family, relatives and other close ones.

Thus, death at native place and community participation in death rites are two important aspects of ‘good death’. The following factors were found to shape the preferences for place of death:

- Patient’s attitudes to, and outlook on, death and dying.
- Religious beliefs such as salvation can only be achieved if one dies at home.
- Socio-cultural practices such as bathing ceremony (which is not possible in case of institutional death where body is given back after post-mortem) and community participation in death rites.
- Previous personal experience of other’s death and dying.
- Fear of being a burden on family in case of institutional death, the dead body is to be carried back to native place which may be difficult for the family.
7.6.1.2 Awareness of prognosis and nearing death: The patients believed that one needs to be aware about the prognosis and nearing death because of the following reasons:

- To help cope in a better way.
- To accept the fact whether the disease is curable or not.
- To take timely decisions regarding financial resources, distribution of wealth, etc.
- To take timely decisions for family such as marriage of children in case children are young, giving responsibility of children to someone if children are minor.
- To prepare the caregivers for the inevitable.

7.6.1.3 Less symptom burden and suffering: The pain and symptom burden among the cancer patients are biological phenomenon but it has certain social aspects attached to it. It was found that it leads to reduced social activity which also alters social roles and leads to non-fulfillment of these social roles by the patients. Thus, patient acquires a sick role while other provides support and care in order to help the patient in recovering from the illness. This intensity of support and care may be different for different individuals. Some of the respondents described their suffering as:

“Pehlān vargā sharīr naḥī reḥā”
(At present, my body is not like as earlier it was).

“Tureā ni jändā, aukhā lāgdā, Bālti-bālti khūn pai āndā”
(I find it difficult to walk, it is hard, there is too much bleeding).

Here, she expressed the amount of bleeding comparable to water in a bucket. The diagnosis of cancer is considered as a life changing event such that there is a drastic change in the life before and after the diagnosis. A female respondent (aged 78 years, cancer of cervix) with complaint of recurrent pain described her suffering as:

“Changī katgāī, mārī rahgāī”
(Good part of life is over and worst is left).
At the end-of-life, when the suffering and pain becomes unbearable for the cancer patients concerns about early and easy death emerged. Some of the narratives express this theme.

“Jahar dā tikā ladeo”
(Inject some poisonous injection).

The patients themselves requested the doctors to give some poisonous injections to them so that they could die with less pain and suffering.

“Rabba mainu chak le hun”
(God, impart me death).

“Aiven jeon nālo tān maun changi”
(Death is better than such a life).

With expression of their suffering, the patients believed that death should be easy and without any suffering.

**7.6.1.4 Less financial burden on family at the end-of-life:** When assessing the costs of treatment to the patients and their families, finance can be considered in four area; direct medical costs, direct non-medical costs (daily living, transportation, etc), indirect cost (loss of earning) and intangible costs (pain, uncertainty). A number of cases relating to financial burden on families of cancer patients are cited here.

**Case:** A male respondent (aged 52 years, Ramgarhia Sikh, illiterate, suffering from cancer of larynx, village Machaki Kalan, Faridkot) was diagnosed with the disease in June 2010 at PGIMER, Chandigarh and after a year of treatment, he decided to stop his treatment in July 2011 due to financial difficulties in the family. He later came to PGIMER, Chandigarh in September 2011 with the complaint of pain and inability to swallow food. He requested doctors to start his treatment again as this time he came with some borrowed money from his brother-in-law but as the disease spread so much and damaged his food pipe that doctors showed their inability to treat him actively. So, they decided to carry on his symptomatic treatment.
Case 123: A male respondent (aged 36 years, Jatt Sikh, completed his education up to graduation, government employee, suffering from cancer of rectum in advanced stage, village Malkana, District Bathinda) told that he is not able to work for the past one and a half year post-diagnosis and his wife who was a school teacher left her job to take care of him. The financial support is provided to the respondent by his parents who are retired government employees and get a monthly pension. Apart from this, the respondent does not have any other financial resources. He is a father of two children (son aged 8 years and daughter aged 6 years) and both of them are school going but due to financial difficulties, the family has shifted the children from a convent school to a government school. The respondent was worried about the expenses of his medication and repeated hospitalisations in this advanced stage of disease. He described:

“Sanu tān mehange ilāj ne khā leyā”
(Costly treatment of the disease has ruined us).

It was found in the study that financial concerns were the most important concern not only for the cancer patients but their families. Thus, the respondents and their caregivers repeatedly mentioned cancer is a disease not only of an individual but the disease that affect the whole family.

7.6.1.5 Less emotional burden on family: During the study, some cases were found in which the families provided ample support to the respondents but they felt dependent and this led to vulnerability among them. As for the respondents, a ‘good death’ is one in which there is less emotional burden on the family. Some of the cases relating to this are discussed below:

Case 124: A female respondent (aged 66 years, Jatt Sikh, illiterate, housewife, suffering from cancer of gall bladder, village Bhagta Bhai Ka, District Bathinda) was a mother of three daughters and a son. Her daughters (aged 42 years, 39 years and 38 years) were married and she stays with her son aged 41 years and his wife and two children (daughter aged 18 years
and son 26 years). She shared that her husband is very caring towards her while her son and daughter-in-law have become indifferent after her diagnosis with cancer. Now, she feels very dependent on her husband and tends to hide her pain and suffering from her husband till it becomes unbearable for her.

It is clear from the case that too much of care provided by caregivers makes the patients feel that they are dependent and as a result the patients tend to hide their suffering.

Case 125: A male respondent (aged 37 years, Jatt Sikh, completed her education upto graduation, suffering from cancer of gall bladder in advanced stage, village Jajjal, District Bathinda) shared that his wife and children spend a good amount of time with him which was not the case before as his wife was working and children were going to school regularly. Now, his wife left her job to take care of him and children often miss their school when he is not well. He noticed this change in support provided to him and feels as a burden on family. Now, he has isolated himself from the family and neither shares his problems with his wife nor talks to his children well. In this case, it is not the family, which isolated the patient but the patient isolated himself considering himself as a burden on the family.

Case 126: A female respondent (aged 65 years, Jatt Sikh, illiterate, housewife, suffering from cancer of gall bladder, village Malkana, District Bathinda) was a widow. She told that her children are very supportive to her but this excessive support and care during illness makes her feel dependent and a burden on them which she expressed as:

"Mai bojha banagai hān ohnā te"
(I have become burden on them).

Another respondent told that she does not share her worries and suffering with her family as they are very concerned about her. So, she always prays for her death so that her family could lead a better life.
Case 27: A female respondent (aged 43 years, Majhabi Sikh, completed her education upto matric, working as domestic help, suffering from cancer of tongue, village Bhagsar, District Sri Muktsar Sahib) was a widow and stays with her only daughter at her native village. She is undergoing treatment at PGIMER, Chandigarh and her daughter left her study to accompany her for treatment. She feels that her daughter has ruined her future for her treatment. The care and support provided to her by her daughter makes her vulnerable to the thought that her death would end the agony of her daughter.

The emotional burden was also a matter of concern for the advanced cancer patients. This sense of being an emotional burden on their families, respondents in the study wished for an early and easy death.

7.6.2 Characteristics of ‘good death’ and ‘bad death’: Caregiver’s perspectives

Among caregivers, two types of concepts related to death emerged which include the concept of ‘good death’ and ‘bad death’.

7.6.2.1 Characteristics of ‘good death’: The caregivers conceptualised ‘good death’ as the one which happens to an individual while sleeping (without the individual actually knowing that death is approaching), takes place at home, patient is not aware of the cancer prognosis and is not hopeless, receiving ample amount of social support, without suffering and symptom burden, without artificial external life support system, and with fulfillment of last wish.

7.6.2.2 Characteristics of a ‘bad death’: The caregivers conceptualised that the institutional death i.e., which takes place at hospital is one of the first characteristics of a ‘bad death’. Secondly, if the patient is aware of prognosis and is hopeless or shattered or fearful about death then the death is not good. Thirdly, if patient is suffering from the symptom burden, then the death is a bad death. Fourthly, if there is a lack of social support and lastly, if the last wish of the patient is not fulfilled, then the death falls in the category of bad death.
A comparison of ‘good death’ and ‘bad death’ from caregiver’s perspective is given in Table 7.38.

Table 7.38: A comparison of characteristics of ‘good death’ and ‘bad death’ from caregiver’s perspective

<table>
<thead>
<tr>
<th>Characteristics of ‘good death’</th>
<th>Characteristics of ‘bad death’</th>
</tr>
</thead>
<tbody>
<tr>
<td>Death while sleeping</td>
<td>Death from diseases like cancer, AIDS</td>
</tr>
<tr>
<td>Death at home/native place</td>
<td>Institutional death</td>
</tr>
<tr>
<td>Unawareness among patient</td>
<td>Awareness among patient regarding the cancer prognosis leading to hopelessness and fear of death</td>
</tr>
<tr>
<td>regarding the cancer prognosis</td>
<td></td>
</tr>
<tr>
<td>Social support for the patient</td>
<td>Lack of social support</td>
</tr>
<tr>
<td>Without symptom burden and</td>
<td>With symptom burden and suffering</td>
</tr>
<tr>
<td>suffering</td>
<td></td>
</tr>
<tr>
<td>Without artificial external</td>
<td>With artificial external life support system</td>
</tr>
<tr>
<td>life support system</td>
<td></td>
</tr>
<tr>
<td>Fulfillment of last wish</td>
<td>Non-fulfillment of last wish</td>
</tr>
</tbody>
</table>

On the basis of Table 7.38, it can be concluded that caregivers made the clear distinction between their concepts of ‘good death’ and ‘bad death’.

7.6.3 Characteristics of ‘dignified death’: Health care provider’s perspectives

The patients and caregivers talked of ‘good death’ and ‘bad death’ while the health care providers talked of ‘dignified death’ in which the patient does not feel dependent or isolated. He/she receives ample amount of end-of-life care and support during the terminal stage.

The following characteristics of ‘dignified death’ are described by health care providers:

(a) Less symptom burden.
(b) Receive required amount of end-of-life care to improve QOL.
(c) Role in end-of-life decision making.
(d) Open communication of patient with both caregivers and health care providers.

The conversation 7.4 and 7.5 are very interesting to note in context of concept of ‘dignified death’.

**Conversation 7.4: On first visit**

Caregiver: “Ehnā de dard ch farak nahī pe rehā” (She did not get any relief in her pain).

