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Osteoporosis and People with Down Syndrome: A Preliminary Descriptive Examination of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing Wave 1 Results

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Abstract

Background: People with Down syndrome (DS) are a high "at risk" group to develop osteoporosis. Increased morbidity associated with older age, higher prevalence of Alzheimer dementia, hypotonia, hypogonadism, and thyroid disease, are all features of DS and predispose this cohort to musculoskeletal complications. **Methods:** The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA) is a representative study of the aging of adults with intellectual disability in Ireland. The sample (N = 753) included 147 people with DS. Data was gathered on participants' health status, behavioural health, health screenings and activities of daily living. The prevalence of osteoporosis and related risk factors among people with DS was specifically examined. **Findings:** Of the 147 participants with DS, 9.4% reported a doctor's diagnosis of osteoporosis; a much lower figure than prevalence of risk factors would suggest. Predisposing factors identified included higher than general population rates of thyroid disease (37.4%), epilepsy (19.3%), sedentary lifestyle (51.7%) and the majority of the females reporting having experienced menopause (61%). Bone health screening was low at (8%) despite the presence of such high levels of risk factors in this population. **Conclusion:** Given the risk factor findings and the hidden nature of osteoporosis, underreported incidence among people with Down syndrome seems probable. Further investigations and systematic screening are required.

Keywords

Intellectual Disability, Down Syndrome, Osteoporosis, Bone Health, Bone Fragility Risk

1. Introduction

Osteoporosis and osteopenia are chronic skeletal conditions characterized by low bone density and microarchitectural deterioration of bone tissue [1] [2] [3]. With ageing, enhanced resorption and decreased bone formation occurs leading to a net loss of bone mass and ultimately risk of osteoporosis and osteopenia [4]. The World Health Organization (WHO), the International Osteoporosis Foundation (IOF) and bone health research literature, identify a number of non-modifiable and modifiable risk factors associated with the development of osteoporosis and osteopenia. Non-modifiable risks include female gender, increased age, family history of osteoporosis, and being Caucasian. Late menarche, early menopause and low endogenous estrogen levels are also associated with low bone mineral density [1] [2] [5] [6]. Modifiable risks include sedentary lifestyle, smoking, poor dietary habits, lack of sunlight and estrogen deficiency. Certain medications are also indicated as risk factors for example anticonvulsants and glucocorticoids [7]. Higher prevalence of risk factors has been shown to lead to both a higher potential of fractures and higher rates of morbidity with devastating consequences for independence, quality of life and overall health and well-being [5] [8].

Osteoporosis and osteopenia have been widely investigated in the general population [5] [9] [10], however relatively under investigated among people with intellectual disability (ID), and especially among people with Down syndrome (DS) [11]-[16].

2. Down Syndrome & Osteoporosis

Down syndrome (DS) is one of the most commonly known genetic causes of ID and its pathogenesis are well documented [17]. Increased life expectancy is unmistakable among people with DS [18] prompting an increased risk to older age health conditions such as osteoporosis. People with DS are specifically vulnerable to musculoskeletal disorders and are more likely to have infrequent health checks or routine screening [19].

Prevalent features among people with DS contributing to osteoporosis include low estrogen levels, late menarche and early menopause in females as well as hypogonadism in males [20] [21]. Increased ageing and early onset of ageing related decline add further burden [22] [23] [24]. Thyroid dysfunction is commonly identified among people with DS, with hypothyroidism the most common presentation [25] [26] impacting significantly on skeletal health and later life osteoporosis [27] [28]. As people with DS age the prevalence of Alzheimer

dementia and associated epilepsy increases [29]. Alzheimer's disease and epilepsy do not directly affect bone status but the subsequent anticonvulsant medications (AEDs) contribute to disruption of bone formation and remodeling especially second generation anticonvulsants [7]. Increased risk of falls, both as a consequence of and a contributor to reduced bone health are also associated with Alzheimer's disease and epilepsy. However, Torr, Strydom [30], in their review warn that decline in adults with DS should not be assumed to be associated with Alzheimer's dementia as functional decline may be as a consequences of a number of underlying conditions especially sensory and musculoskeletal impairment.

