A comparison between older persons with Down syndrome and a control group: Clinical characteristics, functional status and sensori-motor function

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Abstract – The increase in life expectancy within the general population has resulted in an increasing number of elderly adults with intellectual disability, and this is reflected in the increased life expectancy in persons with Down syndrome, currently about 56 years. The aim of this study was to study the clinical characteristics, the functional status and sensori-motor function of 10 older persons with Down syndrome (mean age 59 years), 13 younger persons with Down syndrome (mean age 44 years) and compare them with 38 adults with intellectual disability without Down syndrome and a control group of people without intellectual disability. All the persons with Down syndrome and intellectual disability resided in two residential living centres in Israel, while the 31 older persons without intellectual disability (mean age 75 years), who served as the control group, lived in an independent living facility. The study considered demographic data, medical backgrounds, physical and functional tests. The results showed that the older persons with Down syndrome in the study were more obese, shorter and had more medical problems than both the older persons with intellectual disability and the control group. The functional performance of the older adults with Down syndrome was more impaired in comparison with both other groups. It is postulated that their slower responses may be explained by a less physically active lifestyle, that may accelerate the onset of disease, resulting in symptoms associated with aging that are detrimental to health.

Keywords: Intellectual disability, Down syndrome, aging, functional ability, exercise, Israel

Introduction

In 1900 the life expectancy of a person with Down syndrome was only 9-11 years, in 1946 it was 12 years and currently it has increased to 56 years. Whilst overall life expectancy has improved, persons with Down syndrome still have a greater mortality at any age compared with an age-matched sample from the general population or compared with persons with intellectual disability due to causes other than Down syndrome (Merrick, 2000a, 2000b; Brown, Taylor & Matthews, 2001).

The observation that persons with Down syndrome have a reduced life expectancy has led to the supposition that they may age prematurely and display signs of aging as early as 30-40 years of age, as well as health related problems which would be found at 70 years of age in the general population (Holland, 1998). Zigman et al. (1997) reviewed several studies on the prevalence of dementia in persons with Down syndrome and found that the reported rates of dementia were 8% by age 35-49 years and 50-75% in those over 60 years of age. Evenhuis (1990) from Holland reported on a longitudinal study of 17 older persons with Down syndrome followed until death and found that 15 of them developed dementia with a mean age of onset at 51.3 years.

The prevalence of various conditions such as diabetes, hypertension, obesity, decrease in flexibility, and sedentary living can be used as indications of premature aging (Cousins, 1998). Individual changes in aging are extremely

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diverse and behavioural changes in day-to-day lifestyle play a major role in aging (Nelson & Dannefer, 1992). Individuals with Down syndrome show premature signs of aging, including elevated levels of functional and behavioural disturbances. These include the early onset of Alzheimer's disease, cognitive decline (Cosgrave et al., 1998) an overall decline in basic autonomy (Holland & Oliver, 1995; Tyler & Shank, 1996; Hestnes, Daniel, Lees & Brun, 1997; Schupf et al., 1998), and muscle weakness (Carmeli, Kessel, Coleman & Ayalon, 2002).

The prevalence of physically debilitating symptoms in aging persons with intellectual disability increases the demand for active diagnostic and therapeutic services. Such conditions include moderate to severe hearing loss and visual impairment (Evenhuis, 1995a, 1995b), a high incidence of balance and gait dysfunction (Pilon & Arsenault, 1997), arthritis and urinary incontinence (Cooper, 1998), obesity (Rubin, Rimmer, Chicoine, Braddock & McGuire, 1998), and non-ischemic heart disorders (Kapell et al., 1998). Determination of premature aging may be indicated by a range of signs and symptoms (NACA, 1993). The evaluation and active screening of cognitive and functional capabilities in elderly persons is important in order to assess their specific needs and to determine appropriate rehabilitative and psychotherapeutic programs.

The present study was conducted in order to evaluate and describe the physical and functional characteristics of elderly persons with Down syndrome, to compare them with persons with intellectual disability without Down syndrome and compare their functional status and capabilities with a control population without intellectual disability.

