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Life expectancy of people with intellectual disability: a 35-year follow-up study

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Abstract

A 35-year follow-up study based on a nation-wide population study of the life expectancy of people with intellectual disability (ID) was undertaken. The study population consisted of a total of 60 969 person-years. A prospective cohort study with mortality follow-up for 35 years was used and the life expectancy of people with ID was calculated for different levels of intelligence. Proportional hazard models were used to assess the influence of level of intelligence and associated disorders on survival. People with mild ID did not have poorer life expectancy than the general population and subjects with mild ID did not have lower life expectancy in the first 3 decades of life. In cases with profound ID, the proportion of expected life lost was > 20% for almost all age groups. The female preponderance was manifested from the age of 60 years onwards, 25 years later than in the general population. Respectively, survival between sexes differed less. Epilepsy and/or hearing impairment increased the relative risk of death for all levels of ID. The prevalence of people with ID over 40 years was 0.4%. People with ID now live longer than previously expected, and the ageing of people with mild ID appears to be equal to that of the general population, posing new challenges to health care professionals.

Keywords ageing, life expectancy, mortality, survival

Introduction

Intellectual disability (ID) is defined by a subnormal level of intelligence (IQ < 70) and adaptive behaviour. This condition influences society on many levels, affecting the individual, the family, and social and economic structures, and results in extensive expenditures (Meerding *et al.* 1998).

Although the predicted life expectancy of people with ID is less than for the general population (Balakrishnan & Wolf 1976; Baird & Sadovnick 1987; Crichton *et al.* 1995), it has been prolonged in all Western societies (Carter & Jancar 1983; Fryers 1986). This lengthened life span has increased the numbers of older people with ID.

Most people with ID live in community settings and use general health services, and therefore,

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health professionals need accurate information on life expectancy to provide counselling for families, as well as to plan care and forecast needs for different services. Most life span studies are based on descriptions of subjects in institutions or on the registers of service providers, sources which are both influenced by the policies in force during certain eras and which may have excluded some groups of people with ID (Eyman *et al.* 1987; McGuigan *et al.* 1995).

A population-based study on ID was carried out in Finland in 1962 and formed the basis for the present follow-up study. Little is known about how the life expectancy of people with ID varies according to age, sex or aetiology. The present authors report estimates of life expectancy for people with ID and the number of aged people with ID based on a large, nation-wide, population-based cohort of 2366 subjects. The number of ageing persons with ID appeared surprisingly high, highlighting the rapidly growing health care needs of this population.

Materials and methods

Population

The present study group consisted of the participants of a large, nation-wide population-based study conducted in 1962. The latter cross-sectional, multidisciplinary study had been undertaken in Finland (population = 5 million) to investigate the number and needs of services of people with ID. The study population of 416 973 people (9.4% of the population) lived in 57 municipalities, representative of the entire socio-economic range within the country (Amnell *et al.* 1964).

Intellectual disability was defined as a subnormal level of intelligence and adaptive behaviour, which is manifested before 18 years of age. It was tested with psychological tests (IQ < 70) and by evaluating adaptive behaviour (WHO 1995). Environmental aspects needed to be taken into consideration because some individuals may behave normally in one environment and subnormally in another.

The municipal officials were asked to report all people suspected or known to have ID. The National Board of Health organized examinations of these individuals. Municipalities reported a total of 4013 persons between 2 and 64 years of age, of which 3748 were examined and 84 were included on the basis of patient records. Upon examination, 2372 people were diagnosed with ID, 212 with limited intelligence and 1155 people with normal intelligence (Table 1). The prevalence of ID in the study was 0.7%.

