

Comprehensive assessment of mortality and associated co-morbidities among Persons with Multiple Disabilities in Tamil Nadu – A preliminary study

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Abstract

Persons with multiple disabilities (PwMD) often experience compounded health challenges, including higher mortality rates and a significant prevalence of co-morbid conditions. This pilot study aims to comprehensively assess mortality patterns and associated co-morbidities among Persons with Multiple Disabilities in Chennai and Chengalpattu districts. A descriptive research design was adopted, and data were collected from 41 respondents using the validated Co-Morbidity and Mortality Assessment Tool (CMAT) developed by researchers. The sample was selected through purposive sampling, including caregivers of expired and living Persons with Multiple Disabilities. The average age among individuals with multiple disabilities was 11.8 years, with a mean disability percentage of 70.9%. A positive correlation (0.47) was observed between age and possession of a disability ID card, while a weak negative correlation (-0.2) was identified between age and disability percentage. No significant relationship was found between age and gender. Regarding mortality, most deceased individuals were female, Hindu, students, educated up to middle school, and diagnosed with multiple disabilities. Respiratory conditions emerged as a leading cause of both morbidity and mortality in this population. These findings highlight the age-specific vulnerabilities, mortality trends, and prevalent co-morbidities among individuals with multiple disabilities. They emphasize the importance of evidence-based interventions to improve health outcomes and enhance the quality of life for this vulnerable group, providing a foundation for further research and targeted strategies.

Keywords: Persons with Multiple Disabilities, Mortality, Co-morbidity, Age distribution

1. Introduction

Individuals with multiple disabilities frequently experience compounded health issues such as higher mortality rates and a high frequency of co-morbid illnesses. These individuals often have a mix of physical, sensory, cognitive, and developmental impairments, which not only increase their vulnerability to chronic illnesses but also complicate their access to healthcare services (World Health Organization - WHO). Despite this susceptibility, there has been

limited research into the precise health outcomes and patterns of mortality of Persons with Multiple Disabilities. This pilot study undertakes an in-depth evaluation of mortality and associated co-morbidities among Persons with Multiple Disabilities in Chennai and Chengalpattu districts, using caregiver-reported data to identify patterns and age distribution.

Methodology

The preliminary study was conducted over a period of one month and the data were collected from National Institute for Empowerment of Persons with Multiple Disabilities (Divyangjan) (NIEPMD) (D), Chennai, Tamilnadu.

Study strategy:

The Mortality and Co-morbidity study was conducted in selected regions following the study protocol. Data were conducted telephonic and direct questionnaire administered to care givers and rehabilitation professionals working for persons with multiple disabilities.

Research Design and Population

This preliminary study was utilized a descriptive research design to explore and document patterns of mortality and associated co-morbidities among Persons with Multiple Disabilities. The study was conducted at the National Institute for Empowerment of Persons with Multiple Disabilities (Divyangjan) (NIEPMD)(D), Chennai, Tamil Nadu. The population included Persons with Multiple Disabilities registered with NIEPMD (D) and their caregivers, focusing on those who could provide insights into mortality patterns and health conditions.

Sampling Method

A purposive sampling technique was employed to ensure the inclusion of respondents who could provide relevant data regarding the health outcomes of Persons with Multiple Disabilities. Participants were selected based on their eligibility and willingness to provide information on the mortality and co-morbidities of Persons with Multiple Disabilities under their care.

Sample Size

To avoid potential bias, mortality data were collected through multiple approaches to ensure a representative sample. First, the death register maintained by the National Institute for Empowerment of Persons with Multiple Disabilities (NIEPMD) was accessed. The register contained 48 entries, from which the researcher selected every alternate entry, resulting in a preliminary list of 24 potential respondents. Of these, data from 14 respondents were successfully collected, as some entries were excluded due to inability to contact or insufficient information.

In addition, mortality data were also collected through a randomized approach, targeting caregivers who visited NIEPMD for services during the period of November 26, 2024, to

November 28, 2024. Data were collected from 41 respondents, comprising 14 caregivers and rehabilitation professionals of expired Persons with Multiple Disabilities and 27 caregivers and rehabilitation professionals of living Persons with Multiple Disabilities. This sample was sufficient to explore the objectives of the preliminary study and refine the tools and methodology for future larger-scale research.