Method

A sample of 23 persons with Down syndrome and moderate intellectual disability from two residential care centres in Israel was examined. This sample consisted of 10 older people with mean age of 59 years, ±2.14 (55-61) (older DS group), and 13 younger people with a mean age of 44 years, ± 3.45 (41-46) (younger DS group). They were compared to two groups of people with moderate intellectual disability, with no specific aetiology. These groups consisted of 14 older persons with a mean age of 61 years, ±4.02 (57-63) (older ID group), and 24 younger persons with a mean age 45 years, ±3.50 (42-47) (younger ID group). In addition a control group of 31 older persons without intellectual disabilities (mean age = 75 years, ±3.19 (73-77)) resident in an independent living facility were studied. It was not possible to use age-matched samples owing to the limited numbers of individuals with Down syndrome and non-specific intellectual disabilities older than 63 years of age living in Israel.

The participants in the control group provided written informed consent to participate in the study, and for the participants with intellectual disabilities this was provided by their legal guardians. All participants required minimal supervision for daily activities, and their daily activities regime was comparable. All participants with pre-existing conditions liable to interfere with the results or to lead to co-morbidity (with non-age-related changes) were excluded from the study (i.e. blindness, amputation, severe osteoarthritis). Co-morbidity conditions included depression, and possible adverse drug reactions.

The evaluation procedures were undertaken on separate days by two physical and occupational therapists, with 4 and 19 years of clinical experience as geriatric therapists.

All medical assessments were performed by the local physician, who provided medical services.

Table 1 shows the inter-rater reliability results for specific evaluation items for the older adults with intellectual disabilities (DS and ID groups combined), and the control group. The Kappa statistic was used to determine the amount of agreement between the therapists' assessment, thereby establishing the inter-rater reliability between them. The Kappa statistic was chosen because it is applicable to categorical variables and because it assesses agreement beyond what may be expected based on chance alone. According to Landis and Koch (1977), Kappa values greater than .75 represent excellent agreement between raters. The entire evaluation procedure took an average of 41 minutes to administer. The Kappa values for participant evaluations ranged from .66 to .94 as indicated in Table 1. All items except medical history taken (.66 for the study group and .69 for the control group) were in excellent agreement.

Table 1. Inter-rater reliability (Kappa values) for evaluation items for the older adults with Down syndrome and non specific intellectual disability (study group) and the control group

Evaluation item	Study group (n = 24)	Control group (n = 31)
Weight	.94	1.00
Height	.94	.94
Body fat	1.00	1.00
Thigh and waist girth	.79	.80
Flexibility	.79	.80
Sensorimotor tests	.79	.89
Medical history taken	.66	.69

Evaluation Procedures

For each participant information in a standard protocol was gathered in the following areas: demographic data, medical data, body composition, and two sensorimotor function tests.

Standard methods were used for anthropometric measurements including body weight (kg), height (cm), waist girth at the level of umbilicus, and thigh girth (at three points: the widest point, and 7cm and 14cm above the base of the patella) using a cloth measuring tape.

To determine the waist:hip ratio (WHR), the waist measurement was divided by the hip measurement at the widest

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point. Healthy females and males should have a WHR of less than 1.8 and 1.9, respectively. Studies show that females and males with ratios greater than 1.8 and 1.9 tend to have excessive fat around the waist. These measurements provide information about fat and muscle mass in the lower quadrant (i.e. pelvis and lower extremity) and serve as indicators for inclination to obesity, which are important because of their connection to health conditions such as heart disease, and muscle strength (Martin, Spenst, Drinkwater & Clarys, 1990).

Body fat determination (TBF 611, Tanita Corp. USA) is based on a bio-electrical impedance analysis method (Thomas, Cornish & Ward, 1992). Bio-electrical impedance measures the length of time taken for an electrical impulse to travel from one place of the body (i.e. hand) to another place on the body (i.e. foot). The impulse requires less time to travel through muscle tissue than fat.

Body mass index (BMI) expresses the relationship of body weight to height. The formula for determining BMI is to divide weight (kg) by height (m^2). A BMI greater than 27.3 for females, and 28.8 for males is an indication of obesity (Payne & Hahn, 1992).