Table 1 Distribution of people with intellectual disability (ID) according to sex, age group and degree of ID in 1962

	Level of ID					
Subjects	Unknown	Profound	Severe	Moderate	Mild	Total
Total	11	368	280	606	1101	2366
Sex:						
Males	4	213	143	267	556	1183
Females	7	155	137	339	545	1183
Down's syndrome*	–	69	67	46	25	207
Age (years):						
2–9	2	92	57	85	138	374
10–19	0	125	86	101	319	631
20–29	0	46	36	85	148	315
30–39	3	53	32	80	163	331
40–49	3	30	23	108	136	300
50–59	3	15	31	104	150	303
60–64	0	7	15	43	47	112

Thirty-five-year follow-up

The present follow-up study was initiated in 1995. The follow-up period was 35 years, i.e. from 1 January 1963 to 31 December 1997. The original examination forms and punch cards were transferred into digital form. Names and dates of birth were sent to the Population Register Centre and parishes for identification and confirmation of whether subjects were alive or had a date of death. In the original material, some names and dates appeared to be unreliable, hampering identification. Out of the group of people with ID who were examined in the original study, 2369 subjects were identified for follow-up. Individuals who died during 1962 ($n = 3$) were excluded from the study. All surviving subjects who were identified from the original 1963 study group ($n = 2366$) form the present study population (Table 2).

Table 2 Distribution of people with intellectual disability (ID) across groups of subjects who were still alive, deceased or unidentified according to sex, age, age at death and level of intellectual disability in 1997

	Level of ID					
Subjects	Unknown	Profound	Severe	Moderate	Mild	Total
Total	11	368	280	606	1101	2366
Alive						
Sex:						
males	1	92	83	129	311	617
females	2	64	63	134	317	579
Total	3	156	146	263	628	1196
Age group in 1997* (years):						
37–44	2	48	50	66	122	288
45–54		70	64	84	276	494
55–64		22	17	46	104	189
65–74		12	9	38	82	141
75–84	1	3	5	22	34	65
85–97		1	1	7	10	19
Deceased						
Sex:						
males	2	117	63	132	232	546
females	6	83	65	195	216	565
Total	8	200	128	327	448	1108
Age group at time of death (years):						
2–9		7	1	1	1	10
10–19		22	4	6	7	40
20–29		29	9	17	18	73
30–39		36	11	16	21	84
40–49	1	32	14	26	44	118
50–59		26	32	58	74	191
60–69	4	33	23	91	124	275
70–79	3	9	25	77	114	228
80–99		5	9	35	43	92
Unidentified		13	6	16	27	62

*Age grouping in 1997 based on age grouping in 1962.

Examinations

The medical examinations included clinical neurological examination with the diagnoses of aetiological factors and associated disorders. Psychological tests were used to determine whether people met the criteria for ID (IQ < 70) and whether their learning capacities were eligible for schooling (Amnell *et al.* 1964). The tests included measures of verbal and non-verbal intelligence. Academic abilities, such as reading, writing and mathematics, were measured. Clinical evaluation of level of the intelligence was done for people unable to participate in the testing. The definition of ID included six classes: normal intelligence, limited intelligence, and mild, moderate, severe and profound ID (WHO 1995).

Statistical analysis

The subjects were classified by sex, the quinquinneum of their birth (e.g. 1901–1905 and 1906–1910), IQ and aetiology of ID. Associated disorders (e.g. epilepsy, cerebral palsy, visual and hearing impairments) were classified dichotomically. The classification was used in all statistical procedures. The proportion of expected life lost and life expectancies were calculated with the survival analysis package developed by the Finnish Cancer Registry (Hakulinen *et al.* 1988). This package produced extensive life tables for all groups, including standard life-table information and also the baseline probability of surviving over the period calculated from the mortality figures of the general population. An age, sex and quinquinneum-specific general population survival probability was obtained from the published statistics for every person entering the interval period, together with the number of those who had died during the interval. The data were analysed as binomial variables with effective number as a total number. The main purpose in using this model instead of Kaplan Meier curves or Cox's model, or other regression models, is to prevent bias with the comparative population. In order to compare the total mortality of different groups, Kaplan Meier curves were calculated (Kaplan & Meier 1958). Cox's proportional hazard models were used to quantify the differences between groups (Cox 1972) using the SPSS software package . For all analyses performed, a $P < 0.05$ was considered statistically significant.

Approval

The present study was approved by the Ministry of Social Affairs and Health and the Ministry of Education. The Data Protection Ombudsman evaluated data protection in this study.