Doctor: “Dekho kaś marījan nu dard di davāī nāl fark nahī paindā. Ohnā nu jadā strong medicine denī paindī hai. Mai ehnā nu ek ajehhī medicine likh ke de rahī han jehri bāhro nahī mīlī. Tuhānu pandrah dinān bād āke āp hī laikē jānī pāyu. Eh davāī kise bachhe nu jā hor kise nu dard hon te ja nashā karan vàle de hath nahī denī” (See, some patients do not get relief in pain. They needs to be give some strong medicine. I need to give her medicine which is not available outside the hospital. You need to visit after fifteen days and take the medicine for her. Take care, that this medicine should not be given to a child or in case of pain or to any drug addict).

Caregiver: “Bas dactar sāhab kuchh wi dedo take dard fhTk hi jave” (Doctor, give her anything so that she gets relief in pain).

**Conversation 7.5: On second visit**

Caregiver: “Dactar sāhab jehri tusT pichlī wār davāī difī sī, ohde nāī tan eh sārā din sute rehndē ne” (Doctor, she sleeps whole day by the medicine which you gave last time).

Doctor: “Mai tuhānu daseā hi sī ke davāī strong denī payu” (I told you that she needs to be given a strong medicine).

Caregiver: “Sāde nāī gal nahi karde. Pehlān ghato ghat gal tān karde sī” (She does not talk to us. Earlier, atleast she used to talk to us).

Doctor: “Dekho bimāri bāre tan tuhānu patā hī hai. Ehnā nu izzat nāl maran deo. Ehnā da dard takīī tan ghat gayā nā davāī nāl” (See! You know about the disease. Let her die with dignity. Atleast her pain and suffering reduced with this medicine.)

From the analysis of the conversations 7.4 and 7.5, the concept of dignity (izzat) emerges in the talks of health care providers. An important
distinction between health care providers and caregivers perspectives on concept of death also emerges. It is clear that health care providers treat cancer patients as isolated individuals but the caregivers looks at the patients as part of a family and a wider social network. This concept is in accordance with Foucault's (1973) contributions to understanding of a social body which he considers as a transient social and cultural artifact. The concept of social body and a physical body is very important in this context. The health care providers views patients as physical bodies which needs to be treated in isolation but the patients and their caregiver’s views body in its social context. A comparison between the characteristics of ‘good death’ as explained by patients and the caregivers, and the ‘dignified death’ explained by health care providers are given in Table 7.39.

Table 7.39: A comparison between the characteristics of ‘good death’ as explained by patients and the caregivers, and the ‘dignified death’ explained by health care providers

<table>
<thead>
<tr>
<th>Characteristic of ‘good death’</th>
<th>Patient’s perspective</th>
<th>Caregiver’s perspective</th>
<th>Health care provider’s perspective</th>
</tr>
</thead>
<tbody>
<tr>
<td>Awareness of patient regarding prognosis</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Place of death</td>
<td>Home/native place</td>
<td>Home/native place</td>
<td>Institutional death</td>
</tr>
<tr>
<td>Symptom burden</td>
<td>Less</td>
<td>Less</td>
<td>Less symptom burden and higher QOL</td>
</tr>
</tbody>
</table>

It is clear from the Table 7.39 that awareness of prognosis is accepted as an important aspect of ‘good death’ explained by cancer patients and ‘dignified death’ explained by the health care providers. For the patients and their caregivers, dying at home or native place was essential component of a
‘good death’ while institutional death was the preferred death by the health care providers. All of the three, patients, their caregivers and health care providers believed that in order to achieve a ‘good death’, the symptom burden should be reduced for the patient.

In the data analysis, the present researcher described the features of ‘good death’, ‘bad death’ and ‘dignified death’ separately from the perspectives of advanced cancer patients, their caregivers and health care providers. It is clear from the Figure 7.2 that some features of ‘good death’ such as death at home/native place, less suffering and symptom burden, and without external artificial life support system were overlapping between advanced cancer patients and their caregivers. Similarly, there were some overlapping features among ‘bad death’ as described by caregivers and ‘dignified death’ explained by health care providers such as awareness regarding nearing death, with external artificial life support system and institutional death.

The patients described a ‘good death’ as one in which a patient is aware of cause of death with less symptom burden as well as less financial and emotional burden on the family and one which takes place at home/native place with community participation. The caregivers defined good death as one in which takes place at home without any kind of suffering and awareness about the nearing death and with social support of the family at end-of-life. The caregivers defined bad death as which occurs due to diseases like cancer, AIDS, etc. in an institutional setting without the social support of the family and fulfillment of last wish, with suffering, symptom burden, and artificial support system. The health care providers defined dignified death as one in which patient has less symptom burden due to improved quality of life with an open communication between health care providers and patients and the patients play an important role in their end-of-life decision making.
Figure 7.2: Concept of death among advanced cancer patients, their caregivers, and health care providers

<table>
<thead>
<tr>
<th>Perspectives of</th>
<th>Type of death</th>
<th>Features</th>
</tr>
</thead>
</table>
| Advanced cancer patients | Good | - Awareness regarding prognosis and nearing death  
- Least financial and emotional burden on family  
- At home/native place  
- Less suffering and symptom burden  
- Without external artificial life support |
| Caregivers | Good | - Fulfillment of last wish  
- Unawareness regarding nearing death  
- From diseases like cancer, AIDS, etc.  
- With symptom burden and suffering  
- Non-fulfillment of last wish  
- Awareness regarding nearing death |
| Health care providers | Dignified | - With external artificial life support system  
- Institutional death  
- Hospice admission for end-of-life care |

Source: Prepared by researcher based on original fieldwork
7.7 ROLE OF MASS MEDIA

Mass media are tools for the transfer of information, concepts and ideas to both specific and general audiences. Mc Dermote and Abrecht (2002) believed that mass media extend “people’s ability to communicate, to speak to others far away, to hear messages, and to see images that would be unavailable without media”. Mass media are very important sources of information about health matters and form a constant backdrop to our lives as they contain many implicit and explicit messages about health (Clarke and Everest, 2006). Mass media – defined in the conventional sense as the electronic media of radio, television, film, and recorded music and the print media of newspaper, magazines and popular literature – are at once artifacts, experiences, practices, and processes. They are economically and politically driven, linked to developments in science and technology, and like most domains of human life, their existence is inextricably bound up with the use of language. Given these various modalities and spheres of operation, there are numerous angles for approaching mass media anthropologically: as institutions, as workplaces, as communicative practices, as cultural products, as social activities, as aesthetic forms, and as historical developments (Spitulnik, 1993).

7.7.1 Content analysis of cancer related news

In media, cancer is associated with death, with long and sickening treatment, with punishments, lack of cleanliness, contagion, unpredictability and traitorousness (Peters-Golden 1982). Cancer has been described as ‘an evil and immoral predator’, as an ‘enemy’ treated through military tactics, as associated with death, fear and hopelessness (Clarke 1992). Cancer is also described as a ruthless and secret invasion, in which cells colonise a body whose defences are then invoked and disease itself is conceived as the enemy on which society wages. So, the cancer experience is not only a lethal disease but a shameful one and brutal notions of treatment are too often justified as ‘counter attack’ (Sontag, 1991).
Clarke (2004) compared the portrayal of breast, testicular and prostate cancer in magazines in United States and Canada from 1996 to 2001 and found continuing dominance of a medical frame such that all the three types of cancer were described with reference to conventional medical research and practice. Clarke and Everest (2006) studied the portrayal of cancer in the mass print media in United States and Canada in the years 1991, 1996 and 2001 with the help of 23 highest circulating English magazines. A total of 131 articles were collected and the analysis of which revealed that cancer is described to be fearful, inevitable disease which grows silently and secretly. The cancer is framed primarily in terms of allopathic medicine. Most of the articles focused on treatment, early detection and biomedical research. Thus, medical frame was much more dominant over the other two frames i.e., political/economy and lifestyle. The study also highlighted the use of battle metaphors like ‘battle plan against cancer’, ‘deadly disease’, ‘disarm the disease’, ‘firing on cancer cells’ and ‘silver bullet’, etc.

Clarke and Ameron (2008) analysed the 40 stories from the 20 highest circulating English-language mass magazines published in Canada or the USA in 2001. The study examined the presence or absence of the social determinants perspective in the portrayal of the two most significant causes of morbidity and mortality in these countries: cancer and heart disease. The media analysis documented an absence of reflection of the social determinants viewpoint. Thus, magazine stories ignored the role of considerations such as income, education level, ethnicity, visible minority or, Aboriginal status, early life experiences, employment and working conditions, food accessibility and quality, housing, social services, social exclusion, or unemployment and employment security in explaining health. Although cancer and heart disease were framed by a medical discourse, articles tend to emphasise the independence, freedom and power of the individual within the medical care system. The research documented the presence of dominant medical model in mass print media.

Media stories take one perspective or another. These perspectives are called frames and refer to the parameters regarding what will be included and
excluded in particular stories. Framing, a term used in media studies, sociology, anthropology, and psychology, refers to the social construction of social phenomenon by mass media sources. Three influential frames for the discussion of health and disease are medical, political/economy and lifestyle. Each views health and illness in a different way. Within the medical frame, health problems such as cancer are thought to be biologically based pathologies originating in the individual body. Treatment, breakthroughs in the medical treatment form the integral part of this frame. The political/economy frame considers diseases, including cancer, as originating in causes that lie outside of the individual such as social structural inequities and related threats to health such as poverty, unemployment, homelessness and environmental contaminants. In the lifestyle frame disease is thought to be the consequence of individual choice to engage in unhealthy behaviour such as diet, smoking, alcohol consumption and sexual promiscuity (Clarke and Everest 2006).

The present study aims to analyse the social construction and portrayal of cancer in mass print media. The English daily newspapers The Tribune (English daily newspaper) and The Times of India (English daily newspaper) published from Chandigarh were selected and a total of 669 articles were analysed (from 1st April 2009 to 31st March 2012). All the collected articles were read and re-read carefully to look for latent and manifest themes. The articles were analysed from four frames including medical, political/economy, lifestyle and social frames. Articles categorised within the medical frame include those relating to cancer as a physiologically based pathology explained and discussed within biomedicine. Articles categorised within political/economy frame portrayed cancer as originating in causes that lay outside the individual, such as workplace dangers or environment contaminants. Lifestyle articles include those which discuss negative health consequences resulting from individual choices regarding diet, smoking, stress and the like. Social frame involved the articles related to social implications of cancer. A total of 213 articles appeared in lifestyle frame, 374 articles in political/economy frame, 43 articles in medical frame and 39 articles in social frame were analysed.
7.7.1.1 Manifest findings: Manifest themes refer to that which is explicitly stated, the intended and surface content.

