

Mortality in people with Intellectual Disability in India: correlates of age and settings

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Abstract

Background: The life expectancy of people with intellectual disability (ID) has increased across the world with the advancements in public health policies and in the medical sciences. Still, people with ID have higher risks of dying prematurely due to associated medical and genetic conditions. However, there is no estimation of the mortality and life expectancy rate available for the ID population in India. In this context, this study was aimed to investigate the mortality rate in ID and its association with age in rural and urban settings in India. Method: Secondary data from the Disability Report for 2003 of the National Sample Survey Organization (NSSO) is used for analysis. Spearman correlation distinguishing age and rural and urban settings, t-test to measure the difference between rural and urban contexts and simple regression with age groups and settings, are carried out. Results: Age was highly associated with the mortality rate in ID. This association was strongly positive in both rural ($\rho = .954$, $p = .001$) and urban ID adults

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($q = .957$, $p = .001$). However, the mortality rate did not differ statistically between rural and urban adults ($t = 2.16$, $p = .062$). For every one-year increase in the age of the population, the mortality rate was found to increase by 3.3 and 3.0 persons per 100,000 in rural and urban ID adults, respectively. Conclusion: This data analysis demonstrates a high mortality rate which significantly increases from the beginning of adulthood in ID Population. Further research is needed to support the findings of this study, and discover determinates of higher mortality rate or low life-span of the ID population in India.

Keywords: Age; India; Intellectual disability; Mortality rate; Life expectancy.

1. Introduction

Similar to the prevalence rate, greater knowledge of the mortality rate or life span for the ID population is highly important issue in the field of public health and rehabilitation policies in India. Unfortunately, there is scarcity of results from such studies on the nation. However, a few studies have been conducted on the prevalence rate of ID, which have attempted to minimize the gap in knowledge, but the issue of the mortality rate remains unaddressed in scientific literature (Maulik & Harbour 2010; Girimaji & Srinath, 2010; Cohen & Brown, 2012; Nahar, Kotecha, Puri, Pandey, & Verma, 2013). A clearer understanding regarding the mortality rate is needed to organize appropriate services to reduce the mortality rate and increase the quality of life in people with ID (Eyman, Grossman, Tarjan, & Miller, 1987; McGuigan, Hollins, & Attard, 1995; Janicki, Dalton, Henderson, & Davidson, 1999; Patja, Iivanainen, Vesala, Oksanen, & Ruoppila, 2000).

With the advancements in public health, science and medical technology, the overall life span of people has increased in both the economically developed world as well in presently developing nations (Oeppen & Vaupel, 2002; Bloom, 2011; Turnock, 2012). Life expectancy rate for the ID population has also improved across the world (Cooper, Melville, & Morrison, 2004). Now, many people with ID are living longer lives similar to their age-matched counterparts (Janicki, 2010). Governmental and nongovernmental agencies, including World Health Organization is bringing in appropriate changes in the Health Policy, and promoting life care and rehabilitation services, with specific targets in Asian pacific-zone countries (Janicki, 2009, 2010). In such a scenario, it is imperative to have data on the longevity of ID victims. It is highly important to collect systematic data on these issues in India to build a knowledge base for creating appropriate rehabilitation and health services and understanding risk factors deriving from a higher mortality rate and associated policy developments (Fujiura, Park, & Rutkowski-Kmitta, 2005). However, there are no systematic research efforts to understand the life expectancy of the ID population in India. Therefore, the issue of the mortality rate becomes extremely important for research.

Intellectual disability is often associated with secondary disabilities or disorders such as cerebral palsy, epilepsy and other neurological and genetic disorders (van Schroyensteen Lantman-De Valk, Metsemakers, Haveman, & Crebolder, 2000; Jansen, Krol, Groothoff, & Post, 2004; Katz, 2009; Chavan & Rozatkar, 2014). Chronic diseases such as cardiovascular, respiratory,

urinary diseases and neoplasm are frequently reported and are associated with early death in this population (Patja, Eero, & Iivanainen, 2001; Patja, Mölsä, & Iivanainen, 2001).