Results

Population characteristics

The cohort included 2366 people (Table 2). The follow-up time produced a total of 61 689 person-years, the mean follow-up time being time being 26.9 years (SD = 10.9 years). At the end of the follow-up period, 45% of the original study population was alive, 13% with profound ID, 12% with severe ID, 22% with moderate ID and 53% with mild ID. The number of deceased subjects was 1108, yielding a rate of mortality 18.0 (95% confidence intervals = 0.22 and 0.38) per 1000 person-years. The median ages for surviving and deceased subjects were 51.0 and 61.8 years, respectively. In the population with ID, females formed the majority from the 60 years of age onwards. In the general population, the corresponding age was 35 years (Härö 1995). The oldest woman alive was 97 years old, and the oldest man was 95 years. The prevalence of people with ID ≥40 years was 0.4% (Table 3).

Life expectancy

For people with mild ID, the proportion of expected life lost did not differ from that of the general population during the first 3 decades of life (Table 4). In the moderate ID group, the proportion of life lost increased slightly, and in the severe and profound ID group, this increased substantially to 20% for all age groups. Low IQ was a significant predictor of mortality in age groups < 30 years (Cox regression, $P < 0.01$).

The expected life span in 1963 calculated for ID population, showed a difference between sexes compared to the general population, albeit of a

Table 3 Estimated number of people with intellectual disability ≥40 years in 1997 according to age groups extrapolated from the 1963–1997 population follow-up study

Age group (years)	Sex			
	Males		Females	
	Number	Percentage	Number	Percentage
40–49	2777	0.7	2096	0.5
50–59	1851	0.6	1649	0.5
60–69	798	0.4	851	0.3
70–79	415	0.3	670	0.3
80+	170	0.4	330	0.3
Total	6011	24.0	5596	19.0

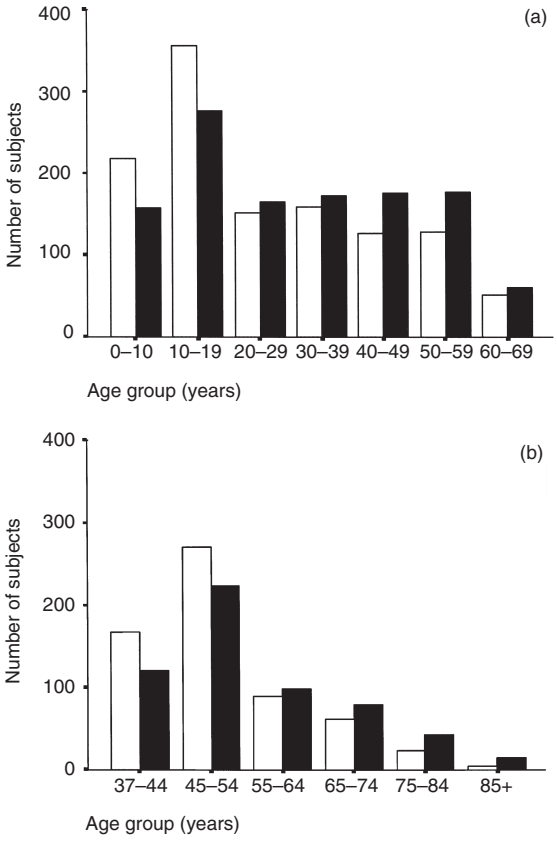

Figure 1 (a) Distribution of the study population in 1962 and (b) the distribution by age of the people who survived in 1997: (open bars) males; and (filled bars) females.