Flexibility of the lower trunk and hamstring muscles was measured (in cm) by procedures adapted from Hoeger (1988) and the functional reach test of Duncan et al. (1990) in a modified long-sitting and forward reach test. The test requires that the individual reach forward in a long-sitting position while keeping the legs straight. The participant reaches forward with hands and arms extended, parallel to a yardstick hanging on the wall. The base of metacarpal V (the point on the little finger side of the hand, just above the wrist) was used as a reference landmark, and the distance moved in the stretch was measured. The best score of three trials was recorded.

Two sensorimotor tests were performed: "timed-up and go" test (TUAG), and a three-minute distance walk test (3MDW). The TUAG was used to measure the dynamic balance and gait speed (Mathias, Nayak, & Isaacs, 1986). The participant was asked to rise from an armchair, walk 3 metres, and return to the chair. Times were measured using a manual stopwatch. The functional factors noted by the observers include: path deviation, trunk sway, flexion of knees or back, abduction of arms, the use of a walking aid, sit-to-stand transfer, walk and turn. The target time period to complete this test for older adults with a good level of independence is between 8 and 10 seconds. The advantages of the test are that it is simple, requires simple tools, is quick to perform (less than 20 seconds including prior instructions), and can be performed by participants who use assistive devices such as a walker, cane or crutches. The procedure has been experimentally tested and found to be a highly reliable tool to measure balance function (Berg & Norman, 1996).

The 3MDW test was used to determine the number of steps (at self-selected walking speeds) and the distance the participant can walk in three minutes (Berg & Norman, 1996). The test was performed in a quiet, obstacle-free outdoor area, 60 metres long and 5 metres wide. The participants walked between 10:00 and 11:00 a.m. in comfortable weather conditions (23^0C, 40% humidity). The monitor walked behind the participant so as not to influence the participant's pace, but as a safety precaution and to calculate the number of steps taken. Immediately after completing the walking test, the participant was seated and heart rate and blood pressure were evaluated. The entire evaluation procedure took an average of 41 minutes (±4.3) to administer

Data analysis

All data was analyzed using SPSS for Windows version 7.2. Data are reported as mean ± one standard deviation. One sample independent unpaired *t*-tests were run to compare differences in demographic and medical data, body composition, body fat and sensorimotor tests between the groups. The critical value for statistical significance was set at an alpha level < .05.

Results

The demographic, body composition and medical data of each group is summarised in Table 2. The values of *t* (df), and p for DS v Control; Older DS vs Older ID; Younger DS vs Control; and Younger ID vs Control are presented in Table 2a.

In general, the younger DS group and younger ID group were both more comparable to the control group in terms of gender. In comparison with the control group, the other groups were fairly similar with regard to both body composition, and medical problems with one exception, body weight was significantly lower ($p < .05$) for the control group, than all other groups older. The older DS group demonstrated a higher incidence of cardiac disease, neurologic problems and also significantly shorter heights and stature compared to all other groups. Individuals with Down syndrome also showed more medical problems than individuals with intellectual disabilities.

Table 3 shows the results of the flexibility and the two sensorimotor tests for persons with DS compared with controls. Functional flexibility tests showed only slight and non-significant discrepancies between the groups. The older and younger DS groups and the control group were able to bend forward in long-sitting positions for 18.7, 21.2 and 20.3 cm respectively. The older DS group demonstrated significantly poorer performance in both sensorimotor tests than the younger DS group and the control group (older DS v control: $t = -3.18$ (df=3.4) $p < .05$). Times longer than 12 seconds to perform the TUAG test may indicate some balance difficulties and increased risk for falling. In both the 3MDW test and the walking velocity measure, the older DS group walked significantly shorter distances at a slower pace (mean of 129 meters in 272 steps, average of 90 steps per minute) than the younger DS group (mean of 162 meters in 340 steps, average of 116 steps per minute) and control group (mean of 150 meters

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Table 2. Demographic, body composition, and medical characteristics of the groups