(A) Theories regarding causes and prevention of cancer: The variety of different ideas about causes of cancer and its prevention were expressed in 213 (147 in The Times of India (English daily newspaper) and 66 in The Tribune (English daily newspaper)) newspaper articles. The articles discussed consumption of alcohol in relation to higher incidence of liver cancer among men and breast and colorectal cancer among women (ANI, 2009a), high-blood sugar levels in relation to increased risk of cancer (ANI, 2010a), consumption of sugary soft drinks in relation to pancreatic cancer (ANI, 2010b), tobacco use in relation to higher risk of head and neck cancer (ANI, 2010c; Vasudeva, 2011) and smoking and dietary habits (PTI, 2010). It is also mentioned that some of the patients do not stop smoking even after the diagnosis and during treatment (ANI, 2012).

The other causative factors as discussed include vitamin pills (ANI, 2009h), use of mobile phones (ANI, 2010d), use of plastic baby bottles (ANI, 2010e), obesity and inactivity (Sinha, 2009a), late child bearing, reduced breast feeding, fertility drugs, etc. The other lifestyle related causes of cancer like anti-ageing creams (ANI, 2009b), painkillers (ANI, 2009c), high dietary intake of phosphate (ANI, 2010f) and high protein rich diet (IANS, 2010), etc. were mentioned.

The newspaper articles also mentioned certain possible precautions against cancer such as change in lifestyle, limiting smoking and drinking habits (ANI, 2009a), popcorn (ANI, 2009g), routine screening (Sandhu, 2009b) and exercise (TNN, 2009a). There was a mention of certain foods which could prevent cancer. Some of the titles depicting this are given below:

- Olive oil helps protect against breast cancer (IANS, 2010)
- 24-hour drinking culture responsible for cancer jump (ANI, 2009a)
- Green Tea helps fight oral cancer (ANI, 2009d)
- Pomegranate juice prevents prostate cancer (ANI, 2009f)
- Popcorn keeps heart diseases, cancer away (ANI, 2009g)
- A apple a day can reduce bowel cancer risk (ANI, 2010g)
Olive oil helps protect against breast cancer!

Health Notes

An apple a day ‘can reduce bowel cancer risk’

Vitamin pills can cause cancer

High vitamin K intake tied to low cancer risks

Drinking tea ‘cuts ovarian cancer risk’

Hepatitis B and C can cause liver cancer: Expert

Diabetes ‘doubles cancer risk in women’

High blood-sugar levels up cancer risk

‘Obese women face greater cancer risk’

Breast implant surgery: Cancer fear looms large

Cellphones may cause cancer but need to do more research: WHO

WHO links brain cancer to cellphone use
There was a mention of certain foods and drinks which can cause cancer. Some of the titles depicting this are given below:

Protein rich diet linked to liver cancer (IANS, 2010)

The lifestyle frame uses an individualistic approach to disease that assumes that health care is accessible and available to all, and that these diseases are preventable and treatable through individual lifestyle choices in combination with the measures prescribed through conventional medicine. The various dos and donots are mentioned in the various newspapers in order to prevent cancer.

<table>
<thead>
<tr>
<th>Dos</th>
<th>Donots</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maintain a healthy lifestyle</td>
<td>Use of tobacco in any form</td>
</tr>
<tr>
<td>Be physically active</td>
<td>Neglect of change in bowel habits</td>
</tr>
<tr>
<td>Keep your weight under check</td>
<td>Neglect of blood in stool</td>
</tr>
<tr>
<td>Maintain proper hygiene</td>
<td>Neglect of unexplained yet persistent</td>
</tr>
<tr>
<td>Cancer screening</td>
<td>abdominal pain</td>
</tr>
<tr>
<td>Know your family history of cancer</td>
<td>Consumption of contraceptive pills</td>
</tr>
<tr>
<td>Know personal risk factors</td>
<td>Have no more than one alcoholic drink per day</td>
</tr>
<tr>
<td>Take a multivitamin with folate everyday</td>
<td>Eat no more than 2 to 3 servings of red meat</td>
</tr>
</tbody>
</table>

The various theories regarding causes and prevention of cancer are given in Plate 7.15.

(B) Environmental causes of cancer: A total of 374 articles took into account the environmental causes of higher incidence of cancer in Malwa region of Punjab. The portrayal of environmental causes of cancer in print media created a national debate (Plate 7.16a and 7.16b).
A number of newspaper reports also pointed at the contamination of underground water with the pesticides. A study conducted by Greenpeace was repeatedly reported in the newspapers, in three Districts Bathinda, Sri Muktsar Sahib and Ludhiana of Punjab to assess the effects of nitrogenous fertilisers on groundwater. A total of 50 samples were collected (18 each from Ludhiana and Sri Muktsar Sahib and 14 from Bhatinda). The village Doda in the Gidderbaha block of Sri Muktsar Sahib District was found to be the worst hit with nitrate level of 601.6 mg/l as against the prescribed level of 50 mg/l for safe drinking by World Health Organisation. The other samples from Sri Muktsar Sahib, Bathinda, Jagraon, Ludhiana and Gidderbaha showed alarmingly high levels of nitrate. The study found that the average application rate is 322 Kg N per hectare in 2008-2009 in the three Districts namely Bathinda, Ludhiana and Sri Muktsar Sahib which is higher than the national average reported by the Fertilisers Association of India for Punjab i.e., 210 Kg N per hectare for 2006-2007 (Sharma, 2009). Garg (2009) also reported the indiscriminate use of fertilisers in Punjab villages that has pushed the state to the brink of health hazards like blue baby syndrome and cancer.

The uranium levels were found to be 62 times higher than the normal in samples of Bathinda (Garg, 2010d). Further, it is reported that uranium is causing the mental retardation among the children in Punjab apart of milder problems related to digestion, respiratory and nervous system. The other health problems include erectile dysfunction, menstrual problems, childless couples, spontaneous abortions, premature births, congenital defects, child mortality and premature deaths (Garg, 2010e). The Bhabha Atomic Research Centre (BARC) found traces of uranium in various regions of Punjab including 13 Districts including Tarn Taran, Moga, Barnala, Sangrur, Ludhiana, Fatehgarh Sahib, Mohali, Ropar, Nawanshahar, Hoshiarpur, Gurdaspur, Amritsar and Pathankot. In these Districts uranium levels have been found above permissible limits (Sharma, 2012). The portrayal of cancer in Malwa region of Punjab and its possible causes in 'Down to Earth' is given in Table 7.40.
Increasing cancer deaths in Punjab Malwa region is becoming a toxic hotspot.
Plate 7.16b: Environmental causes of cancer

© High arsenic level in water causes cancer

Cancer count up by 80% in a yr
120 to 125 Cases Per Lakh in Malwa

tombel turns into cancer belt

Pawar doesn’t know of Punjab’s cancer belt!

Uranium contamination
Now, cancer jeeps ferry Punjab’s gloom

Cancer belt gets super specialty hospital
Malwa women prone to breast cancer: Study

Unchecked pesticide use harming health

Two cancer deaths in Abhar

Cancer concerns bring S. Punjab’s water samples

Uranium may not be cor...
Table 7.40: Cancer in Malwa region of Punjab and its possible causes in 'Down to Earth'

<table>
<thead>
<tr>
<th>News headline</th>
<th>Reference</th>
<th>Possible cause of cancer mentioned</th>
<th>Cancer hit areas mentioned</th>
</tr>
</thead>
<tbody>
<tr>
<td>Punjab crop loss spurs debate on pesticide use</td>
<td>Vol 10, No. 9 Sep. 30, 2007</td>
<td>Excessive pesticide use</td>
<td>Punjab</td>
</tr>
<tr>
<td>Health care in Malwa in shambles</td>
<td>Vol 16, No. 12 Nov. 15, 2007</td>
<td>Excessive pesticide use</td>
<td>Villages Jajjal, Malkana of District Bathinda</td>
</tr>
<tr>
<td>Punjab Agricultural University plays host to pesticide lobby</td>
<td>Vol 16, No. 12 Dec. 31, 2007</td>
<td>Excessive pesticide use</td>
<td>Punjab</td>
</tr>
<tr>
<td>Toxic Nexus</td>
<td>Vol 16, No. 12 Dec. 31, 2007</td>
<td>Excessive pesticide use</td>
<td>Malwa region of Punjab</td>
</tr>
<tr>
<td>Pesticide-ridden Punjab to begin cancer registration</td>
<td>Vol 17, No. 2 June 15, 2008</td>
<td>Excessive pesticide use</td>
<td>Punjab</td>
</tr>
<tr>
<td>Cancer state</td>
<td>Vol 17, No. 2 June 15, 2008</td>
<td>Excessive pesticide use</td>
<td>Malwa region of Punjab</td>
</tr>
<tr>
<td>Uranium traces in Punjab children</td>
<td>Vol 17, No. 23 April 30, 2009</td>
<td>Excessive pesticide use, heavy metals, uranium (from Iraq where the U.S. army used uranium in its warhead)</td>
<td>Faridkot District of Punjab</td>
</tr>
<tr>
<td>Uranium in food, water in Bathinda</td>
<td>Vol 18, No. 4 July 15, 2009</td>
<td>Underground water contamination with uranium</td>
<td>Giana, Malkana and Jajjal of District Bathinda</td>
</tr>
</tbody>
</table>

Based on the various reports that published in print media led to the constitution of a standing parliamentary committee on agriculture headed by MP Basudev Acharia that visited the cancer-hit villages in Talwandi Sabo, Bathinda (Mann, 2012).
(C) Breakthroughs in medical treatment of cancer: Earlier studies on the portrayal of cancer in mass print media discussed the dominance of medical frame but in present study, only 43 articles out of a total of articles mentioned about the scientific breakthroughs in the field of cancer treatment. These scientific breakthroughs mentioned the development of new methods of diagnosing cancer in its earliest stages, development of better drugs and shortening of cancer treatment. Nelkin (1995) argued that the description of new drugs as 'magic bullets' or 'breakthrough' sensationalise and simplify otherwise complex science stories. In the articles under study, similar kind of terminology like 'gene decoded' (ANI, 2009e), 'golden bullet' (ANI, 2010h), 'new treatment' (ANI, 2010i), 'breakthrough' (Cannon, 2009), 'gene identified' (PTI, 2009), 'gene found' (Reuters, 2010), 'faulty genes found' (PTI, 2011), 'landmark discovery' (PTI, 2011), 'life saving drugs' (Kannan, 2012) was found. The breakthroughs in cancer treatment are described as the ways that may lead to an effective treatment of cancers (PTI, 2010). The new and cheaper treatment options are described as 'a hope for patients who could not afford costly treatment' (Kannan, 2012).