The burden of associated conditions, poor health care, poverty, and dependency on others for their personal care make the ID population highly vulnerable to poor quality of life and lowered life span compared to their age-matched peers (Ouellette-Kuntz, 2005). In such cases, the ID population with coexisting conditions requires greater attention and care compared to ID people without the comorbidity (Datta, Russell, & Gopalakrishna, 2002). Among the ID population, people with severe disability have higher rate of comorbid conditions, thus they are more threatened for survival (Patja *et al.*, 2000; Arvio & Sillanpää, 2003). But, with improved health care, the infant and child mortality rate has declined in India and this fact should have influenced the life span of the ID population positively (Bloom, 2011; UNICEF, 2011). Nonetheless, we need to interpret these findings in the light that the majority of the Indian population with ID live in rural areas, where the health facilities are more inadequate than the urban areas. Hence, we need to know if there is an urban-rural divide with regard to the longevity of the people with ID in order to take appropriate measures to enhance longevity, particularly quality living. In this context, this study is primarily aimed to estimate the mortality rate in ID adults above age 18 years, correlated to age, and prediction of the mortality rate on the basis of age in rural and urban settings.

2. Material and Method

This research is based on secondary data that was obtained from a disability report published by the National Sample Survey Organization (NSSO, 2002). This was the first time that the Indian Ministry of Social Justice had covered the ID population in its survey for disabilities. In this report, ID was represented by the term mental disability/mental retardation. A Survey was conducted at national level in which a total of 70,302 households were covered – of those 45,571 households were urban and 24,731 were rural. It was a random sampling, and sample size was calculated by applying the formula for cross-sectional research design. The survey did not report data on mortality or life span of ID people, which was calculated by the researchers of this paper.

The Spearman correlation was considered to estimate the strength and direction of the association with the age of ID adults in rural and urban

population. A Student t-test was used to verify the difference between the mortality rates in two settings. In order to observe the likelihood of mortality in the adult population, a regression analysis was carried out between age groups and mortality rates in both settings, where age was considered an independent variable. We have used Statistical Package for Social Sciences (SPSS) version-21, for statistical analysis.

3. Results

The NSSO report does not have any information on mortality or life span of ID in India. To estimate the mortality rate, the prevalence rate of the age interval (15 to 19 years, mean age = 17) is taken as standard prevalence at the beginning of adulthood (bold in Tab. 1). Then the prevalence rates of the following age groups were subtracted from the standard prevalence rate of the mean age group of 17 years to construct the table for the mortality rate (Tab. 1).

Table 1 - *Estimated mortality on basis of prevalence in different age intervals*

Age groups	Mean age	Prevalence and mortality, case per 100,000			
		Rural		Urban	
		Prevalence	Mortality	Prevalence	Mortality
0 to 14	7	107	-	131	-
15 to 19	17	172	-	164	-
20 to 24	22	141	31	137	27
25 to 29	27	105	67	87	77
30 to 34	32	91	81	86	78
35 to 39	37	64	108	93	71
40 to 44	42	39	133	46	118
45 to 49	47	23	149	50	114
50 to 54	52	23	149	25	139
55 to 59	57	17	155	12	152
60 above	62	11	161	7	157

In ID adults, the mortality rate found positively associated with their chronological age in rural ($\rho = .954, p < .001$) and urban ($\rho = .957, p < .001$) population. Mortality rates between urban and rural population does not differ statistically ($t = 2.16, p = .062$) (Fig. 1 and Tab. 2). The ANOVA, $F = 70.65, p < .001$, allows the regression analysis in ID adults in rural and

urban, $F = 77.02$, $p = < .001$ population. Analysis demonstrates that in rural, ($R^2 = .910$), and urban ($R^2 = .917$) 91% of mortality rate in ID adults is explainable by their age. Regression predicts that the mortality rate increases by 3.20 in rural and 3.02 in urban, with the increase of age by one year in the population (Fig. 1, Tab. 2 and 3).

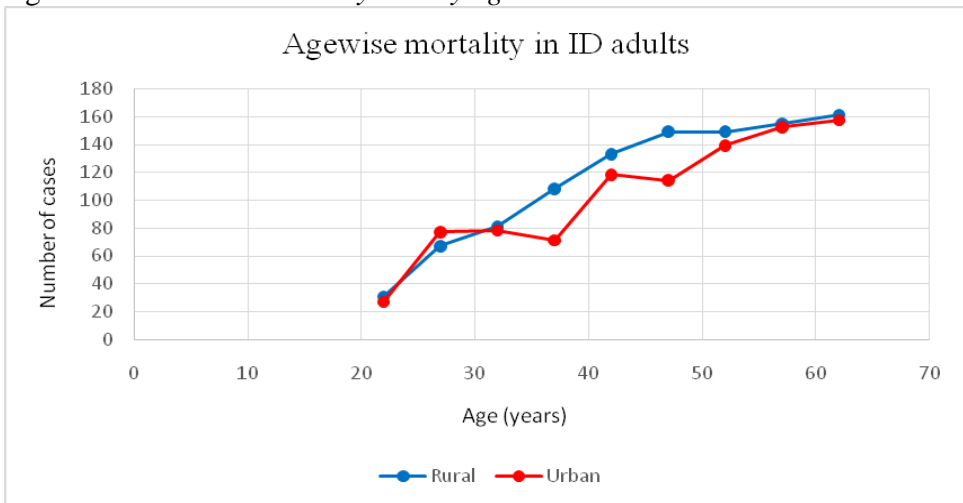
Table 2 - Mortality association with age in ID adults (above 18 years) separated by rural and urban setting