	Older		Younger		Control group
	DS	**ID**	**DS**	**ID**	
Participants (number)	10	14	13	24	31
Age (yr)	59±4	61± 3	44±3	45 ±4	75±7
Gender (%) M/F	9/91	11/89	48/52	52/48	16/84
Body weight (kg) M F	 66.6±4.4 67.1±3.6	 64.1± 4 63.4 ±4.3	 70.4±5 69.8±7	 68.4 ± 6 67.6 ± 6	 65.2±4.9 65.3±4.4
Height (cm)	149.4±5.6	152 ± 4.9	158.7±6.2	160 ± 5.5	160.7±3.3
Body fat (%)	21	20	21	19	20
Waist girth (cm) M F	 87.2±3.2 89.3±3.4	 85.2 ± 2.5 86.6 ± 3.1	 86.5±2.2 89.9±8.8	 87.7 ± 7.2 86.4± 4.5	 84.3±3.3 87.5±4.4
Thigh girth (cm) Widest point M/F M F	 50.5±3.2 49.0±4.1	 58.9± 3.6 51.3 ± 4.4	 51.7±4.7 50.9±5.7	 50.5± 5.1 51.7 ± 4.9	 49.4±3.7 52.2±4.9
Waist:Hip ratio M/F	1.7	1.8	1.7	1.7	1.7
Body Mass index M F	 26.1 26.8	 26.2 26.3	 25.9 25.6	 25.4 25.7	 25.2 25.9
Single/widowed (%)	100	100	95	100	78
Cardiac disease* (%)	39.7	11.9	30.4	2.3	26.4
Hypertension (%)	38.8	21.3	28.2	3.3	31.8
Diabetes (%)	17.6	2.6	10.3	0	19.9
Respiratory disease (COPD, asthma) (%)	27.3	20.1	25.5	13.5	24.5
Hepatic disease (%)	10.6	0	5.0	0	11.1
Neoplastic disease (benign & malignant tumours) (%)	3.6	0	0	0	4.1
Renal disease (insufficiency and chronic UTI) (%)	9.6	0	7.3	0	10.6
Neurological disease (%)	40.7	45.8	37.6	51.2	11.5
Vascular disease (%)	19.6	0	9.9	0	11.9
GI diseases (%) (gastritis, duodenal ulcer, chronic constipation)	15.8	20.2	11.7	5.6	18.9
Medication (no.)	3	4	4	2	4

DS – Down Syndrome
ID – non specified intellectual disability

N.S.– non-significant
M – male; F – female

* cardiac diseases include ischemic heart or congestive heart failure

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in 308 steps, average of 102 steps per minute), (Older DS v Control: t = -2.09, df= 19.2, p <.05).

Discussion

This study endeavoured to compare the clinical and functional characteristics between groups representing three populations – aging adults with Down syndrome, aging adults with intellectual disability without Down syndrome and elderly persons without intellectual disability. The study examined the test scores gained using a cross-sectional design by different age cohorts of older and younger adults with Down syndrome, and with non-specific intellectual disability. Standard evaluations were used for elderly and younger adults with intellectual disability residing in residential care as compared with control group of elderly adults residing in independent care facilities, with the mean age of the control group 14 years older than the oldest group of persons with Down syndrome and non-specific intellectual disability. Moreover, the effects of long term residential care and the manifestation of institutionalisation were important in this study as will be seen further in the discussion.

It is commonly believed that older adults with intellectual disability tend to demonstrate premature signs of aging, characterised by changes in body composition, functional decline and increased morbidity. Exactly how early in their lives they present these signs must still be investigated further, however in the current study signs of premature aging were not present in the younger group (45 year olds). Previous studies concerning elderly adults with intellectual disability have suggested that these individuals develop some aging characteristics earlier than adults without intellectual disabilities (Prasher, Chowdhury, Rowe & Bain., 1997; Crichton, Mackinnon & White, 1995). The present study has provided added evidence of premature aging in individuals with intellectual disability. Burt et al. (1995) examined the changes in functioning with aging in a longitudinal study in adults (22-56 years old) with Down syndrome and concluded that these individuals show only minimal age-related decline in functioning. Their study does not support the idea that adults with Down syndrome show rapid age-related declines before age of 50. Our findings demonstrated that young individuals of 45 years old with DS do not show early signs of aging, while the older group of persons with DS appeared similar to the control group of older people support the idea of premature aging in Down syndrome. Due to the small number of participants, the results have to be interpreted with caution.