For mortality assessment, inclusion criteria involved caregivers of persons with multiple disabilities, including Cerebral Palsy, Autism Spectrum Disorder, Deaf-Blindness, Intellectual Disabilities, and multiple disabilities, who had passed away within the last 15 years. It also included healthcare professionals working with such individuals in rehabilitation centres or special schools across Chennai and Chengalpattu districts. The exclusion criteria for mortality assessment ruled out caregivers and healthcare professionals of individuals with multiple disabilities who are still alive or had passed away more than 15 years ago, as well as healthcare professionals not associated with rehabilitation centres or special schools.

For co-morbidity assessment, the inclusion criteria focused on persons with multiple disabilities associated with rehabilitation centres or special schools in the same regions. For co-morbidity assessment, individuals with multiple disabilities who were no longer alive or had a single disability, along with those with disabilities not recognized under the RPWD Act, 2016, were excluded. These criteria ensured a targeted and appropriate sample for the study.

Data Collection:

Data were collected using the Co-Morbidity and Mortality Assessment Tool (CMAT) developed by researchers. The tool underwent a rigorous validation process to ensure its reliability and validity for assessing mortality trends and co-morbid conditions among Persons with Multiple Disabilities. The content validity index was 1. The CMAT is a comprehensive instrument designed to collect structured data on individuals with disabilities. It is divided into three key sections: Demographic Information, Co-Morbidity Status, and Mortality Details, each addressing distinct aspects of the individual's health and living conditions.

The Demographic Information section gathers baseline details, including the relationship of the informant to the Persons with Multiple Disabilities, gender, age, district, and socio-economic details like education, occupation, and family income. It also captures diagnostic details such as the age of disability diagnosis and whether the Persons with Multiple Disabilities possesses a government-issued disability ID card. The Co-Morbidity Status section focuses on the health history of the Persons with Multiple Disabilities, documenting illnesses, age of onset, types of treatments received (e.g., allopathy, homeopathy), and medication adherence over the past six months. This section provides insight into the prevalence of various health conditions and treatment patterns. The Mortality section is specific to individuals with disability who passed away and includes information on the date and age of death, primary and secondary causes of death, and circumstances surrounding the passing. It also explores healthcare access, barriers to medical services, and the frequency of hospitalizations in the preceding months.

Designed to accommodate both living and expired Persons with Multiple Disabilities, the CMAT uses structured skip patterns for clarity and efficiency. If the CMAT will administered to caregiver of expired Persons with Multiple Disabilities, researcher will skip

section C. This tool not only aids in understanding mortality and morbidity trends but also identifies gaps in healthcare and other critical interventions, providing valuable data for enhancing the quality of life and care for Persons with Multiple Disabilities.

Data Analysis:

Data were analysed using descriptive statistical methods of SPSS to summarize the prevalence of co-morbidities, age-specific mortality trends, and the primary and secondary causes of death. Correlation analysis was used to identify key relationships among variables.

Ethical Considerations

The study was conducted in accordance as per ethical guidelines. Ethical clearance was obtained from NIEPMD's Institutional Ethics Committee. Informed consent was secured from all participants, ensuring their voluntary participation and the confidentiality of collected data. Participants were assured that the findings would be used solely for research purposes.

3. Review of Literature

Research highlights that co-morbidities such as cardiovascular diseases, respiratory conditions, and neuropsychiatric disorders are prevalent among Persons with Multiple Disabilities, amplifying their health challenges. Ouellette-Kuntz et al. (2015) emphasized the compounded burden of multiple chronic conditions among Persons with Multiple Disabilities, which impacts their quality of life and contributes to premature mortality. Salter et al. (2016) found that adolescents and young adults with disabilities are a high-risk group for mortality due to co-morbidities such as cardiovascular diseases and poor health behaviors. Furthermore, Landes et al. (2022) revealed that individuals with intellectual and developmental disabilities experienced disproportionate mortality risks during the COVID-19 pandemic due to increased susceptibility to co-morbid conditions and healthcare inequities.