Settings	$M \pm SD$	ρ	p	t	p
rural	114.89 + 45.98	.954	.001	2.16	.062
urban	103.67 + 43.38	.957	.001		

Table 3 - Mortality estimation on basis of age in rural and urban settings

Predictor variable	Dependent variable: Setting	Model (ANOVA)		Regression		
		F	p	R^2	B_0	B_1
Age	rural	70.65	.001	.910	-19.65	3.20
	urban	77.02	.001	.917	-23.73	3.03

Figure 1 - Estimated mortality rate by age



4. Discussion

According to the NSSO survey report, the prevalence rate of ID increases in the children’s population from the age of birth until adulthood. This situation may give a false impression that the higher rate of ID is acquired

during the post-natal period. However, this may not be true. It may be due to many other factors, such as stigma, poor awareness, cultural beliefs, one's personal attitude and also the slower process of self identification and the poor referral practices in India (Scior, 2011; Kishore & Basu, 2011). On the contrary, at the beginning of adulthood, the prevalence rate drops, alternatively a high mortality rate is observed at this transitional stage in life. Although it is evident in literature that those people with ID are the victim of lower life expectancy compared to the general population (Patja *et al.*, 2000; Lavin, McGuire, & Hogan, 2006). In European studies, the average life expectancy of ID population with moderate level of ID is observed around 45 years (Katz, 2003; Lavin *et al.*, 2006), however, people with a milder form of ID are living almost a life equal to that of the general population (Janicki, 2009). The data on average life expectancy and its difference between rural and urban settings, if any, for the Indian ID population are unavailable for the comparison.

Our study indicates that mortality rates sharply increase from the beginning of adulthood, with higher rates in the rural areas for any age group. But the rural-urban differences were not statistically significant. It may imply that on rates of mortality per se, the environment has no impact. However, one might assume that in rural areas, many more adults with ID will pass as neuro-typical and are not included in the statistical surveys. Some further comment might be that this undercount may have created a bias and therefore may have affected the results.

Rather, age was highly associated with the mortality rate in ID. The association between age and mortality was strongly positive both in rural and urban areas. With the increase of every 1 (one) year of age in the population, the mortality rate increases by 3.3 and 3.0 persons per 100,000 in rural and urban ID adults respectively. It is clear that people with ID from rural areas do not have higher mortality rates, even where the health care facilities are not adequate as compared to the urban settings. These findings imply that we need to create a necessary infrastructure to provide services to address the health needs of adults with ID, in general. There is also a need for services to address the overall needs of adults with ID that help them lead an independent and quality life.

Findings of the present study corroborate with other studies which have demonstrated lower life span for ID especially where disability is moderate and severe (Eyman, Grossman, Chaney, & Call, 1990; Patja *et al.*, 2000; Katz, 2003; Lavin *et al.*, 2006). People with a profound level of disability are subject to a further shorter life span due to their associated conditions,

and the severe risks posed from other medical needs and reduced mobility (Eyman, Call, & White, 1989; Eyman *et al.*, 1990).

5. Strengths & Limitations

This is the first research article of this kind that has attempted to predict the mortality rate of ID adults in rural and urban populations in India. The findings are based on the small data set that was collected almost one and half decades ago, in a cross-sectional manner. Looking at the nature of this data and the way it was collected by untrained surveyors on the basis of parental interviews and enumerator's judgment, without adopting any standard-used instruments; we can infer that the majority of cases screened in this survey have had moderate and severe levels of ID (NSSO, 2002). People with milder and borderline ID might have been excluded. Considering the limitations of the data, findings of this study should be read carefully and possibly in the light of other relevant studies. However, irrespective of methodological limitations, this research is able to provide an approximate idea of mortality rate in the ID adult population.

6. Conclusion

This analysis shows a strong relationship between the chronological age and mortality rate in the Indian ID population. The mortality rate significantly increases from the beginning of adulthood, which is an important issue for the public health. However, due to the nature of cross-sectional data, this analysis is unable to investigate temporal relationships with the factors causing a higher rate of mortality in Indian ID adults. The issues of mortality and consequently relative life span are highly crucial; thus this study suggests further research in this area.

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