Physical activity benefits bone mass, stability, balance and contributes to improved quality of life [31] [32] however physical activity levels at rate to accrue health benefit is low among those with DS [33]. Further, the prevalence of overweight and obesity has been noted at higher levels among people with DS than the general population [34] [35]. Obesity has a cumulative effect on bone health due to the retention of vitamin D by the increased adipose tissue, therefore making it less available for bone metabolism [36] as well as the extra loading on bones and joints increasing the likelihood of falls and possible fracture [37]. Obesity may also be a reflection of imbalanced or poor dietary habits. Known secondary causes of low bone mineral density include poor nutrition and gastrointestinal conditions such as coeliac disease, gastro-reflux disease, and chronic constipation, all highly prevalent among adults with ID and DS [38] [39]. Poor dietary habit, gastrointestinal conditions along with low solar exposure impacts on vitamin D and dietary mineral absorption resulting in an adverse impact on overall bone health [40].

People with DS have a higher level of health need and experience greater health inequalities in comparison to the general population [41]. Health screening and the identification of specific risks for osteoporosis, prevalent among this cohort, are sparsely investigated and subsequently morbidities can go undetected [42]. Bone health screening is often overlooked [11] [43]. However with no consistent approach to bone screening, evident increased burden of risk factors for osteoporosis yet no clear guidance of the risk burden among people with DS, further investigation is required. Therefore the aim of this paper is to examine the prevalence of risk factors predisposing people with DS to osteoporosis and the relationship of those identified risks to a reported doctor's diagnosis of osteoporosis.

3. Methods

The data for this paper was drawn from *The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing* (IDS-TILDA) which is a national longitudinal study on aging and intellectual disability. The study commenced in 2009 exploring a number of health, social and life domains of older adults with ID over time (for further information see reference [44]). Data is collected every 3 years and the data presented here is from the first wave of the study.

3.1. Sample

In Ireland people with an ID who are in receipt of services are registered on a National Intellectual Disability Database (NIDD). This database formed the sampling frame employed by the IDS-TILDA study. The inclusion criteria required people to be registered on the NIDD and be aged 40 years or older at the time of the study. IDS-TILDA recruited 753 people of all level of ID and from all living circumstances. A question on etiology of intellectual disability was used to identify the 147 persons with Down syndrome.

3.2. Ethical Review

Full ethical approval was granted by Ethics Committees established by the service providers involved in the study and by the Faculty of Health Sciences Ethics Committee, Trinity College Dublin. Consistent with this review, all information was presented to participants in an easy-to-read format in order to obtain informed consent from the participants, and, family or guardians were also invited to support consent or provide agreement where applicable.

3.3. Measures

Following examination of the literature, the WHO guidelines and the International Osteoporosis Foundation (IOF) guidelines, common risk factors were identified and matched with comparable data from the IDS-TILDA data collected in Wave 1 (see **Table 1**).

IDS-TILDA variables such as physical activity and dietary intake were grouped and categorized to further facilitate analysis.

Physical Activity

Ireland has adopted the WHO recommendations [45] of at least 150 minutes of moderate intensity physical activity throughout the week with a focus on strength, balance and gait. Participants in this study were asked to describe their physical activity, both duration and intensity of engagement in terms of mild physical activity (minimal sweating or exertion for a period or 10 - 20 minutes such as bowls or golf), moderate physical activity lasting 10 - 20 minutes (light sweating or a moderate increase in breathing or heart rate, such as dancing or swimming) and vigorous physical activity lasting 10 - 20 minutes (causing heavy sweating and a notable increase in breathing or heart rate, such as vigorous swimming, running or jogging).

They also reported frequency in terms of more than once a week, once a week, 1 - 3 times a month, or hardly ever or never. Responses were then grouped into three categories (see **Table 2**). People also identified if they had mobility difficulty by answering a global question on level of difficulty experienced when walking 100 yards.

Dietary Intake

Ireland utilizes a food pyramid of the main food groups [46] reflecting the staple Irish diet. Portion sizes were illustrated for participants. For fruit, vegeta-

bles, potatoes, bread and cereal, meat, fish, poultry, milk cheese and yogurt, savoury and sweet snacks, fizzy drinks, water, tea, coffee and cordial people indicated the number of portions by frequency per food item *i.e.* more than four portions per day, 2 - 3 portions per day, 1 portion per day, 5 - 6 portions per week, 2 - 3 portions per week, 1 portion per week, 1 - 3 portions per month or never consuming this item. Each food item was then grouped and categorized in terms of being below, meeting or exceeding recommended daily allowances, taking into consideration age, gender and activity level.

