Disability Adjusted Working Life Years (DAWLYS) Of Leprosy Affected Persons In India

The Leprosy Mission Trust India
Leprosy, a chronic mycobacterial disease, is well known to cause irreversible disabilities if not treated early with MDT.

Social stigma, widespread misconceptions, and ignorance underlie late reporting and progressive disabilities resulting in economic and social disadvantages.

Effective rehabilitation and appropriate public health programs require precise data on prevalence, incidence, and consequences of leprosy disabilities.
Murray & Lopez brought the concept of calculating the burden of disease through **Disabilities Adjusted Life Years (DALYs)**, to facilitate comparisons of all types of health outcomes.

A DALY is a health outcome measure with two main components:
- Quality of life reduced due to a disability,
- Lifetime lost due to premature mortality.

In the process of calculating the DALYs, some weightage is given for specific disability and age discounting also has to be made.
This idea can be expanded to compute the loss due to both premature disability and mortality or other socio-economic disability.

Such ideas have been reported for many studies but not for leprosy.

The disability caused by leprosy can be insidious in onset, and the repercussions are seen gradually, and increasing in severity.

Thus, the DALY concept can be adapted to estimate the number of productive years lost due to the disability, and can be termed as disability adjusted productive work years lost or **Disability Adjusted Working Life Years (DAWLY)**.
Unlike in computation of DALY for some diseases, the data for use in the context of leprosy can be subjective, based on recall and many response biases.

However, the concept is a useful one in the context of India’s National Leprosy Eradication Programme (NLEP), and its application would help in planning, evaluating and implementing disability prevention programs.

Hence, it was proposed to investigate the methodology of computing DAWLY in leprosy affected persons as part of a major research on assessment of post-elimination status of leprosy in India.
The studies were conducted in the three states of Uttarpradesh, Westbengal and Chattisgarh during the period, June 2007 to September 2010.

Three representative rural blocks were chosen from each state.

A total 1281 leprosy affected persons with visible (grade 2) disability were identified.

In order to detect a 40 per cent loss of productive years on an average, with alpha of 0.05, and an error rate of 20 per cent, the minimum sample size was calculated as 150.

Therefore, representative stratified random samples of 50 patients from each of the three States were selected for an in-depth interview by a qualified, trained field investigator, using a specially prepared check-list.
The interview sought to collect a detailed work-life history from 18 years till 60 years of age.

- chronologically identifying the occupation, income earned,
- interruptions and changes of jobs,
- time when leprosy was discovered, reported and treatment started,
- break of job/loss of income since leprosy was detected and treated,
- reduction of wages/income from similar employees of the same job,
  - duration of work-loss, re-entry into the work force after any medical/surgical intervention,
- revised wage and proportionate losses with durations,
The overall mean DAWLY (± SE) of the disability adjusted life years was 28.6 (±0.67) which indicated a significant (P<0.05) reduction of 13.4 years or 31.9 per cent from the ideal productive period of 42 years.

The 95 per cent of DAWLY confidence interval was 27.22 to 29.88.

The mean DAWLY ± SE by age when disability started is shown in Table I.
Table I. Mean DAWLY, 95% CI and per cent reduction in life-years according to age when disability started

<table>
<thead>
<tr>
<th>Age when disability started (yr)</th>
<th>No</th>
<th>DAWLY</th>
<th>Reduction in life years (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Mean ± SE</td>
<td>95% CI</td>
</tr>
<tr>
<td>&lt;20</td>
<td>22</td>
<td>24.6 ± 1.66</td>
<td>21.19, 28.09</td>
</tr>
<tr>
<td>21 – 30</td>
<td>54</td>
<td>25.7 ± 1.08</td>
<td>23.51, 27.86</td>
</tr>
<tr>
<td>31 – 40</td>
<td>54</td>
<td>30.7 ± 1.05*</td>
<td>28.61, 32.82</td>
</tr>
<tr>
<td>41-60</td>
<td>20</td>
<td>34.8 ± 1.73+</td>
<td>32.31, 37.24</td>
</tr>
</tbody>
</table>

* P<0.05 compared to previous value
+ P<0.001 compared to value at<20 yr group
The patients who were affected by leprosy before the year 2000 had a DAWLY of 25.2 yr, a reduction of 40 per cent, as compared to the patients affected with leprosy after 2005 having a DAWLY of 30.2 yr, a reduction of 28.09 per cent in the life years.