(D) Social aspects of cancer: Mass media can affect many aspects of one's social life especially in relation to health but the earlier studies on coverage of cancer in print media often ignored the social aspects of cancer. The focus remained on the medical breakthroughs in the field of cancer treatment rather than the social life and social problems faced by the cancer patients. The perspective of patient is often described in terms of pathology of disease, its treatment and physical suffering of patients but the present paper focussed on social aspects of cancer patients as well.

A total of 39 articles (21 in The Tribune (English daily newspaper) and 18 in The Times of India (English daily newspaper) were analysed for social frame of portrayal of cancer. One of the article described the diagnosis of cancer as traumatic which effects the physical, emotional and spiritual well-being of the afflicted person such that all aspects of person including work, relationships and social interests gets affected. Some of the articles mentioned cancer survivours as icons and heroes, and created a kind of
positive stigma while others described the negative stigma related to cancer especially breast cancer. The cancer treatment is described as 'achieving remission from the disease' (Chawla, 2010).

An article entitled “serving with cheer” also highlighted the need for a dignified cancer care as cancer means stigma in countries like India (Nath, 2010). The issues like cancer pain management are also discussed in print media. The article mentions that cancer is a devastating diagnosis but the cancer pain is manageable. It is suggested that in order to deal with the cancer pain effectively, it is very important to take the medication regularly and to educate, and create awareness among the patients, and their caregivers (Chawla, 2010). The other terms like ‘comfort’, ‘dignity’, ‘relief’ and ‘quality of life’ are also discussed in context of cancer (Chawla, 2010).

It has been described that cancer care in India, especially for the lower and middle classes, can turn out to be a nightmare. Further, it is stated that while the treatment protocols and consequent costs vary across a broad range depending upon the site of cancer, and the stage at which it is detected, oncologists attest that it can be a huge drain on the resources of a family. The average cost of ₹ 1,602 per week is reported in an Indian health care setting (Kannan, 2012). A number of case studies relating to financial difficulties faced by cancer patients have also been reported by the print media. Some of these are discussed as under:

**Case N₁:** A female cancer patient from village Mehma Bhagwana described her financial difficulties. She reported that ₹ 1.5 lakh has been sanctioned by the Punjab government but she has only received ₹ 60,000 so far due to inadequate amount of bills produced by her.

**Case N₂:** A female cancer patient, an agricultural labourer from the village Chatthewal, explained that she has already spent more than ₹ 1 lakh for her treatment and due to lack of money, her family has abruptly stopped her treatment.
Case N3: Another female cancer patient (a maid servant) also struggled to bear the treatment expenses. Her son works as a labourer while her husband died 10 years ago in 2001. She explain that she has already submitted the required documents in the office of Deputy Commissioner, Bathinda a few months ago in January 2012 to get the financial aid but so far no aid has come her way.

Some of the narratives of cancer patients have also been used by print media for creating awareness. Some of these are given as under:

“Cancer is not end of the world. It is like any other disease” as a cancer patient prepares to undergo surgery at AIIMS, New Delhi.

“I am in the pink of health. Cancer has more to do with the state of mind. The body will respond positively to medication only when it is in tune with the mind”.

“I tell all the patients to start treatment as soon as possible and not to be afraid of the side-effects that other patients suffered”, a doctor quoted.

Article entitled “killer called breast cancer” mentioned that the counselling and family support are vital for all those going through cancer and other maintained that the loss of social network among cancer patients shorten the life expectancy (Rai, 2009). Other social variables covered by the articles include the interpersonal relationships and quality of life.

An article entitled “killer called breast cancer” described the women as katti phati (broken and torn) after their breast removal surgery and also pointed out that such women are often rejected by their husbands (Rai, 2009). Lantz and Booth (1998) expressed that a woman’s breasts symbolises both motherhood-central to woman’s traditional identity and female eroticism key to sexual attractiveness and thus, sign of femininity. Breast cancer poses a threat to ‘ideal’ roles for women and ‘perfect’ feminine body. Thus, the disease which effects physical appearance and social roles often effects interpersonal relationships especially between patient and his/her spouse. The analysis of the articles revealed that the mass media often create ‘categories’ and singles
out certain individuals for special attention. The terms like ‘stigma’ (Nath, 2010), ‘sexual dysfunction’ (ANI, 2010) and ‘change in interpersonal relationships’ (Rai, 2009) were also used in context of breast cancer patients. Thus, a special category of breast cancer patients was created.

Breast cancer was described as a ‘killer disease’ and its survival as ‘heroism’ (Rai, 2009). The cancer survivors were referred to as ‘icons of survival’ (Nath, 2010), ‘conquerors of cancer’ (Bose, 2009b) who not only battled with the disease but also fought social customs to become proud survivors of a ‘nasty disease’. Similar observations were made by Seale (2002) who found breast cancer to be linked to heroism, desired transformation and positive stigma.

Some of the survivor stories in relation to breast cancer are given as under:

**Case N4:** A female cancer patients (52 years old housewife from Bathinda) report that she was diagnosed with breast cancer few years back. At the time of diagnosis, the immediate thought that came to her mind was that what would happen to her family after her death as both of her sons were unmarried, and she was the only woman in her house to take care of her family. So, she decided to carry forward best possible treatment for herself. She underwent surgery followed by six rounds of chemotherapy at Rajiv Gandhi Cancer Institute and Research Centre (New Delhi) accompanied by continuous medication. Now, as a precaution, she undergoes mammography every three months. Her last mammogram was conducted in September 2011 and showed normal results.

**Case N5:** A female (aged 62 years, breast cancer, school teacher) was diagnosed with breast cancer in the year 2007. At this time, she derived her strength from her students. As a teacher, she has always told her students to do well whatever the odds. When she was diagnosed with cancer, she decided to be courageous and brave enough to overcome the disease.
In relation to breast cancer, the personal testimony of Member of Parliament, Priya Dutt is described. In the articles, she states the cases of her mother and her sister-in-law, who also died of cancer (Taneja, 2010).

7.7.1.2 Latent findings: Latent themes include the investigation of deeper and perhaps unintended themes. The latent themes were searched both in the titles and the texts of the newspaper articles.

The titles to the articles are suggestive of the tone and implicit messages that are highlighted with each disease (Clarke and Everest, 2006). The titles of the articles in the present study described cancer as an enemy to the human body against which there is need to launch a crusade or fight. Breast cancer has been described as a disease directly related to death in article entitled “killer called breast cancer”. Some of the tiles not even used the term ‘cancer’ but instead used ‘C’ and described ‘C word alone is devastating’ (Brewington, 2009), ‘C word is dreaded’ (John, 2010) and the ‘C’ slayers (Bano, 2010). Clarke (1992) also found in his study that the word ‘cancer’ is often replaced by the terms like ‘BIG C’.

In the text of articles the phrases like ‘devastating disease’ (Nath, 2010), ‘dreaded disease’ (Rai, 2009; Kanwar, 2012), ‘disease of western hemisphere’ (Bose, 2009b), ‘life threatening disease’ (Sharma, 2010), ‘malignant disease’ (Sinha, 2011), ‘biggest killer of human race’ (Bose, 2011), ‘tropic of cancer’ (Sen, 2011), ‘king of all maladies’ (Editorial, 2012), ‘emperor of all maladies’ (Iyer, 2012) were found to be used for cancer. It is also called as ‘nasty disease’ such that there is nothing good about it. The only solution to the disease is awareness and early detection (Bose, 2010c). It is mentioned that this six letter word has the potential to make the worlds and lives fall apart (Mann, 2011). It is further reported that cancer is not a new disease and it has been a health concern since the dawn of humanity (Swarup, 2011).

The article entitled “life beyond cancer” mentioned that though the word ‘cancer’ is enough to send shivers down the spine of even the toughest but still there is life beyond cancer and gave the six survivour stories describing the fighting spirit of cancer along with the social factors like social support.
Cancer is described as the the worst way to die (Taneja, 2010). The cancer patients are mentioned as the 'victims' in some of the articles (AFP, 2012). The other expressions include 'cancer is a pause in life' and 'diagnosis made her completely shattered' (Jaiswal, 2011). At the same time, it is also mentioned that the 'C' word no longer evokes the dread it once did and there are several good reasons for this such as progress in treatment, lesser cost and lesser time for the treatment (Gupta, 2012).

Cancer is described as a disease which does not differentiate between sexes i.e., between men and women though the pattern of the disease is different in the two because of the variations in the anatomy of the two sexes (Bose, 2010).

(A) Use of battle metaphors: The use of battle metaphors is not unique to media narratives but being something we all live by (Lakoff and Johnson, 1980) and they are important in creating rhetorical effects in media representations. Thus, the cancer experience may be considered as being like a battle (Sontag, 1991), other sporting struggle (Seale, 2001), thereby allowing the language of sports reporters, war correspondents and health writers to merge at a certain level (Seale, 2002).