Table 1. Measured risk factors for osteoporosis.

Known Risk Factors—IOF, WHO & Scientific Literature	IDS-TILDA Equivalent Data
Non-Modifiable	
Older age	Age
Female/menopausal	Gender/Have you gone through the menopause
Hypogonadism	Have you any other chronic health conditions male gender
Secondary osteoporosis	Doctors diagnosis of osteoporosis
Thyroid disease	Doctors diagnosis of thyroid disease
Other endocrine	Doctors diagnosis of rheumatoid arthritis
Rheumatoid arthritis	Doctors diagnosis of gastrointestinal reflux
GIT conditions	Doctors diagnosis of coeliac disease
Coeliac disease*	Doctors diagnosis of scoliosis
Scoliosis*	Doctors diagnosis of diabetes mellitus
Diabetes mellitus*	Doctors diagnosis of muscular dystrophy
Muscular dystrophy*	Doctors diagnosis of cerebral palsy
Cerebral palsy*	
Modifiable	
Sedentary lifestyle	Levels of physical activity
	Mobility—difficulty walking 100 yds
Poor calcium intake	Dietary intake and supplementation
Vitamin D	Dietary intake, supplementation
Low body mass	BMI calculated as weight divided by height squared
GIT condition	Doctors diagnosis of chronic constipation*
Anticonvulsant drug use	Anticonvulsant medications
Corticosteroid drug use	Corticosteroid medications anxiolytics,
Anxiolytics, sedatives, neuroleptics and antidepressants	sedatives, neuroleptics and antidepressants medications

***Conditions with low prevalence rates and subsequently not included in overall table stratified by age and gender.**

Table 2. Physical activity categorization.

Sedentary	engaged in 10 - 20 minutes of mild, moderate or vigorous exercise less than once a week, 1 - 3 times a month or hardly ever or never
Semi-active	engaged in 10 - 20 minutes of moderate exercise once a week and/or vigorous exercise 1 - 3 times a month
Active	engaged in 10 - 20 minutes of moderate or vigorous exercise more than once a week

3.4. Data Collection

Data was collected using a two phased approach of a pre-interview questionnaire, which was posted to the participant once consent had been received, and then the main questionnaire was administered via a face-to-face interview. On receipt of consent the field researcher contacted the participant and arranged an appointment for a time and place suitable to the participant. At this point the field researcher forwarded a pre-interview questionnaire which collected demographics, health conditions data, healthcare utilisation, and prescribed medications information. The main interview was conducted as a computer assisted personal interview. The main questionnaire consisted of 17 modules encompassing social, community, physical health, mental health and cognitive assessment [44].

3.5. Data Analysis

For the purposes of this study the statistical package for social science (SPSS) v20 was utilized for all analysis. Preliminary analyses were initially carried out with included frequencies, distribution and identification of missing values. With consideration to missing data, valid percentages only are presented throughout the paper. Descriptive statistics were used to analyse the demographic data and overall relationships between variables were explored and stratified by age and gender.

4. Results

As may be seen in Table 3, there were more females than males at 56% (n = 83) vs 44% (n = 62) respectively. Their ages were predominantly below 65 years, with 3 participants aged 64 years, all of whom were female. Participants lived in a variety of settings, community group home being the largest (42.9%, n = 63) followed by residential type setting (37.4%). The majority of participants (70%, n = 95) were within the mild to moderate range of ID. A large number of the cohort had no formal education (28.6%, n = 42) with just 39.5% (n = 58) reporting they attained some primary education. Whilst the vast majority visited their General Practitioner (GP) regularly very few used specialist services such as endocrinology (2.7%) or geriatrics (1.4%).

4.1. Examining the Risk Factors for Osteoporosis

4.1.1. Non-Modifiable Risks

Just 9.7% (n = 14) of the participants reported a diagnosis of osteoporosis, all of whom were female, with the majority within the 50 - 64 year age category (see Table 4). Approximately 13% (n = 19) reported having had a fracture, with prevalence twice as high among women (68.4%, n = 14) compared to men (31.6%, n = 5). Hip fractures were the highest reported type of fracture (26.5%, n = 5) experienced.