Changes in body composition represent one of the more dramatic biological markers of advanced age and are especially pronounced after the age of 70 years (Bemben, Massey, Bemben, Boileau & Misner, 1995). Although persons with Down syndrome are generally of short stature, their height differences compared to the two control groups were not significant. Although the mean age of the control group was 14 years higher than that of the older DS group, the study showed no significant differences between the two groups with regard to body composition. It seems to indicate that the accelerated aging seen in the intellectual disability group might be indirectly reflected by body composition values. Age-associated loss of muscle mass and sarcopenia (Proctor, Balagopa & Nair, 1998), with concomitant loss of strength and decreased joint flexibility

Table 2a: Critical values of t (df) in One-tailed test (∝1), and probability for the participants.

	Older DS vs Control			**Older DS vs Older ID**			**Younger DS vs Control**			**Younger ID vs Control**		
	t	df	p	t	df	p	t	df	p	t	df	p
age	-3.85	19.2	.001	-4.14	13.7	.001	N/A			N/A		
gender	-1.47	4.8	.10	-1.30	4.0	.01	N/A			N/A		
Marital status	-2.81	21.7	.001	Like wise			N/A			N/A		
Body weight	-2.35	2.9	.05	-2.13	3.1	.05	-2.90	1.8	.05	-2.35	3.0	.05
Height	-1.79	10.9	.05	-2.13	4.0	.05	-1.78	11.1	.05	-2.35	3.1	.05
Cardiac diseases	-3.01	12.8	.005	-1.72	19.1	.05	-4.60	3.3	.005	-2.78	24.9	.005
Neurological diseases	-3.64	28.8	.001	-3.36	4.2	.001	4.78	8.8	.001	-6.86	5.0	.001
Vascular diseases	-3.35	7.7	.005	-3.88	18.7	.001	-9.92	3.2	.001	-3.10	10.7	.01
Respiratory diseases	-12.92	3.9	.001	-5.40	4.7	.001	-4.78	8.7	.001	-4.43	11.0	.001
Renal diseases	-9.92	3.1	.005	-3.25	8.9	.005	-3.16	9.4	.001	Like wise		

DS - Down syndrome

ID - Unspecified intellectual disability

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and mobility, contribute to frailty in the older adults and expose these individuals to increased risk for falls and fractures (Voorrips, Lemmink, van Heuvelen, Bult & Van Staveren, 1993; Evans, 1996; Gallagher et al., 1997; Carmeli, Coleman, Llaguna, & Cross, 2000; Carmeli, Reznick, Coleman, & Carmeli, 2000).

Our results lead us to assume that relative inactivity in adults may also lead to premature aging changes in body composition and may constitute increased risk for losing independence, and that the older DS group appears equally at risk to that as the older control group.

Table 3. Sensorimotor tests of older and younger persons with Down syndrome compared with controls

Test	Younger	Older		Comparison between older DS and controls		
	DS N=13	DS N=10	CG N=31	% dif	*t* value	df
Flexibility (cm)	21.1	18.7	20.3	7.8	-4.30*	2.1
TUAG (seconds)	7.0	13.2	7.3	80.8	-3.18*	3.4
3MDW (meters/steps)	162/340	129/272	150/308	14.0	-2.09*	19.2

df - degrees of freedom
*Sp < .05 between Older Group and Control Group (CG)

Most of the medical histories have revealed non-significant differences between the older DS group and control group with two exceptions. Heart disorders were considerably more prevalent among individuals with Down syndrome, often congenital, diagnosed early and well-treated. The incidence of neurological diseases in both the Down syndrome and non specific intellectual disability groups, mainly convulsive disorders, was found to be significantly higher than in the control group, which supports the notion that these individuals will probably require more assistance and care in the future (Sarkisian, Hays & Mangoine, 2002). A study in Holland (Van Buggenhout et al., 1999) investigated 96 persons with Down syndrome (mean age 44.8 years) and found epileptic seizures in 16.7% of all cases, but in 50% of the cases with dementia. Early onset of medical problems and prolonged poor health might accelerate aging processes. It is noticeable that individuals with Down syndrome pose more medical problems than individuals with non-specific intellectual disability with only one exception; that of neurological diseases. This may reflect a predisposition to health problems among individuals with Down syndrome.