Table 4 Proportion of expected life* lost in the 35-year follow-up study according to age group in 1963, level of intellectual disability (ID) (IQ calculated with the survival analysis package developed by the Finnish Cancer Registry) and sex

Age group in 1963 (years)	Level of ID (IQ)	Sex	
		Males	Females
0–10	Mild (50–69)	–4.8	–3.3
	Moderate (35–49)	0.6	13.6
	Severe (20–34)	–7.7	4.0
	Profound (0–19)	35.3	24.8
11–20	Mild (50–69)	–4.1	–5.7
	Moderate (35–49)	1.6	0.9
	Severe (20–34)	2.2	11.3
	Profound (0–19)	26.0	18.5
21–30	Mild (50–69)	–0.04	4.7
	Moderate (35–49)	16.0	13.8
	Severe (20–34)	4.9	37.6
	Profound (0–19)	19.0	33.3
31–64	Mild (50–69)	5.5	14.0
	Moderate (35–49)	–1.7	20.9
	Severe (20–34)	15.1	22.0
	Profound (0–19)	23.7	42.9

*When proportion of expected life lost is negative, the group has a better survival rate than the general population.

smaller magnitude, except for profound ID, where no definite difference was shown (Table 5, Figs 1 & 2). Women with profound ID in the 20–39-year-old age group had a poorer life expectancy than men, but surprisingly, this was reversed in the age group < 20 years (Fig. 1). In older groups, age itself was a significant predictor of mortality.

Associated disorders

The disorders associated with higher mortality were multiple (Table 6). Epilepsy and low IQ were associated with reduced survival in the 2–9 and 10–1-year-old age groups in 1962. Interestingly higher IQ was a risk in the 30–39-year-old age group. Down's syndrome decreased survival in the 30–39-year-old age group, but not in older subjects. Visual impairment decreased survival after the age of 49 years. From 30 years of age, the ageing itself was a significant risk factor. The need of care

Table 5 Expected life span for the general population and the study population of people with intellectual disability (ID)in 1963

		Mean length of life (years)			
		Women		Men	
Age group in 1963 (years)	Level of ID	General population	People with ID	General population	People with ID
2–10	Mild	67.1	69.3	60.4	63.3
	Moderate	67.8	58.6	61.1	60.7
	Severe	65.8	63.2	58.7	63.2
	Profound	67.6	50.8	60.7	39.3
11–20	Mild	59.8	63.2	52.7	54.8
	Moderate	58.8	58.3	51.8	50.1
	Severe	59.0	52.3	52.7	51.6
	Profound	59.2	48.2	52.7	39.0
21–30	Mild	49.3	47.0	42.6	42.6
	Moderate	49.4	42.6	42.2	35.5
	Severe	50.5	31.5	42.4	40.0
	Profound	49.3	32.8	43.2	35.0
31–66	Mild	30.0	25.8	24.2	22.9
	Moderate	27.6	21.9	23.6	24.0
	Severe	28.4	22.0	24.5	20.8
	Profound	33.29	19.0	27.9	21.3

Table 6 Significant factors ($P < 0.05$) contributing to low survival rates in people with intellectual disability (ID)using Cox's regression by age groups*

Age group in 1963 (years)	Risk factor	Ninety-five per cent confidence limits
2–9	Low IQ	0.02–0.84
	Epilepsy	0.38–0.84
	Hearing impairment	1.30–39.37
10–19	Low IQ	0.13–0.95
	Epilepsy	0.10–0.81
20–29	Low IQ	0.15–0.32
30–39	High IQ	0.38–0.90
	Ageing within group	1.41–1.81
40–49	Low IQ	0.12–0.71
	Visual impairment	0.21–0.50
	Ageing within group	1.38–1,82
50–64	Ageing within group	1.33–2.71

*Variables in the equation: age, square of age, sex, level of ID, epilepsy, Down's syndrome, visual and hearing impairment, and visual impairment. The interaction terms sex/age and sex/level of ID were left out of the final analysis because these were deemed to be insignificant.

correlated with IQ (Pearson's correlation = 0.653, $P < 0.01$); people in institutionalized care were more often profoundly disabled and had more associated disorders. Institutional care indicated poorer survival in all age groups.

Discussion

The present study is the longest and only population-based follow-up study reported on people with ID. The strengths of this study are a nation-wide cohort with a high rate of retention of subjects, a lengthy follow-up period with comprehensive information permitting reliable ID classification, and coding of background variables, such as associated disorders and need for care. Accurate and extensive statistics increased the reliability of the present study. Throughout the study period, Finland has been a stable welfare state with continuously improving services for people with ID.