The highest reported health condition was thyroid disease (37.4%, n = 55) and again this condition was more predominant among females with the greatest

prevalence among 50 - 64 year olds. However only 2.7% (n = 4) attended endocrinological services. Seizure activity was evident (19.3%; n = 28), the most common type experienced was tonic clonic seizures (51.7%, n = 15) and the majority of those experiencing epilepsy had attended an epilepsy clinic for review within the last year (75.0%, n = 21). More females than males reported epilepsy with their rates increasing with age but the reverse was true for males, with a greater prevalence among the younger age category 40 - 49 year olds. As expected anticonvulsant use (20.4%, n = 30) was reflective of the levels of epilepsy.

Table 3. Demographics of the participants with Down syndrome.

N = 147	*n*	(%)
Gender Male	65	(44.2)
Female	82	(55.8)
AGE 40 - 49 Years	79	(53.7)
50 - 64 Years	65	(44.2)
65+ Years	3	(2.0)
Living Circumstances Independent/Semi	29	(19.7)
Community Group Home	63	(42.9)
Residential	55	(37.4)
Level of ID Mild	20	(14.7)
Moderate	75	(55.1)
Severe/Profound	41	(30.1)
Education Achieved No Formal Education	42	(28.6)
Primary/Some Primary Level	58	(39.5)
Secondary	1	(0.7)
Other	18	(17.0)
Don't Know	21	(14.2)
Health Care Utilisation (within the last year) General Practitioner (GP)	130	(88.4)
Dental	85	(57.8)
Optician	63	(42.9)
Physiotherapy	34	(23.1)
Dietician	31	(21.1)
Hearing	25	(17.0)
Endocrinologist	4	(2.7)
Geriatrician	2	(1.4)

Table 4. Non modifiable and modifiable risk factors associated with low bone mineral density according to gender and age.

Variable	Total N = 147		Women n = 83						Men n = 64					
			40 - 49 years n = 39		50 - 64 years n = 40		65+ years n = 3		40 - 49 years n = 40		50 - 64 years n = 26		65+ years n = 0	
	f	%	*f*	%	*f*	%	*f*	%	*f*	%	*f*	%	*f*	%
Non Modifiable														
History of Osteoporosis	14	(9.7)	3	(7.7)	11	(27.5)	0	(0.0)	0	(0.0)	0	(0.0)	0	(0.0)
Thyroid Disease	55	(37.4)	13	(33.3)	24	(60.0)	0	(0.0)	11	(27.5)	6	(25.9)	0	(0.0)
Epilepsy	28	(19.3)	3	(7.7)	13	(32.5)	1	(33.3)	7	(17.5)	4	(16.0)	0	(0.0)
Anticonvulsant Drug Use	30	(20.4)	4	(10.3)	12	(30.0)	1	(33.3)	7	(17.5)	6	(24.0)	0	(0.0)
Arthritis	21	(14.3)	6	(15.4)	10	(25.0)	0	(0.0)	4	(10.0)	1	(4.0)	0	(0.0)
Experienced Menopause	50	(61.0)	15	(39.5)	33	(80.5)	2	(66.7)	-	-	-	-	-	-
Don't Know	13	(15.9)	5	(13.2)	7	(17.1)	1	(33.3)	-	-	-	-	-	-
Mobility (walking 100 yds.) No Difficulty	107	(72.8)	32	(82.1)	22	(53.7)	1	(33.3)	34	(85.0)	18	(75.0)	0	(0.0)
Some Difficulty	17	(11.6)	4	(10.3)	9	(22.0)	0	(0.0)	3	(7.5)	1	(4.2)	0	(0.0)
A Lot of Difficulty	7	(4.8)	0	(0.0)	3	(7.3)	0	(0.0)	2	(5.0)	2	(8.3)	0	(0.0)
Cannot Do at All	16	(10.9)	3	(7.3)	7	(17.1)	2	(66.7)	1	(2.5)	3	(12.5)	0	(0.0)
Modifiable*														
Body Mass Index (BMI) Underweight	2	1.7	1	(3.0)	0	(0.0)	0	(0.0)	0	(0.0)	1	(5.0)	0	(0.0)
Healthy Weight	34	29.6	5	15.2	11	42.3	0	0.0	12	34.3	6	30.0	0	(0.0)
Overweight	31	27.0	11	33.3	3	11.5	1	100.0	8	22.9	8	40.0	0	(0.0)
Obese	48	41.7	16	48.5	12	46.2	0	0.0	15	42.9	5	25.0	0	(0.0)
Chronic Constipation	10	(6.8)	0	(0.0)	6	(15.0)	0	(0.0)	3	7.5	1	(4.0)	0	(0.0)
Gastroesophageal Reflux	10	(6.8)	3	(7.7)	3	(7.5)	1	(33.3)	2	(5.0)	1	(4.0)	0	(0.0)
History of Smoking	7	(4.8)	1	(2.6)	2	(5.0)	0	(0.0)	3	(7.5)	1	(4.0)	0	(0.0)
History of Alcohol Intake	65	(44.2)	19	(48.7)	14	(35.0)	1	(33.3)	18	(45.0)	13	(52.0)	0	(0.0)
>2 Drinks/Day 3 - 4 Days a Week	2	(3.1)	0	(0.0)	0	(0.0)	0	(0.0)	1	(5.7)	1	(5.9)	0	(0.0)
Hypnotics and Sedatives	14	(9.5)	3	(7.6)	5	(12.5)	0	(0.0)	4	(10.0)	2	(8.0)	0	(0.0)
Antidepressants	26	(17.7)	3	(7.6)	10	(25.0)	0	(0.0)	9	(22.5)	4	(16.0)	0	(0.0)
Anxiolytics	17	(11.6)	4	(10.3)	4	(10.0)	0	(0.0)	4	(10.0)	5	(20.0)	0	(0.0)