This change in loss was significant (P<0.01).

The mean DAWLY ± SE by year when disability started is shown in Table II.
## RESULTS

Table II. Mean DAWLY, 95% CI and per cent reduction in life-years according to year when disability started

<table>
<thead>
<tr>
<th>Year when disability started</th>
<th>No</th>
<th>DAWLY</th>
<th>Reduction in life years (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Mean ± SE</td>
<td>95% CI</td>
</tr>
<tr>
<td>&lt;2000</td>
<td>41</td>
<td>25.2 ± 1.44</td>
<td>22.33, 28.16</td>
</tr>
<tr>
<td>2001 - 2004</td>
<td>26</td>
<td>28.5 ± 1.63</td>
<td>25.15, 31.86</td>
</tr>
<tr>
<td>2005 - 2009</td>
<td>83</td>
<td>30.2 ± 0.80*</td>
<td>28.62, 31.79</td>
</tr>
</tbody>
</table>

* P<0.01 compared to that in <2000
The mean of DAWLY, the 95 per cent confidence interval as well as the per cent reduction in life years according to the occupational status, is given in Table III.

The patients in skilled occupations had a DAWLY of 25.32 yr, a reduction of 39.71 per cent, as compared to the unskilled patients, who had a DAWLY of 29.23 yr, a reduction of 30.41 per cent in the life years.

This difference was not significant.

Among 150 leprosy patients, 124 (82.67%) were unskilled labourers. Most of the leprosy patients were farmers, or labourers, and a few were beggars.
The mean DAWLY ± SE by Occupational status is shown in Table III.

**Table III. Mean DAWLY, 95% CI and per cent reduction in life-years according to occupational status**

<table>
<thead>
<tr>
<th>Occupational status</th>
<th>No</th>
<th>DAWLY</th>
<th>Reduction in life years (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Mean ± SE</td>
<td>95% CI</td>
</tr>
<tr>
<td>Skilled</td>
<td>26</td>
<td>25.32 ± 2.07</td>
<td>21.06, 29.58</td>
</tr>
<tr>
<td>Unskilled</td>
<td>124</td>
<td>29.23 ± 0.68</td>
<td>27.89, 30.58</td>
</tr>
</tbody>
</table>
DISCUSSION

- Between 5 to 10 per cent of Indians have some impairment or disabiling condition, which means that India has a huge population of disabled people (GOI, Census 2001). India needs to make a shift from the medical model of intervention to community-based rehabilitation of the disabled.

- The computation of DAWLY provides an indicator that can be used to assess current status and impact of interventions. Despite all the limitations, DAWLY, as computed seems simple, easily understood, and a useful parameter.
Unlike calculation of traditional DALY based on evidence of mortality and severe morbidity, the DAWLY used in this study relies on subjective information on absence and irregularity in economically productive or remunerative work.

There might be considerable reduction in reliability of data depending on the skills of the interviewer as well as the commitment and co-operation of the respondent.

Both these conditions can be handled through proper training of the investigator and suitable undisturbed environment to carry out the interview.
CONCLUSION

- Despite the free availability of MDT, many patients still delay treatment till visible disabilities occur and the affected person is unable to perform his normal work.

- The findings of the study showed that on an average one third of the patients (30%) work life is lost due to leprosy.
The operational definition of DAWLY as used in this research may need further refinements to make it more sensitive in measuring the leprosy burden.

A prospective cohort study rather a retrospective one may be more reliable and valid to indicate not only the time lost due to a disability but also the time regained after reconstructive surgery and other therapeutic intervention.

More studies are needed to make DAWLY a better tool.
Thank You