In the present study, the liberal uses of battle metaphors like 'fight cancer' (Pollack, 2010; Bose, 2010), 'killer disease' (Rai, 2009), 'deadly disease' (Sandhu, 2009b), 'bomb' (Bose, 2009b), 'war on cancer' (AFP, 2010), 'battle against cancer' (AFP, 2010), 'battling cancer' (Daily Post, 2012) and 'anti-cancer war' (Tribune News Service, 2012b) in both headlines and body of the articles was found. Some of the titles with battle metaphors are given below:

Dendritic cell therapy helping fight cancer (TNN, 2009a)
Pink October-Cancer awareness: A crusade against cancer (Sarin, 2009)
Killer called breast cancer (Rai, 2009)
Fight cancer (Naik, 2009)
India sitting on a cancer bomb (Sinha, 2009b)
I’ll beat cancer: Lisa Ray (TNN, 2009b)
‘Golden bullet’ for cancer (ANI, 2010h)
Could cancer win the war (AFP, 2010)
Fighting breast cancer (Taneja, 2010)
A ‘vaccine’ to fight prostate cancer (Pollack, 2010)
New drug to arrest lung cancer spread (Sinha, 2011)
Battling the king of all maladies (Editorial, 2012)

The analysis of the use of language reveal that these were employed to primarily convey the important development of a medical system related to cancer and secondly, to portray cancer as an ‘enemy’. A previous study (Clarke and Everest, 2006) also note the use of battle metaphors like ‘deadly disease’, ‘battle against cancer’ etc., in relation to cancer. One of the articles discussed that every cancer patient has a ‘damocles sword’ hanging on one’s head as the disease can recur any time (Nath, 2010). Cancer treatment is also portrayed with metaphors of war and aggression such that radiation was compared to a ‘double edged weapon’ (Nath, 2010). The article entitled “golden bullet for cancer” also described the use of gold nanoparticles as ‘bullet’ for cure of cancer (ANI, 2010h). The completion of cancer treatment is described as ‘end of war’ (Jaiswal, 2011).

Other article stated that combining chemotherapy and radiation treatment pose a high risk of toxicity, resulting in painful and disfiguring burns (Brewington, 2009). Thus, cancer was equated with pain, suffering and death. The terms like ‘fight cancer’ were used in titles of articles as well as in the text (Naik, 2009; TNN, 2009a). One article also called for a ‘valiant fight’ against the dreaded disease, cancer (Bose, 2009b). A case describing the ‘fight’ of a cancer patient with the disease is given as under:

Case N6: A male cancer patient (aged 29 years, cancer of food pipe) was diagnosed with cancer only after few months of his marriage in the year 2009. The doctors said that his cancer is in its last stage and immediately put him on palliative care. At this time, he decided that he has to live for his parents and his wife, and that he could not die leaving them suffering behind. He
underwent chemotherapy and radiotherapy at Rajiv Gandhi Cancer Institute and Research Centre in New Delhi and his medication still continues. Cancer has perforated his stomach but he is described as confident enough to 'conquer the disease'.

One of the articles described the experience of a patient as ‘depressed but not defeated by the disease’. Other patient who survived cancer was described as ‘given a tough fight to the disease’ (Bose, 2009b). In the cancer survivor stories, the terms like ‘cancer tamed’ are used. (Sharma, 2011). The survivours are described to ‘exemplify winning spirit’ (Jaiswal, 2011), offering ‘hope’ and ‘inspiration’ (Mann, 2011). Thus, the cancer survivours were described to have won ‘wars’ and fought ‘fights’ and ‘battles’. The metaphorical representation of cancer in titles of various newspaper articles is given in Plate 7.17.

(B) Use of scary statistics: Numbers are important for creating extreme contrasts. Classically, these are used to exaggerate effects so that the news value of an article is automatically enhanced (Seale, 2002). Numbers, as Bell (1991) observed works by enhancing the facticity of reports appearing to be objective to a credulous and somewhat innumerate public. Clearly, numbers and statistics can play an important part in generating oppositional extremes that enhance emotional engagement, so any analysis of media anthropology must be alert to their presence.

It is reported that sixty two years post-independence, India has seen tremendous progress. The longevity of life has doubled, common ailments have been controlled and, as a matter of fact, a few of them have even vanished. But many other health problems have crept in, one of the important one being the rapid increase of cancer in India (Bose, 2009c). In print media, fear is reinforced by scary statistics. In various articles, cancer has been described as a leading cause of deaths around the world. World Health Organisation’s estimate of 84 million cancer deaths by 2015 was mentioned in one of the articles (Naik, 2009). Other mentioned that every year 100,000 women get breast cancer in India and 40 per cent of them die because it is
detected too late (Rai, 2009). Also eighty per cent of patients reach the doctor after the second stage. Some of the article also gave disease specific data. One of the articles mentioned that 1.3 million deaths worldwide occur due to lung cancer (Bedi, 2009). Some cancer statistics were also linked to certain factors like age and obesity. One article mentions that most of the cancer deaths takes place in 30-69 age group (Express News Service, 2012) while other mentions that one in twelve women develop cancer because they are overweight (Sinha, 2009a). It is observed that print media related diseases such as diabetes (ANI, 2010k) and tuberculosis (ANI, 2011) to increased cancer risk. Some of the regions are also specifically associated with cancer in the print media. Some of the titles depicting the same include:

- Cancer second largest killer in valley (Sodhi, 2010)
- Cancer highly prevalent in Malwa region (Garg, 2010f)
- Cases of lung cancer on rise in valley (PTI, 2010)
- Cancer fear grips Amargarh residents (Majeed, 2011)
- Malwa women prone to breast cancer: Study (Sandhu, 2012)

These statistics clearly indicate that the print media relate cancer to death and fear with the use of scary statistics and projecting certain areas as more prone to cancer than the others. The use of scary statistics for portrayal of cancer in print media is given in Plate 7.18.

(C) Use of personal testimonies: Lupton (1994) argue that the survival stories of patients that appear in media are ‘living examples of the victory of medical interventions’. McKay and Bonner (1999) analysed three Australian women magazines over the period of three years and found forty-two personal testimonies of breast cancer patients which reflect a general growth in interest in personal stories about illness experience, and a general shift ‘away from reliance on medical institutions and toward personal responsibility for health and well-being.

Across the two newspapers, there were many instances of compelling personal testimonies and human interest stories of men and women diagnosed with cancer. A total of thirteen personal testimonies were described
Cancer highly prevalent in Malwa region

Cancer count up by 80% in a year:
120 to 125 Cases Per Lakh in Malwa

Every year, 100,000 women get breast cancer in India and 40% of them die because it is detected too late or they are too shy to get themselves examined. Eighty per cent of them reach the doctor after the second stage.

Cervical cancer claims one Indian every seven minutes.

Migrant women prone to cancer.

Cases of lung cancer on the rise in Valley

70% cancer cases reported at PGI involve breast and cervix.

Increasing cancer deaths in Punjab.

Malwa women prone to breast cancer: Study

Cervical cancer claims one Indian every seven minutes.

Migrant women prone to cancer.

Cancer threat looms over Tarn Taran dist.

Malwa region is becoming a toxic hotspot.

53 students diagnosed with cancer in state.

Cancer cases in state.

PGI involve breast and cervix.

Increasing cancer deaths in Punjab.
(ten women and three men). Thus, the articles targeted the women readership in form of cancer survivor stories. Among women, seven were breast cancer survivors; others were myeloid leukemia, pancreas and bone cancer survivors. The age of female breast cancer survivors ranged between 18 and 79 years. Thus, it was described as ‘disease of all ages’. The idea behind some of the breast cancer survivor testimonies was to create awareness regarding breast self examination and consultation with doctor in case of any abnormality. Among men, one each was kidney and oesophagus cancer survivors. One male was breast cancer patient who was under treatment. Fernandes (2012) pointed out that breast cancer is not just found among women but it is also found among the men. He cited a case study of a male breast cancer patient who had a painless lump in his breast and on detection, it was found to be breast cancer. Later, a surgery was carried out to remove the lump from the breast. It was difficult for him to accept his breast cancer diagnosis as he was always the only man in the queue of women and frequently asked whether he was in a right queue.

In one of the survival story, a girl who just celebrated her 18th birthday was mentioned to describe a lump in her breast but timely decision of her mother to take her to hospital for check-up (as she had family history of breast cancer) saved her life (Rai, 2009). This testimony described the importance of early detection in treatment of cancer. The other story underlined the importance of regular follow-ups for cancer patients. One woman, who ignored lump in her breast, was described to develop breast cancer. She also missed out on her follow-ups after her surgery and this led to recurrence of breast cancer (Bose, 2009c). Other story described the recurrence of breast cancer in a survivor after 13 years (Bose, 2009b). Thus, these stories not only supported the idea that cancer is curable if detected early but these also created fear regarding recurrence of the disease. A case study of a male breast cancer is given contrary to the belief that breast cancer is often described as a woman’s disease (Rai, 2009). The other testimonies focused on aspect that allopathic treatment is the best treatment for cancer. A female breast cancer patient is described to visit a homeopath due to fear of surgery but later she moved to allopathy again as homeopathy was not of much use.
Celebrity cancer stories were covered by these newspapers. The most high profile personal testimony was that of actress Lisa Ray who suffered from multiple myeloma, a rare cancer. Her cancer journey was entitled “I will beat cancer” which highlighted her positive attitude to defeat cancer (TNN, 2009b). The other celebrity cancer stories include Priya Dutt's “fighting breast cancer” which described her 'never say dying' spirit (Taneja, 2010). The journey of Punjab's Chief Minister Prakash Singh Badal's wife (Surinder Kaur Badal) has also been discussed at full length but she died of cancer. At her death, she has been described as 'pillar of strength' who lost her life to cancer. The story regarding death of son of Punjab's ex-Chief Minister Harcharan Singh Brar have also been covered. The other celebrity cancer story to be covered was that of Yuvraj Singh. In these articles, he is described as a 'star batsman' who is battling cancer (Times news Service, 2012; Tribune News Service, 2012c). The personal testimony of Lance Armstrong has also been discussed. The personal testimonies of various celebrities in print media are given in Plates 7.20a and 7.20b.

7.7.1.3 Cancers at specific sites: Cancer of cervix is reported as most common cancer among Indian women. It is further reported that it affect the age group of 50 to 55 years, but all the sexually active women are at risk of contracting it. It is caused by HPV (Human papilloma virus). It is further mentioned that cervical cancer adds 6 million new cases each year while in India it leads to one female death every minute (Tandon, 2011). In print media, cancer of cervix is commonly associated with poor socio-economic status, improper hygiene and poor sanitation of the private parts of both the partners. The other factors like smoking and use of hookah (a single or multi-slemmed instrument for smoking flavoured tobacco) are also associated to cervical cancer (Rashid, 2010).

Lung cancer is the most common malignancy worldwide as far as incidence and mortality are concerned (Sinha, 2011). Oral cancer is the most
Plate 7.19: Personal testimonies of cancer patients in print media

They exemplify winning spirit

Fought cancer bravely to live and inspire others

Former British Prime Minister and statesman Winston Churchill, who is considered one of the greatest orators of the 20th century, once said, “Attitude is a little thing that makes a big difference”. He also said, “Never, never, never give up. And these two quotes perhaps best describe the indomitable spirit of hundreds and thousands of cancer patients who have bravely fought the disease to live and become a source of inspiration to other patients. As we celebrate yet another Cancer Awareness Day, it is time to salute the ever-winning spirit of our very own Terry Foxes, who have won the personal battles with the disease, but continue to fight the war against cancer by making people aware of the advantages of its early detection and treatment. Anuja Jalalwai meets four such bravehearts.