4. Results

The study presents detailed statistics on co-morbidity and mortality among persons with disabilities. From frequency table, the average age was 11.8 years among Person with Multiple Disabilities as shown in Table 1. Disability percentages showed a mean of 70.9%. And the analysis found most participate were male as shown in Table 2.

| | Count | Female | Male |
|-------|-------|--------|------|
| 0-5 | 1 | 0 | 1 |
| 6-10 | 9 | 3 | 6 |
| 11-15 | 8 | 2 | 6 |
| 16-20 | 7 | 3 | 4 |

Table 1: Age group distribution

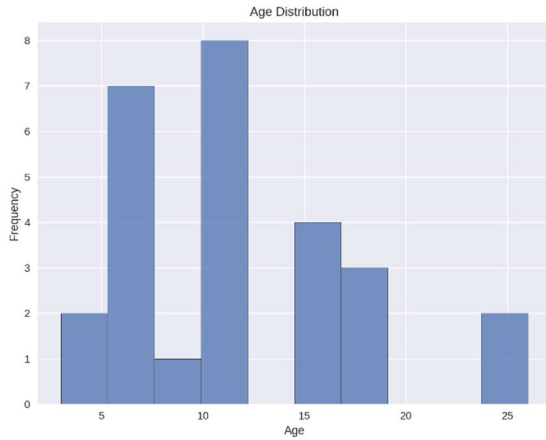


Figure 1: Age wise distribution

| | Count | Percentage |
|--------|-------|------------|
| Male | 19 | 70.37% |
| Female | 8 | 29.63% |

Table 2: Gender Distribution

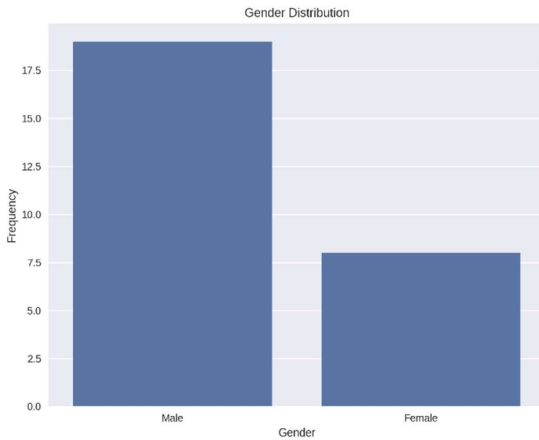


Figure 2: Gender wise distribution

Age positively correlated with having disability ID care (0.47) from chi-square t-test. Older individuals may be more likely to receive a disability ID card because of prolonged exposure to administrative processes, increased activism or awareness, or maybe more pronounced or documented disabilities over time. It could also indicate discrepancies in younger individuals acquiring ID cards due to unaware of disability ID card. It was major identification of the study which showed that drawback to identify Persons with Multiple Disabilities diagnosis and disability percentage. Some cases they may miss their benefits. The correlation coefficient of -0.2 indicates a weak negative relationship between age and disability percentage. It suggests that as age increases, the percentage of disability tends to slightly decrease. Disabilities might be identified and documented more comprehensively in younger individuals, leading to higher percentage ratings when they are assessed. The evaluation of disability percentages may change with age due to evolving diagnostic criteria, different evaluators, or less emphasis on

percentage documentation for older individuals. Those with very high disability percentages may have a higher risk of mortality, which could skew the data toward lower percentages in older age groups. There is no significant relationship between age and gender. According to the finding there is no connection with ages of Persons with Multiple disabilities and their gender. Gender showed weak positive correlation with having comorbidities (0.28) but weak negative correlation with disability percentage (-0.09). Most participants were male students attending special schools, and allopathy emerged as the predominant treatment system.

Regarding mortality, most deceased individuals were female, Hindu, students, and had studied up to middle school. Multiple disabilities, including deaf-blindness, were common, with respiratory diseases being the primary cause of death. As shown in Table 3, Respiratory conditions are a leading cause of morbidity and mortality among individuals with multiple disabilities. Chronic health conditions associated with disabilities can weaken the immune system, making individuals more prone to infections like pneumonia and bronchitis (Gibson, 2013). Dysphagia, common in conditions like cerebral palsy or intellectual disabilities, increases the risk of aspiration pneumonia (Sullivan et al., 2000). World Health Organisation also provides data on respiratory diseases as a leading cause of mortality globally.

| Primary causes | Count | Percentage |
|---|-------|------------|
| Respiratory diseases | 6 | 42% |
| Fall | 4 | 29% |
| Cardiovascular diseases | 3 | 22% |
| Diseases of blood or blood forming organs | 1 | 7% |