Among female participants over 60% had experienced the menopause with almost a fifth of those reporting early menarche (before the age of 50 years), mean age of onset 44.8 years SD ± 4.27 with a range of 38 - 53 years respectively. A further 21% (n = 31) were unsure if they had experienced the menopause. Over 25% (n = 40) of participants reported some level of difficulty with walking 100 yards of which over 10% (n = 16) could not walk this distance at all. Middle

aged women (50 - 64 years) presented with the greatest amount of difficulty (46.4%, n = 19).

4.1.2. Modifiable Conditions

In terms of BMI, the majority of participants were within the overweight and obese categories at 68.7% (n = 79) with only 29.6% within the healthy weight category and just 2 participants identified as underweight. Almost 7% reported chronic constipation with a similar number reporting gastric reflux (6.8%, n = 10). Few had a history of smoking (4.8%, n = 7) with even fewer consuming excessive amounts of alcohol (3.1%, n = 2). Reported levels of hypnotic & sedative, antidepressant and anxiolytic use were 9.5% (n = 14), 17.7% (n = 26) and 11.6% (n = 17) respectively. No participants with DS were taking corticosteroids, medicines noted by the WHO as among the higher contributing risk to osteoporosis development. See Table 4 for overall non-modifiable and modifiable risks stratified by age and gender.

Dietary Behaviours

The majority of people ate three meals a day interspersed with snacks. Many people with DS did not consume the recommended daily 5 portions a day of fruits and vegetables (87.7%, n = 128), dairy (36.3%, n = 53) and carbohydrate (23.8%, n = 35). With regards to sweet/fizzy drink/candy intake, just over 50% met the suggested daily amount with the remaining 50% exceeding recommendations, with men more likely to exceed. Also, almost 43% (n = 35) of women did not consume the recommended amounts of carbohydrate intake on a daily basis. Overall the vast majority of men and women did not achieve daily recommendations for fruit and veg with men (93.8%, n = 60) faring worst. Of concern in terms of bone health implications, over a third of both women and men (34.1% n = 28 and 39.1%, n = 25 respectively) did not attain the daily recommendations for dairy intake, a healthy source of calcium (see Table 5).

Physical Activity

As outlined in Table 6 a large proportion of participants did not engaged in physical activity at levels to accrue health benefit with 51% (n = 76) of participants doing very little or no physical activity. This was particularly evident among the over 50 age group where just 38% (n = 26) engaged in active or semi-active physical activity and even among the 40 - 49 year olds levels of active engagement were very low with just 10.1% (n = 8) reporting active levels of physical activity. Men led relatively inactive lifestyles with 54% (n = 35) falling within the sedentary category and 40% (n = 26) reaching only the semi-active level. Inactivity was also associated with level of ID with 83% of those with severe/profound ID being relatively inactive.