Functional flexibility of the trunk flexion and hamstring muscle stretching were similar in all groups (DS, ID and controls). This indicates that all groups studied demonstrated similar degrees of soft tissue mobility and lumbar flexibility despite their differences in age. Loss of flexibility is one of the earliest noticeable changes occurring in elderly adults aged 70 years or older (Chesworth & Vandervoort, 1989). The fact that a 60 year old person with intellectual disability demonstrates similar degrees of flexibility to that of 75 year old without intellectual disability may be a consequence of a more passive lifestyle. It may be associated with the constant help and assistance they receive in their daily living activities and may reflect a "use it or lose it" phenomenon. The flexibility results are somewhat surprising and merit special attention. Since individuals with Down syndrome often possess poor skeletal muscle tone with soft tissue elasticity, one might have expected a relative advantage with respect to flexibility as they aged, however, this was not the case. Since we did not evaluate muscle tone in the present study, we can only assume that a "sedentary" lifestyle probably played a major role in determining flexibility levels at age 60 among individuals with Down syndrome comparable to those of 75 year old individuals without intellectual disability.

The TUAG test is one of the more user-friendly functional assessment tests in the clinic, whereas the 3MDW test is an outdoor functional test used to assess the endurance capacity of the skeletal muscle of lower extremities, the heart and lungs (Bendall, Bassey & Pearson, 1989). The older DS group scored lower in the functional tests, which may reflect on their general state of health or sedentary lifestyle and may indicate an increased mild risk for falling. The TUAG test is used to assess a person's ability to perform a task that is probably performed many times throughout the day by elderly adults. Adults who take more than 20 seconds to complete the test are at high risk of falling and are not considered safe to be alone outside. This test can also supply further information about the participant's functional ability and rehabilitation requirements. Poor performance (slower than 20 seconds) may be used to justify therapeutic intervention as a preventive measure. The older DS group needed significantly more time to complete the test than the control group, but still finished the test within the normal timeframe. Ongoing follow-up is needed to detect, sooner rather than later, any deterioration in performing that specific task.

In the 3MDW test at self-selected walking speeds, the older DS group covered shorter distances and were significantly slower than both the younger DS group and the control group. According to Bohannon, Andrews and Thomas (1996) a paced walking speed for elderly adults of 70 steps per minute is considered a slow walking velocity, and paced walking speed of 80 steps per minute is considered a slow-to-moderate walking speed. One explanation for our data may be that daily living and recreational activities of persons

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with intellectual disability do not provide sufficient stimuli to preserve functional mobility to the extent found in the control group. Consequently, results indicating low endurance capacity may conceivably reflect either poorer health conditions or less-intense life activities, and a tendency to loss of condition (Weinstein, 1998; Boyd, 1997).

Several improvements in the evaluation procedures may warrant consideration. For example, use of magnetic resonance imaging (MRI) as a reference method for quantifying the muscle mass is more accurate, but significantly more expensive and time-consuming (Williams, Going, Milliken, Hall & Lohman, 1995).

Conclusions

Our findings suggested that aged individuals with intellectual disability do present several indications of premature aging and in particular those individuals with Down syndrome. The mechanisms, although still unknown, may be associated with physically inactive lifestyles, which in individuals with Down syndrome may lead to acceleration of functional disabilities and overall less favourable health as they age. Further information concerning psychological and behavioural characteristics of inactive older adults will be useful for directing diagnostic and preventive measures to the most vulnerable groups such as individuals with learning disabilities.

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