RENU SINGHAL (02) - Renu Singhal, former UT Chief Architect, has seen it all through the suffering and pain. She has undergone denial and depression.

Her war has not ended as she sits at a corner at the PGI counseling patients. From designing buildings to counselling has been a long journey. She says cancer has made her “brave”.

As president of the Sahayta Cancer Babhun Centre at Sector 19, which was started in 1997 by her sister, Neetu Tuli, who died of cancer in 2006, Renu said the NGO was engaged in creating awareness among patients that cancer was not the end of the world.

“She was not convinced,” Renu said. “It was in 1996 that was diagnosed with the disease. The initial reaction was of denial. That was followed by days of depression. I thought my life was finished. Even when doctors and my husband said I would be fine, I was not convinced,” Renu said.

“When I finished my treatment, I thought of the others who would also have the same desire. I also realized that early detection is important,” she added.

SANDEEP’S MARVEL (07) - The year 2006 was a bad one for Sandeep. His separation with his wife was followed by detection, chemotherapy, and depression. “I was working in Delhi when I started feeling weak and suffered from low-grade fever,” he said.

“I came back to Chandigarh to get it checked and discovered that I was suffering from cancer. I left my job as my doctor said I had only three months to live. I was completely shattered, but Sahayta’s president helped me a lot,” he added.

“It was then that he decided to get associated with this organization. Sandeep was now working as volunteer with Sahayta and now counselled cancer patients at the PGI. He said his outlook had changed. “I live my life with fun and pursue my hobbies as a part-time job. I participate in inter-ventor program in the PGI now,” he stated.

“I used to clean the track of debris and oil spills and oversee survey movement in case a safety car was called out,” he added.

SHOBHA KOSER (06) - Kathak dancer Shobha Koser was diagnosed with cervical cancer when she was 54. She said, “My instant reaction was of denial. Then I feel little hope and depression.

“I came back to Chandigarh to get it checked and discovered that I was suffering from cancer. I left my job as my doctor said I had only three months to live. I was completely shattered, but Sahayta’s president helped me a lot,” she added.

“It was then that Shobha was diagnosed with cervical cancer when she was 54. She said, “It was a bad phase for me. I was not able to sleep well. It was a very difficult time for me.”

“During chemotherapy, my hair started falling and I felt bad to go to school. But my colleagues were very supportive. They told me not to worry and I would be alright very soon. I am not on medication, but regularly visit the PGI for check-ups. My sister, Neelu Tuli, who died of cancer in 2013, has made her “brave”.

“Since my initial reaction was of denial, that was followed by days of depression. I thought my life was finished. Even when doctors and my husband said I would be fine, I was not convinced,” Renu said.

“When I finished my treatment, I thought of the others who would also have the same desire. I also realized that early detection is important,” she added.

ANITA (07) - It was indeed a shock when she was detected with breast cancer. And I got support from my family and colleagues, said Anita, who had two sons.

“My war has not ended as she lives and gives back,” she added. “I came back to Chandigarh to get it checked and discovered that I was suffering from cancer. My instant reaction was of denial. Then I feel little hope and depression. Even when doctors and my husband said I would be fine, I was not convinced,” Renu said.

“When I finished my treatment, I thought of the others who would also have the same desire. I also realized that early detection is important,” she added.

ANITA (07) - It was indeed a shock when she was detected with breast cancer. And I got support from my family and colleagues, said Anita, who had two sons.

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fatal disease in men causing 22 to 29 per cent deaths. Among women, cervical cancer continues to be a major killer (Express News Service, 2012). Pancreatic cancer is described as disease which ‘kills’ about 96 per cent of its ‘victims’ within five years of diagnosis and the type of cancer with lowest survival rates (AFP, 2012).

Both breast cancer and cancer of cervix are described as the cancers which makes up to 50 per cent of all cancer cases among Indian women. Breast cancer is described as second most common cancer among Indian women after cancer of cervix, and the most common among the urban Indian women (Bose, 2010; Sharma, 2010). Breast cancer in Indian women is different as it is diagnosed even in women in their 30s and 40s, unlike the western countries, where it is commonly seen in women in their 50s and 60s (HT Live Correspondent, 2010).

Breast cancer is described as a disease with no well-established risk factors. It is mentioned that the breast cancer is a multi-factorial disease, with the risk factors ranging from the hormonal to the genetic factors. A timely diagnosis is crucial for curbing and curing it (ANI, 2011). Breast cancer is attributed to a variety of factors such as westernisation and urban lifestyle, obesity, late marriage, late child birth and use of hormones (HT Live Correspondent, 2010). It is reported that the urban population is more aware of the disease but the life expectancy and urbanised lifestyles have contributed to the increased number of cancer cases (Vasudeva, 2011). The women are reported to be at greater risk of cancer after menopause (Kanwar, 2012). The family history is also described as an important risk factor for breast cancer but it is also maintained that the women in the age group 40-49 years with no family history of breast should also undergo annual screening for the cancer (AFP, 2012).

In print media, a number of risk factors of breast cancer are mentioned. Some of them are modifiable risk factors while others are non-modifiable risk factors.
The modifiable and non-modifiable risk factors for cancer are as follows:

<table>
<thead>
<tr>
<th>Modifiable risk factors</th>
<th>Non-modifiable risk factors</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Lifestyle</strong></td>
<td>Previous breast cancer</td>
</tr>
<tr>
<td>Alcohol consumption</td>
<td>Having one first-degree relative with breast cancer</td>
</tr>
<tr>
<td>Smoking</td>
<td>Childless women or those having children after the age of 30 years</td>
</tr>
<tr>
<td>Exposure to chemicals</td>
<td>Girls who have early menstruation (before age of 12) and late menopause (after 55)</td>
</tr>
<tr>
<td>Obesity</td>
<td>Less or no breastfeeding</td>
</tr>
<tr>
<td>Stress</td>
<td>Increasing age</td>
</tr>
</tbody>
</table>

The various symptoms of breast cancer mentioned in print media are swelling of all or part of the breast; skin irritation and dimpling; breast pain; pain in nipple or the nipple turning inwards; redness, scaliness or thickening of the nipple of breast skin; discharge from nipple other than breast milk; and a lump in the underarm area.

In print media, it is described that the awareness of early warning signs of breast cancer and risk factors can go a long way in helping in early diagnosis and effective treatment (HT Live Correspondent, 2010). A number of warning signals of breast cancer are discussed such as swelling in breast or armpit (completely painless to start with), bleeding from the nipple, thickening or ulceration of the skin over the breast and drawing of the nipple are the common signs of breast cancer. Quotes like “God helps those who help themselves” are also used to describe the importance of early detection (Bose, 2010). Breast cancer tests such as mammography are described as being painful but in the same article it has been urged to go for annual screening for early detection (Narayan, 2012). The other article reports that only 5 per cent women in India undergo annual screening (Sinha, 2012).

In print media, the treatment suggested for breast cancer include surgery or multi-modality regime consisting of surgery, chemotherapy,
Plate 7.20a: Personal testimonies of various celebrities in print media

‘I’m coming back’
Actress and cancer survivor Lisa Ray looks forward to her second innings in Bollywood

Sick away cancer then and ready to make her comeback, actress Lisa Ray, who fought a long battle with multiple myeloma, a rare form of cancer, for over 10 years, is happy to announce her comeback. "My hair is growing back and it is looking awesome right now. I am just loving it. I feel blessed and it just got together I have never looked so good before."

Ray says she wants to resume her acting and modelling career. But what inspired her to make the comeback is the offer of her acting colleague's book. "It was the best thing I could do. I am grateful to the world for my comeback."

Ray headed to India after her stem cell transplant in February. "It was the best thing I could have done. I am grateful to the world for my comeback."

Ray says she wants to resume her acting and modelling career. But what excites her most right now is the offer of her acting colleague's book. "It was the best thing I could do. I am grateful to the world for my comeback."

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Plate 7.20b: Personal testimonies of various celebrities in print media

Fighting breast cancer

HE BEAT CANCER BUT QUIT THIS BATTLE

Armstrong Stripped Of Tour Titles After Refusing To Contest Doping Charges

A merican cyclist Lance Arm­
strong, a legendary champion of a gruelling sport and a re­
silient cancer survivor who in­
spired millions of people across the world, including Indian cricketer Yuvraj Singh, may have turned out to be just another dope cheat.

Armstrong had transcended his sport to gain mass respect. The popular Livestrong yellow brace­

cuded to raise funds for his cancer foundation, were worn by millions. But on Friday, he was stripped of his record seven Tour de France titles and slapped with a lifetime ban from competition by the US Anti-Doping Agency. This followed Armstrong’s announce­

A defiant Armstrong main­

The Hero In 1996, at 25, Lance Armstrong was diagnosed with stage Three testicular cancer. Employed as a teacher and part-time cyclist, he dropped out of school and trained full-time. He pinned a photo of his cancerous testicle to his helmet and set out to win the Tour de France with a prosthetic leg. He won his first Tour in 1999, and went on to live for five more years after that. "That's all the more reason to keep going," he would say. "I'm just a bogie on the roads, and I'm not sure if you've seen one."

The bottom line is I stood by the fraud. In 2001, Armstrong had admitted to using performance-enhancing drugs and suspended him from competition. In 2005, after four years of inactivity, he returned to the sport and won his fourth Tour de France title. During this period, the US Anti-Doping Agency (USADA) concluded that Armstrong had violated the Anti-Doping Rules when he used performance-enhancing drugs. Armstrong refused to cooperate with USADA’s investigation and was given a lifetime ban from competition by the organization.

The Breakdown In 2011, USADA announced that it had found evidence of Armstrong's involvement in a doping ring. Armstrong went to court to challenge the decision, but lost. The USADA then announced that it had obtained evidence that Armstrong had used performance-enhancing drugs during the 2001, 2002, and 2003 Tours de France. Armstrong refused to participate in the USADA's investigation, and was given a lifetime ban from competition. In 2012, Armstrong announced that he would not contest the decision and would resign from his leadership role at Livestrong.