Other Factors Impacting on Bone Health

Although numbers were small additional health conditions, as outlined in Table 7, were reported by participants with DS that directly or indirectly affect bone health. These included coeliac disease at 5.5% (n = 8), scoliosis (2.7%, n = 4), diabetes (1.4%, n = 2), muscular dystrophy (1.4%, n = 2) and cerebral palsy

(0.7%, n = 1). Conditions indirectly affecting bone health were notably higher, these included cataracts and Alzheimer's dementia at 29.9% (n = 44) and 15.6% (n = 23) respectively. Finally only 17% (n = 25) of all the participants reported taking vitamin D supplementation.

Reported Bone Density Screening

Only 7 people reported having had a dual-energy X-ray absorptiometry (DXA) scan and just 3 within the last 2 years. No men reported having had a scan no matter what age. Further, no person with a history of fracture reported having had a DXA and screening levels were low among those reporting risk factors such as experience of menopause (n = 50), thyroid disease (n = 55) and epilepsy (n = 28) at 30% (n = 6), 21.4% (n = 6) and 30.8% (n = 4) respectively. For the DXA question there were only 87 participant answers.

Table 5. Food group intake recommendations according to gender distribution.

	Female (n = 82)						Male (n = 65)					
	Below Requirement		Meets Requirement		Exceeds Requirement		Below Requirement		Meets Requirement		Exceeds Requirement	
	f	%	*f*	%		%	*f*	%	*f*	%	*f*	%
Carbohydrates	35	42.7	38	46.3	9	11.0	-	-	65	100	-	-
Fruit and Veg	68	82.9	12	14.6	2	2.4	60	93.8	4	6.3	-	-
Dairy	28	34.1	46	56.1	8	9.8	25	39.1	36	56.3	3	4.7
Meat	2	2.4	78	95.1	2	2.4	4	6.3	60	93.8	-	-
Sweets	-	-	47	58.0	34	42.0	-	-	25	40.3	47	59.7

Table 6. Levels of physical activity engagement according to gender, age & level of ID.

		Active		Semi-active		Sedentary		No. in sample
Age Groups		*f*	%	*f*	%	*f*	%	
Female (n = 82)	40 - 49	5	12.8	20	51.3	14	35.9	39
	50 - 64	1	2.5	14	35.0	25	62.5	40
	65+	-	0.0	1	33.3	2	66.7	3
Male (n = 65)	40 - 49	3	7.5	17	42.5	20	50.0	40
	50 - 64	1	4.0	9	36.0	15	60.0	25
	65+	-	0.0	-	0.0	-	0.0	-
Level of ID (n = 136)*	Mild	1	5.0	14	70.0	5	25.0	20
	Moderate	8	10.7	34	45.3	33	44.0	75
	Severe/Profound	-	0.0	7	17.1	34	82.9	41

*Missing obs = 11 (People who did not identify their level of ID[1]).

[1]Little's MCAR test fails to reject the null hypothesis that the data is missing at random and therefore there is no evidence that the missing data is affecting the findings—p-value = 0.328.

Table 7. Other health conditions directly and indirectly effecting bone health.

Other health conditions directly effecting bone health		
	f	%
Coeliac	8	(5.5)
Scoliosis	4	(2.7)
Diabetes	2	(1.4)
Muscular dystrophy	2	(1.4)
Cerebral palsy	1	(0.7)
Health conditions indirectly effecting bone health		
Cataracts	44	(29.9)
Alzheimer's dementia	23	(15.6)
Asthma	7	(4.8)
Cancer	2	(1.4)
Vitamin D supplementation	25	(17.0)

5. Discussion

As was previously noted, DS in itself has been shown to be a risk factor for the presence of osteoporosis and osteopenia [11] [15] [16] [47] [48] [49]. Findings here concur that people with DS are a high "at risk" group. The confirmed prevalence of thyroid disease, early menopause, specific medications that interfere with bone metabolism, and levels of inactivity and sedentary lifestyle, all culminate in increased likelihood of developing osteoporosis or osteopenia.