The prevalence of ID and the distribution of its levels in the 1962 study are comparable with other subsequent population studies (Balakrishnan & Wolf

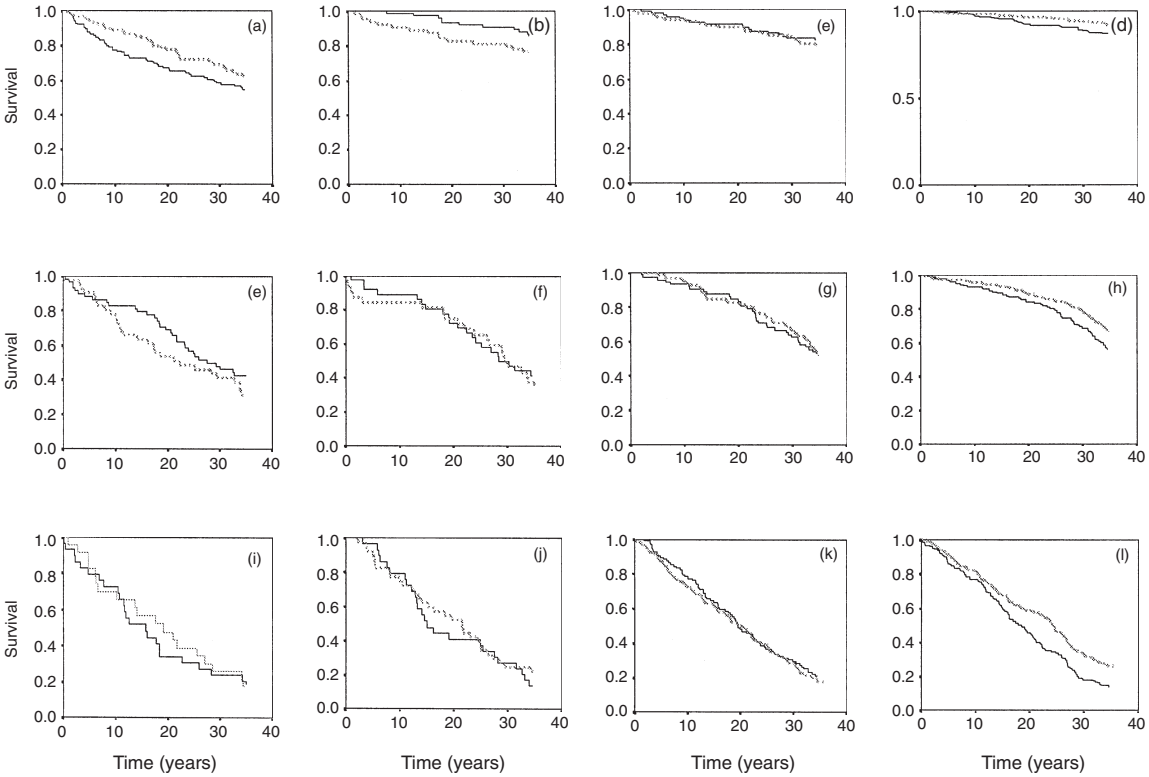

Figure 2 Survival of people with intellectual disability (ID) by level of ID and age: (a, e, i) profound ID; (b, f, j) severe ID; (c, g, k) moderate ID; (d, h, l) mild ID; (a–d) 2–19 years; (e–h) 20–39 years; (i–l) ≥ 40 years; (—) males; and (·····) females. Note that, as in the general population, sex does not affect survival.

1976; Slavica *et al.* 1995). The prevalence of aged people was also consistent with later studies and demonstrated a poor survival rate for the elderly with ID (Carter & Jancar 1983). The prevalence of ID in new-borns in Northern Finland was higher (Rantakallio & von Wendt 1986) than in the present study, but the mortality of infants with ID is higher than that of other infant groups. Males are over-represented in the younger age groups relative to other studies (Rantakallio & von Wendt 1986; Louhiala 1995). Intelligence quotient has been a widely used measure in epidemiological studies, but other factors, such as underlying and associated disorders, mobility, morbidity and social skills, also contribute to life expectancy (Fryers 1993).