The Film Armstrong has been the subject of a documentary film, "The Armstrong Lie." The film explores the myth of Armstrong as a cancer survivor who overcame his disease by starting NDMCT, and the reality of his doping and drug trafficking.

The sedan. He maintained that he remained the most tested and tested of athletes and was clean. He said he had decided not to contest the charges because he had no faith in the system. Armstrong's popularity surged.

Armstrong's popularity surged.

In 2013, Armstrong's doping cases were dropped by the USADA. Armstrong admitted to doping and suspended him from competition. In 2015, Armstrong announced that he would not contest the decision and would resign from his leadership role at Livestrong.

Armstrong's popularity surged.

Armstrong was stripped of his record seven Tour de France titles after refusing to contest doping charges. Armstrong's doping case was one of the most high-profile cases in cycling history. The case raised questions about the integrity of the sport and the role of doping in professional cycling.

The Sedan: Lance Armstrong's car, which he used during his Tour de France victories, was the subject of a documentary film, "The Armstrong Lie." The film explored Armstrong's doping and drug trafficking and the impact on the sport of cycling. Armstrong was stripped of his record seven Tour de France titles after refusing to contest doping charges. Armstrong's doping case was one of the most high-profile cases in cycling history. The case raised questions about the integrity of the sport and the role of doping in professional cycling.
radiotherapy and hormone therapy. Surgery is described as removal of breast which often leads to physical disfigurement (Bose, 2010). Radiotherapy is described as a tedious process (both in terms of time and money) that lasts for over few weeks in context of breast cancer patients (Sinha, 2010a). Apart from the suggestions for the possibilities of various types of treatment for breast cancer, some of the articles also discuss about the breast conservation surgery but is described as the type of surgery which a very few surgeons in India practices and it is also possible at an early stage. A number of deciding factors for the kind of treatment are also listed in various articles. These include stage of the disease and biopsy results. Any new treatment options are described as a 'hope to millions of women suffering from breast cancer' (ANI, 2010h).

Sharma (2010) reported that “yoga may make you fitter and improve mood, but it would not make the malignant lump go away”. The article also cited the case of a 55 year old woman who opted for yoga and naturopathy and went on a raw, uncooked food diet for three months but again returned to allopathy in an advanced stage of breast cancer.

Regarding the survival rate of breast cancer, it is mentioned that more than 9 out of 10 women diagnosed in the early stages survive as oppose to 1 in 5 in later stages (Sharma, 2010). It is further stated that the breast cancer usually recurs around the area where the tumour is detected for the first time (Sinha, 2010b).

Futuristic expressions are also given in relation to cancer treatment such as:

- Shortening a cancer patient’s ordeal (Brewington, 2009)
- Vaccine for breast cancer in three years (PTI, 2011)

The data collected from 669 newspaper articles was analysed by using manifest and latent themes. In manifest themes, four sub-themes, breakthroughs in medical treatment of cancer, theories regarding causes and prevention of cancer, environmental causes of cancer and social aspects were analysed. The analysis of data clearly reveals that the political/economy frame is the most dominant frame of portrayal of cancer in mass print media.
followed by lifestyle frame. This finding is not in line with the earlier studies of Clarke (2004), Clarke and Everest (2006) and Clarke and Ameron (2008). In lifestyle frame, the list of causes of cancer was large even, at times contradictory. The prevention possibilities were exclusively framed if they were entirely within the individual capabilities of individual action. In political/economy frame, environmental causes of cancer such as uranium, fertilisers, pesticides and arsenic in ground water were mentioned. In medical frame, a total of 43 articles mentioned about the scientific breakthroughs in diagnosis and treatment of cancer. In social frame, the aspects like stigma, quality of life, interpersonal relationships, gender roles and social roles were discussed. In latent themes, sub-themes like use of military metaphors, use of scary statistics and use of personal testimonies were analysed. The liberal use of military metaphors like ‘battle’, ‘war’, ‘bullet’, ‘fight’, ‘conquer’, ‘killer’, ‘bomb’ was found. The findings were in favour of Sontag (1991) who stressed that metaphors are essentially military where cancer is concerned. Similar use of scary statistics was found and personal testimonies of 13 cancer survivors and patients were also found apart from celebrity testimony of actress Lisa Ray, cricketer Yuvraj Singh and politician Priya Dutt. The study is a step ahead in the field of media anthropology and qualitatively analysed the social construction and portrayal of cancer in mass print media. The distribution of newspaper articles over three periods i.e., 1st April 2009 to 31st March 2012 is given in Table 7.41.

<table>
<thead>
<tr>
<th>Frames</th>
<th>Time period</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1st April 2009 to 31st March 2010</td>
<td>1st April 2010 to 31st March 2011</td>
</tr>
<tr>
<td>Lifestyle frame</td>
<td>77 (62.10)</td>
<td>42 (28.58)</td>
</tr>
<tr>
<td>Political/economy frame</td>
<td>25 (20.17)</td>
<td>71 (48.29)</td>
</tr>
<tr>
<td>Medical frame</td>
<td>17 (13.70)</td>
<td>23 (15.65)</td>
</tr>
<tr>
<td>Social frame</td>
<td>5 (4.03)</td>
<td>11 (7.48)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>124 (100)</strong></td>
<td><strong>147 (100)</strong></td>
</tr>
</tbody>
</table>

Table 7.41: Distribution of newspaper articles over three periods
A comparative distribution of different frames over three years is given in Bar-diagram 7.1.

**Bar-diagram 7.1: Comparative distribution of different frames over three years**

It can be concluded that from 1st April 2009 to 31st March 2010, that lifestyle frame is the most dominant followed by political/economy, medical frame and social frame. From 1st April 2010 to 31st March 2011, political/economy frame is the most dominant frame followed by lifestyle frame, medical frame and social frame. From 1st April 2011 to 31st March 2012, the most dominant frame of portrayal of cancer appear to be political/economy frame followed by lifestyle frame, medical frame and social frame.

**7.7.1.4 'Cancer train': Portrayal in media and personal experiences of patients:** There is a high incidence of various cancers in cotton growing belt of Punjab including Bathinda, Mansa, Faridkot and Sri Muktsar Sahib (Kochhar, 2006). Though the government records show less number of cancer cases in comparison to actual number (Misra, 2007). The Malwa region is now called the ‘cancer belt’ and Bathinda- Bikaner train which carries the cancer patients from Punjab to Acharya Tulsi Regional Cancer Treatment and Research Institute in Bikaner as ‘cancer express’ or ‘cancer train’ as it
carries the cancer patients from Punjab to Bikaner for much affordable treatment (Dogra, 2007). Sharma (2008b) reported that number of cancer patients in Malwa region of Punjab grew manifold in recent years. He referred the Abohar-Bikaner train which carries the cancer patients to Bikaner as ‘cancer train’ (marizon ki train). This particular train had virtually become the hope for cancer patients from Bathinda, Sri Muktsar Sahib, Mansa, Ferozepur, Moga, Barnala, Faridkot and Sangrur. The villages Giana, Jajjal, Malkana, Laleana of Talwandi Sabo block of Bathinda District are among the worst-hit by cancer. Sandhu (2009a) reported that the Lalgarh-Abohar-Jodhpur train No. 339 is now referred to as ‘cancer train’ as it carries the cancer patients from Punjab to Bikaner for their treatment. The train has become a lifeline for the stricken patients. The reason for which cancer patients visit Acharya Tulsi Regional Cancer Treatment and Research Institute in Bikaner is the affordability of the treatment as it is a state run hospital funded by the central government and charges for the treatment are very nominal there. Sengupta (2011) reported the travel of cancer patients from Bathinda to Bikaner as a ‘a train ride to cancer care’. The portrayal of ‘cancer train’ in print media is given in Plate 7.21.

Unable to find a berth on a regular train and absence of convenient modes of public transport in their villages – all in Punjab’s infamous ‘cancer zone’ – they are taking their entourage in this pooled vehicles to the cancer hospital in Bikaner that, for years, has become their second home. These community organised vehicles are called ‘cancer jeeps’ (Dua, 2011). The portrayal of ‘cancer jeeps’ is given in Plate 7.22.

Rajaydeep (2009) reported the epidemic form of cancer in village Malkana of District Bathinda. He further reported that in the face of government apathy and lack of means, many villagers are now taking recourse to ‘black magic’ in the hope that it would help in ridding the disease of the village. He further added that during his visit to the village, he came to know about that dozens of villagers had fallen prey to various forms of cancer in the past and moreover, the state health authorities had not rendered any medical assistance to the villagers. He also noted that outsiders are reluctant
'Cancer train' a lifeline for stricken patients

There was little hope of survival for 17-year old Sukhjit Singh, a resident of Ramilwala village in Moga district, who was diagnosed with blood cancer earlier this year. However, as soon as his parents came to know about a cancer hospital located in Bikaner, they boarded the Abohar-Jodhpur passenger train from Batala on the night of May 12, 2014, and reached the district town in Rajasthan the next morning. The train on which this young boy travelled for treatment at the hospital is popularly known among locals as the cancer train, which ferries at least 60 cancer patients every day from Punjab to Rajasthan.

Through the train, there is no air-conditioned coach and has only one sleeper class bogey, but it serves the needs of those affected with the deadly disease on a daily basis.

Beginning its journey from Batala at 4:00 am, the express passes through Pakka, Malout, Udham, Phillaur, Dera Bassi, Haripur, Gomti, Shewan, Siangla, Dargh, Mandi, Dhab, and Mandi Dabwali in Punjab's cotton belt before entering Haryana and entering Rajasthan. This reporter travelled along with the cancer patients on the train last week in order to know what motivated them to travel all the way to a dusty town in Rajasthan for being treated at a cancer hospital.

Sukhjit's uncle, Kanghwa Singh, said doctors in Moga and Ludhiana could not precisely diagnose his nephew's illness and advised a lot of money on tests and the other doctor.

Continues on page 11
to allow their children to marry anyone in the village. Some of the interesting case studies in relation to 'cancer train' are discussed here.

**Case 128:** A male respondent was a cotton growing farmer from Bathinda was diagnosed with cancer of oesophagus in the year 2009. He started his treatment at a private hospital in Ludhiana but due to expensive treatment he left his treatment. On suggestion from another cancer patient from the village, he went to Bikaner for his treatment. He told that he travels by *Kainsar gadi* (cancer train). About his journey, he further told that the train carries a large number of cancer patients from Abohar and Bathinda to Bikaner for a cheaper treatment. While travelling, a number of cancer patients and their families have to sleep on floor as the train is always overcrowded.