Osteoporosis is receptive to treatment and preventable; however in this study active health promotion was not evident. For example, physical activity engagement at levels that would accrue health benefit was not evident. Although rates of physical activity were very low, some participation is better than none and promoting engagement in exercise that is fun, enjoyable and diverse needs to be encouraged. With imagination and resourcefulness people with DS can be encouraged to engage, however as Heller and colleagues indicate [50], it is their carers and supporters that make the difference and lead by example.

Attendance at specialists such as an endocrinologist was also low, and although people attended their GP regularly the levels of calcium and vitamin D supplementation was low. In Ireland, a northern hemisphere country, it is acknowledged that sunlight levels are considered low and supplementation is suggested [8]. Genant and colleagues advised that further pharmacological interventions ought to be targeted at those with highest risk of fracture but little evidence of this was found for people with DS [8]. The findings that overall dietary balance in the sample was poor, suggests future research ought to examine whether dietary status is an issue of poor choices or a lack of awareness among health professionals and carers. Considering that many of the participants in the study lived in supported settings, either community group homes or residential

settings, where the daily dietary decision making may be taken out of their hands, these findings support the implementation of education to improve overall diet and consideration for supplementation for people with DS.

Levels of diagnosed osteoporosis were not particularly high, but low screening rates with high presence of risk factors perhaps suggest hidden undiagnosed disease, especially among males. No male reported the presence of osteoporosis or osteopenia nor having had a DXA despite risk factors including the prevalence of hypogonadism among men with DS. In addition 13.4% of the participants in this study reported having experienced a fracture with hip fractures occurring at twice the rate reported by those in the general population study The Irish Longitudinal Study on Ageing Wave 1 results (TILDA) [51]; yet only 8% reported having had a DXA scan. Overall the attendance for DXA is concerning and perhaps a possible explanation maybe that people with DS are fearful of engaging and therefore non-compliant, may have physical deformities that prevents appropriate positioning in the scanner or it may simply be a case where the carer is not aware of the risks people with DS face. Consideration ought to be given to the, Van Allen and colleagues [52] suggestion, and endorsed by Carfi and colleagues [16] of regular systematic screening for people with DS especially as the WHO also recommends such screening for all individuals with one or more strong risk factors. They would argue menopause is one such factor, and as can be seen here, a large number of the women had gone through menopause, and, perhaps hypogonadism among males could be another. Whilst they do concede that population screening is not a cost effective approach, making more widely available techniques such as quantitative ultrasound ought to be explored [8]. The TILDA study included bone screening for general population participants, however confirmation of the doctor's diagnosis of osteoporosis was much less than numbers found to meet criteria through screening. In the TILDA study they found that 86% (n = 1365) with objectively measured evidence of osteopenia and 72% (n = 218) osteoporosis did not have a doctor's confirmation of diagnosis [53]. Overall greater surveillance of health risks is seen as a way to improve the health status of older adults with ID [54].

It must be highlighted that people with DS do experience communication challenges and expressing their health needs can often pose challenges. However, as people with DS age their increased vulnerability to the development of Alzheimer's dementia is well recognized and perhaps a contributing factor to other clinical signs and symptoms of underlying medical conditions going unrecognized [55]. Alzheimer's dementia also increases the person's susceptibility to falling thus increasing the risk of fracture. Instigating measures to prevent and address osteoporosis at an early stage would be preferable, along with increasing carer's awareness of the potential and insidious nature of osteoporosis along with its disagreeable consequences.

Limitations to this paper must be recognized; the group studied is larger than most published papers on DS and were drawn from a representative sample of

people with ID but there were small numbers in some of the subgroups considered. Further, the presence of osteoporosis was based on a doctor's reported diagnosis and was not objectively measured however future waves are addressing this concern.

6. Conclusion

Evidence emerges from this study that identified risks which include thyroid disease, epilepsy and its associated medications, inactivity and dietary imbalance are at levels which, based on prior general and DS population studies, would increase the risk of developing osteoporosis. Coupled with the predisposition that already exists among people with DS this is a recipe for future deleterious consequences. Considering prior reports of differences between self-reported and objectively measured osteoporosis, the high prevalence of risk factors among people with DS found here supports further objective investigation of symptoms, and rigorous risk surveillance along with support and encouragement to strengthen positive behaviours such as increased participation in physical activities, to contribute to the promotion of good bone health.

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Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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