Table 3: Frequency of primary causes

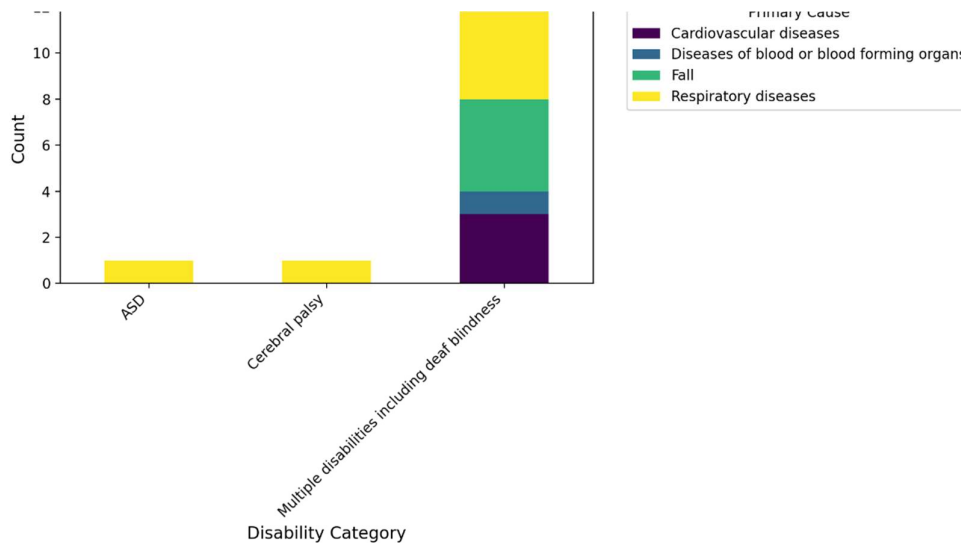


Figure 3: Distribution of Primary cause of death by disability category

The average age at passing was 15.2 years, and the disability percentage averaged 72.68%. Notable correlations included weak negative relationships between age at passing and primary cause (-0.16), disability category and primary cause (-0.35), and disability percentage and primary cause (-0.59). Cardiovascular diseases and blood disorders showed the highest disability percentages (82–85%), whereas respiratory diseases were associated with lower percentages (67–70%). As shown in Table 4, Co-morbidities were frequently observed in cases of respiratory diseases (p=0.014).

| | Co-morbidity - Yes | Co-morbidity - No |
|---|--------------------|-------------------|
| Cardiovascular diseases | 3 | |
| Respiratory diseases | 5 | 1 |
| Fall | | 4 |
| Diseases of blood or blood forming organs | | 1 |