**Case 129:** A male respondent was a government school teacher for past thirty years. He was diagnosed with cancer of gall bladder in 2006. He discussed the diagnosis with some cancer patients from his village and they gave him advice to visit Bikaner for his treatment. He told that he has to travel by "*mañzan vāllī gadi*" (train which carries patient) every fifteen days for his treatment. He was happy that travel for patient is free and concession is available to the attendants as well but overcrowding of the train is always a problem.

**Case 130:** A male respondent (son of an advanced cancer patient suffering from cancer of prostate) told that he has to lift his father in his arms as there is no arrangement of wheel chairs on the platform. He argued that:

"*Cancer gadi aini mashhur hai, pher wi sarkār kuchh nahi kardi*" (Cancer train is so famous even then the government is not doing anything).

He ponted out to the lack of medical facilities, availability of wheel chairs, etc. at the platform as well as in the train. He argued that a large number of cancer patients travel by this train but there is no emergency medical facility in the train for these
patients. Instead there is overcrowding and many a times patients get no place to sit and they have to sleep on the floor of the train.

Case131: A female respondent suffering from cancer of cervix and undergoing treatment at Bikaner told that it takes around 12 hours to reach Bikaner from Bathinda. There is overcrowding in the train and many-a-times patients do not find a berth to sleep at night which makes their journey uncomfortable but they have no other option. Her husband also argued that sometimes he and his wife have to sleep on floor in order to reach the hospital.

Case132: A female cancer patients from village Mahinangal, District Bathinda suffering from cancer of cervix was diagnosed in 2004. Though she went to a number of doctors in and around Bathinda, with complaint of jaundice followed by urinary problems along with pain and vaginal bleeding with no clear diagnosis. She was advised to visit Bikaner hospital by a private hospital. She was diagnosed with cancer at Bikaner hospital and from then, she was undergoing treatment there. She travels by the infamous 'cancer train' as it is commonly referred. The train lacks the basic facilities like adequate sitting capacity, water facilities for the cancer patients.

Thus, a number of case studies depict the problems faced by cancer patients while they travel from Bathinda to Bikaner such as poor sitting facility at the platform, overcrowding in the train and unavailability of medical facilities in case of any medical emergency in the train.

The international interest appeared to be prominent when news about 'cancer train' appeared in NPR (National Public Radio) News. It was a 10 minute 13 second radio broadcast on May 11, 2009 titled, "In Punjab, crowding onto the cancer train". The show was hosted by Robert Siegel and Michelle Norris. The correspondent was Daniel Zwerdling and the interpreter was Sukhmani Kohli. It gave a detailed description of the train and covered
Plate 7.22: The 'cancer jeeps' of Punjab

Balm for cancer-hit Malwa

Few are the cars that are now even up in a single cancer drug facility present high-tech "cancer jeeps" in the state of Malwa. These include cars that are made to order and used by thousands of cancer patients among the Punjabi's suffering from cancer in the region. The cars are used to transport cancer patients to hospitals and clinics for treatment of cancer drugs on Friday.

The decision came as part of the Indian Council of Medical Research (ICMR) and the Punjab state government's efforts to reduce the cost of cancer drugs. According to the same report, the average cost of cancer drugs in the country for 2016-17 was Rs. 30,000 per lakh population.

"Incidence tax-exempt states account for the bulk of India's medicine production. As a result, excise duty cut on cancer drugs will have any impact on the overall production of such drugs," commented an expert on the matter. With the price reduction, thousands of cancer patients will be relieved after the Central government decided to slash the prices of cancer drugs.

"The Central Government has woken up if not alarmed and pollution caused by the excessive use of pesticides for mal plants. "At least, at some stage the price reduction will help in the reduction of the price of drugs," commented another expert. With The Disease Striking More Alarming, trains to Bikaner Go Full

Now, cancer jeeps ferry Punjab's gloom

With The Disease Striking More Alarming, trains to Bikaner Go Full

A vehicle that takes the patients to and fro from Bikaner to their treatment centre every day.

Alarmingly, trains to Bikaner Go Full

The "cancer jeeps" have become a new term for these special vehicles that take the patients to and fro from Bikaner to their treatment centres. With the price reduction, thousands of cancer patients will be relieved after the Central government decided to slash the prices of cancer drugs. Many experts have praised the decision, saying that it will have a positive impact on the overall production of cancer drugs.

"The Central Government has woken up if not alarmed and pollution caused by the excessive use of pesticides for mal plants. "At least, at some stage the price reduction will help in the reduction of the price of drugs," commented another expert. With the price reduction, thousands of cancer patients will be relieved after the Central government decided to slash the prices of cancer drugs. Many experts have praised the decision, saying that it will have a positive impact on the overall production of cancer drugs.

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the journey of patients from Bathinda railway station to the Bikaner hospital (available at www.youtube.com).

Two British youths from London, Jacob Proud and Greg Herdes, visited Bathinda and made documentary on the popular ‘cancer train’ and also covered some of the villages like Jajjal, Malkana and Deon of District Bathinda. The documentary is entitled as ‘cancer train’ (Goyal, 2010). The documentary has been received by researcher through a personal communication.

Similar problems of cancer patients have been mentioned by a number of electronic media coverages. A documentary has been broadcasted by Day and Night Television in Punjabi language entitled, “Cancer da kaihar”. This documentary covered the problems of a number of cancer patients and their families. It also covered the problems faced by cancer patients while travelling from Bathinda to Bikaner via ‘cancer train’ (www.youtube.com). Another coverage under the title, “Toxic food- Poison on our plate?” was broadcasted in the Programme ‘Satyamev Jayate’ (episode 8 broadcasted on June 24, 2012 at 11 am) on Star Plus channel also covered the detailed description about use of pesticides, problems faced by cancer patients in Punjab and touched upon the issue of ‘cancer train’. A national debate has been generated by the episode that the pesticides which are promoted as necessity (www.satyamevjayate.in). The portrayal of cancer in various electronic media is given in Plate 7.23.

A 19 minutes 11 seconds report “The killing fields of Punjab” was broadcasted on April 25, 2011 at 9:30 pm by Headlines Today to cover the issue of excessive pesticide use in Punjab which turned Malwa’s fields into ‘cancer fields’. The report focussed on the use of endosulphan, a pesticide which has been banned in 70 countries and also in states like Kerala in India. In the report, the pesticides are referred to as ‘slow poison’ and Malwa region is referred to as ‘cancer capital of Punjab’.

Another documentary entitled, “Cancer in Punjab” made by AP.S. Mann is available in three parts and it covers the problems faced by cancer patients
in a greater detail. These include their physical problems such as symptom burden, suffering and pain, and social problems such as financial concerns, lack of family support, etc are covered (www.youtube.com).

It is clear from the analysis of coverage by electronic media especially, the portrayal of ‘cancer train’ that the coverage of cancer is stigmatising and the train that carries patients from Bathinda to Bikaner is repeatedly referred to as ‘cancer train’. On the other hands, through mention of personal testimonies of various cancer patients, the social problems faced by the cancer patients are also highlighted. These include financial problems, selling of farm land, suicides, inability to carry forward the treatment, problem of finding a suitable match for children of cancer patients, etc.

7.8 OBSERVATIONS FROM THE FIELD

Some of other observations during data collection are also interesting to note. One of the doctors at PGIMER, Chandigarh explained that diagnosis with cancer is like a sword hanging on one's head. It is better not be diagnosed with such a disease and die with dignity, and respect. She explained the case of her uncle who was a 78 years old and lung cancer patient undergoing treatment at PGIMER, Chandigarh. She told that the doctors treating her uncle made him go through all the possible diagnostic tests and later told the family that his cancer is in advanced stage, and untreatable. Thus, she feels that old age patients should not be made to undergo such tests and rather only symptomatic treatment should be given so that they could die with dignity.

One of the nurses at Department of Radiotherapy, PGIMER, Chandigarh was diagnosed with advanced cancer in the year 2011. She retired in the year 2000 and served the department for more than 30 years. She shared that she served cancer patients for so long and is well aware of the treatment and medication related to the disease. She knew that she was not given any kind of active treatment and given only symptomatic treatment. She explained that in her case knowing too much about the disease is a problem for her as she could see her end approaching her. She further shared
Plate 7.23: Portrayal of cancer in various electronic media
that she want to die with dignity by which she meant less symptom burden, less pain and suffering.

A nurse at Guru Gobind Singh Medical College and Hospital Faridkot, whose father was suffering from cancer of gall bladder also shared that having too much information about a disease is worst thing. After her father was diagnosed with cancer, she started comparing her father’s condition with other patients whom she encounters daily in the OPD. At the time of interview, her father was completely cure and was on follow-up stage. She explained that even if her father complains of fever or slight pain, she fears of recurrence.

Another nurse at the same hospital shared that her father had toothache for three months and when he went to a dentist, then the dentist showed his concern that this pain might be due to cancer. She shared that at that time, she started comparing his father’s pain with other oral cancer patient’s pain, their suffering, treatment and its side-effects. The further examination revealed it to be tooth problem and not the cancer. The respondent told that she relives the experience of those families who bring their cancer patients to her hospital daily.

7.9 IMPORTANT TERMS USED

7.9.1 Active treatment

The active treatment is a type of treatment which aims at curing the disease and bringing back the patient to previous state of health. The active treatment for cancer includes chemotherapy, radiotherapy, surgery and follow-up.

7.9.2 Symptomatic treatment

The symptomatic treatment is a type of treatment which aims at curing only the symptoms related to disease so as to reduce the suffering of the patients and improve their QOL. It is used for the diseases and particular stages of disease when cure is not possible. The symptomatic treatment for
cancer includes medication for pain relief, symptom control such as vomiting, nausea, urinary inconsistence, constipation, etc.

7.9.3 Health care providers

Health care provider is an individual or an institution that provides preventive, curative, promotional or rehabilitative health care services in a systematic way to the patients, their families or communities. They include doctors, nurses and other paramedical staff that provide services to the patients.

7.9.4 Caregivers

Caregivers are the individuals who are involved in primary care-giving to the patients. The caregivers can be informal caregivers including family and formal caregivers including doctors, nurses and other medical staff. The caregivers can also be primary and secondary depending on the role they play.