Life expectancy

People with mild ID share a similar life expectancy with the general population. In younger age groups, the expected life span was higher than that of the general population. However, people with profound ID have a decreased life expectancy in all age groups, with few individuals reaching old age. Presumably, this is connected with serious neurological deficits and more severe associated disorders. Severe and moderate ID decreased the life expectancy for similar reasons. Nonetheless, the ID population is growing rapidly, creating increasing demands to provide services over a long period. Preventative health care in paediatrics in particular has also improved the health of people with ID, decreasing the risk of development of associating disorders. In addition, the adult population in 1962 represented the healthy survivors and the life expectancy of people born in 1960s are most likely better than the former group. In Finland, the 40-year-old age group is rather large which indicates that there will be a rapidly increasing number of people with ID in next decade.

The present results differ from previous studies mainly because of differences in the populations analysed. Previous studies have been carried out with exclusive cohorts showing diminished survival for all levels of ID (Balakrishnan & Wolf 1976; Dupont *et al.* 1987; Eyman *et al.* 1988; Kurtz *et al.* 1994; McGuigan *et al.* 1995; Conroy & Adler 1998). These earlier studies were based on institutionalized subjects or registers of people with ID. Institutionalized individuals frequently have more severe disabilities than non-institutionalized people, leading to their poorer survival rates. Profound ID was likewise associated with poor survival in the present study. Register-based studies are dependent upon the policies of service providers, which have changed markedly over the few decades in western societies, thus hampering comparisons. Furthermore, individuals with mild ID are more likely to live without services. In Finland, the prevalence of ID is between 0.7% (Amnell *et al.* 1964) and 1% (Louhiala 1995), corresponding to 30 000–50 000 people with ID. In contrast, the official registry held information on 19 000 people receiving special services in 1997. Thus, the number of individuals with ID has been severely underestimated by studies which have only been based on registers.

Associated disorders and risk factors

The risk factors for people with ID seem to differ from the general population since the survival between sexes differed less than in the general population for all levels of ID. More males with ID are born, but the difference stayed small, even when sex was controlled for the analysis. This difference has been described earlier (Forssman & Åkesson 1970; Strauss *et al.* 1998) and is not syndrome-specific (Crichton *et al.* 1995). Females form the majority in this population 25 years later than in the general population because of the different population structure and survival pattern: mild ID seems to be protective factor in early decades of male life. In the profound and severe ID groups, gender could not predict the survival, which perhaps reveals the influence of environment producing the differences in life expectancies of sexes in the general population.

People with ID generally have more limited exposure to environmental factors such as smoking and alcohol consumption, and nutrition. Children with ID, especially boys, are exposed less to domestic accidents than their age-mates with normal intelligence, being more protected by their parents and caregivers. In addition, people with ID are rarely in traffic and occupational accidents, and their suicides are rare (Strauss *et al.* 1998). Epilepsy increased the mortality of people with ID (Forssman & Åkesson 1970; Sillanpaa *et al.* 1998) and the negative impact of hearing impairment may be a result of the severity of the neurological damage rather than being an independent risk factor. Down's syndrome increased mortality in age 50, but with only very few elderly persons with Down's syndrome, not later, which confirms previous studies (Eyman *et al.* 1990). More detailed evaluation is needed to assess the effect of different aetiologies on survival and life expectancy. However, the present study does provide a foundation for some cautious assumptions about risk factors.

Conclusion

The life expectancy of people with mild ID is equivalent to that of the general population, while life expectancy diminishes as the level of ID decreases. Birth cohorts in Western societies have diminished, but with better survival and preventive measures, the number of people with ID is not likely to decrease. This leads to a new and growing group of ageing people with special needs who will have to be catered for by health services. Families and care givers need to be aware of the needs of ageing people with ID. Community-based living, in combination with sufficient health services, will improve quality of life and diminish institutional care needs.

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