Table 4: Primary cause vs co-morbidity

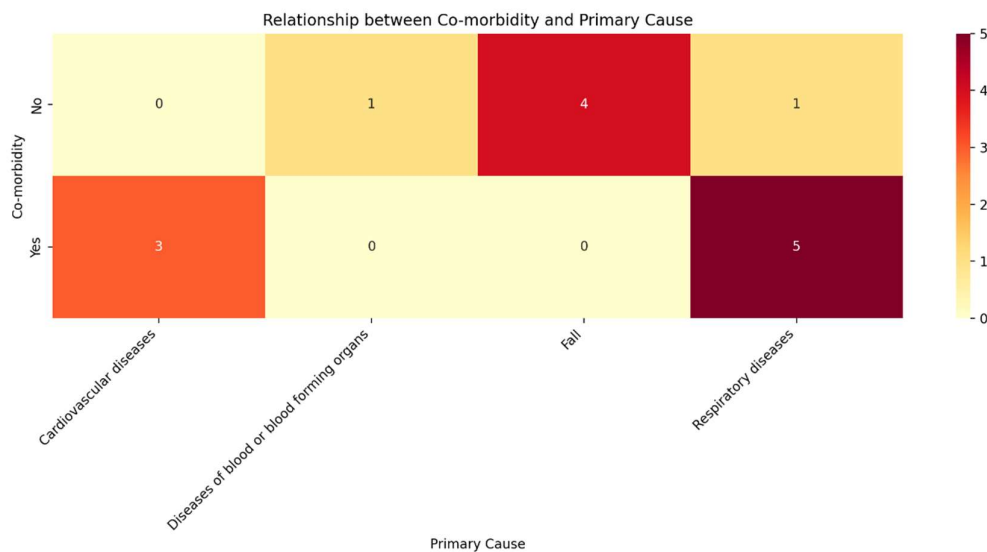


Figure 4: Relationship between co-morbidity and primary cause

5. Discussion

The study found that the mean age of the sample was 11.81 years, with a predominantly young cohort. This aligns with global findings that disabilities often manifest early in life and are linked to lifelong health challenges (WHO, 2011). The young demographic highlights the importance of early detection and intervention to address health vulnerabilities and improve life expectancy among Persons with Multiple Disabilities. The results revealed neuropsychiatric diseases, including seizures and spastic conditions, as the most common diagnoses, with cardiovascular and respiratory disorders being primary causes of mortality. This finding is consistent with studies by Ouellette-Kuntz et al. (2015), which identified a high prevalence of chronic diseases in Persons with Multiple Disabilities, significantly contributing

to their health burden. The overlap between neurological and cardiovascular risks suggests the need for integrated care strategies that address multiple health dimensions simultaneously.

The prevalence of co-morbid conditions highlights the compounded health challenges faced by Persons with Multiple Disabilities. Similar findings by Salter et al. (2016) emphasize that co-morbidities, when combined with underlying disabilities, significantly increase the risk of premature mortality. Addressing these co-morbidities through targeted interventions, including preventive screenings and tailored treatment plans, is crucial for reducing mortality risks. A moderate negative correlation between age and disability category ($r = -0.460$) and a strong negative correlation between disability category and age at diagnosis ($r = -0.505$) suggest that severe disabilities are often diagnosed earlier in life. These findings reflect the importance of early diagnostic frameworks to address complex needs promptly, a gap also noted in the literature by Landes et al. (2022). The chi-square analysis found no significant association between gender and disability categories ($p = 0.4335$), indicating that gender does not play a substantial role in determining the type or severity of disabilities. This aligns with global patterns that suggest disability prevalence is not inherently gender-biased but may be influenced by social and environmental factors.

7. Suggestions:

The findings underscore critical areas of focus for improving outcomes among Persons with Multiple Disabilities. Early intervention is essential, given the young age distribution observed in the population. Robust early intervention programs that prioritize holistic care, education, and rehabilitation can significantly mitigate the long-term impacts of disabilities. Providing early access to multidisciplinary services ensures better developmental and health outcomes. The prominence of neuropsychiatric, cardiovascular, and respiratory conditions among Persons with Multiple Disabilities highlights the importance of integrated healthcare services. Comprehensive management of co-morbidities requires policy measures that enhance access to specialized healthcare providers and encourage collaboration among specialists in neurology, cardiology, and respiratory care. Such integrated approaches can effectively address the complex health needs of this population. Overcoming barriers such as economic limitations, physical inaccessibility, and communication challenges demands tailored community-based interventions and caregiver support programs. These initiatives are vital for creating an inclusive and supportive healthcare environment. Finally, the pilot study lays the groundwork for future research directions. Larger-scale studies are necessary to validate these findings and delve deeper into additional factors influencing mortality and health outcomes among Persons with Multiple Disabilities. Investigating the roles of socioeconomic determinants and environmental exposures will provide a more comprehensive understanding of the factors shaping health disparities and outcomes in this vulnerable population.

8. Conclusion

This pilot study provides valuable insights into the mortality patterns and associated co-morbidities among Persons with Multiple Disabilities in Chennai and Chengalpattu districts. The findings reveal a predominantly young population with significant age-specific vulnerabilities and a high prevalence of neuropsychiatric, cardiovascular, and respiratory disorders as leading health challenges. The study also highlights the compounded impact of

co-morbid conditions on mortality risks, emphasizing the urgent need for integrated healthcare services tailored to the unique needs of Persons with Multiple Disabilities. The moderate to strong negative correlations observed between age, disability categories, and age at diagnosis underline the importance of early identification and intervention to address complex health issues effectively. The lack of significant association between gender and disability categories suggests that health disparities in this population may be driven more by systemic and environmental factors than inherent gender differences.

Overall, this study underscores the critical need for comprehensive, evidence-based strategies to improve health outcomes and quality of life for Persons with Multiple Disabilities. These include early diagnostic frameworks, integrated care approaches, enhanced caregiver support, and equitable healthcare policies. By addressing these factors, stakeholders can work toward reducing mortality risks and fostering a more inclusive and supportive environment for this vulnerable population. Future research should focus on expanding the sample size, exploring socio-environmental determinants, and refining intervention strategies to ensure sustainable improvements in health and well-being for persons with multiple disabilities.

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