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An exploration of the bone health of older adults with an intellectual disability in Ireland

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Abstract

Background Many risk factors have been confirmed for poor bone health among the general population including age, gender and corticosteroid use. There is a paucity of investigation among people with intellectual disability; however, research points to differing risks namely anti-epileptic medication use, Down syndrome and poor behaviour lifestyle.
Methods Data was extracted from the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing in Ireland. In total, 753 participants took part, and data was gathered on participants' health status, behavioural health, health screenings and activities of daily living. The prevalence of osteoporosis and related risk factors were specifically examined.
Results Overall, 8.1% reported a doctor's diagnosis of osteoporosis with over 20% reporting history of fracture. Risk identified included older age ($P <$ 0.0001), female gender ($P < 0.0001$), difficulty walking ($P < 0.0001$) with older age and being female the stronger predictors for osteoporosis, odds ratio = 6.53; 95% confidence interval 2.82–15.11 and odds ratio = 4.58; 95% confidence interval 2.29–9.17, respectively. There was no gender difference regarding the level of fractures; however, epilepsy and anti-epileptic medication were strong predictors. Overall, 11.1% attended for bone screening diagnostics.
Conclusion Despite low levels of reported doctor's diagnosis of osteoporosis risk factor prevalence was high. Considering the insidious nature of osteoporosis and the low levels of diagnostic screening, prevalence could be possibly higher.

Keywords bone health, developmental disabilities, fracture, intellectual disability, osteoporosis

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Introduction

Osteoporosis is described as a multifactorial disorder characterised by low bone mass and micro-architectural deterioration of bone tissue leading to enhanced bone fragility and a consequent increase in fracture risk (World Health Organisation 1994; Kanis *et al.* 2013; Cooper 2014). The insidious nature of the condition leads to under diagnosis, often only detected post clinical fracture (Kanis *et al.* 2013; Kanis 2002). Internationally, the World Health Organisation's (WHO) operational definition of osteoporosis is well established and utilised for over 20 years (World Health

Organisation 1994). The presence of osteoporosis is defined as having a bone mineral density (BMD) value of 2.5 standard deviation (SD) or more below the young female adult mean, with severe osteoporosis described as above in the presence of 1 or more fragility fractures. BMD is measured by dual-energy X-ray absorptiometry (DXA), which is the 'gold standard' for diagnosis of osteoporosis, evaluation of fracture risk and monitoring skeletal changes(Kanis *et al.* 2008). More recently, alternate BMD measurement devices have been introduced, and the International Society for Clinical Densitometry has confirmed that these peripheral bone density measurement devices have value for assessing fracture risk and identifying people who may require further diagnostics with DXA. One such technique is the quantitative ultrasound (QUS), which is a quick, non-invasive method of scanning the os calcis (heel), a highly trabecular and weight-bearing bone similar to the hip and spine, the sites commonly utilised for DXA.

There have been a plethora of studies among the general population describing the pathogenesis and impact of osteoporosis; however, there are limited investigations describing prevalence among adults with intellectual disabilities (ID). It is known that people with ID experience higher levels of adverse health conditions than people without ID (van Schrojenstein Lantman-De *et al.* 2000). Indeed McCarron *et al.* (2013) identified higher prevalence of multimorbidity and complex conditions in comparison to the general population. Very often health needs go unmet and unrecognised (Lennox & Kerr 1997; Beange & Durvasula 2001; Cooper *et al.* 2004; Kerr 2004; Emerson & Hatton 2013). One such area quite often neglected or omitted on physical health checks is bone health with preventative services also underutilised (Lewis *et al.* 2005; Michael 2008; Srikanth *et al.* 2011).

Exploring risk factors

Ageing is a well-documented contributor to bone loss (Datta *et al.* 2008), and until recently, longevity in persons with ID was lower than the general population. These trends are changing; Kelly & O'Donohoe (2014) describe an increase from 29% in 1974 to over 48% in 2013 among people with ID over the age of 35 years. However, it is also important to note that osteoporosis is not always the result of accelerated bone loss due to ageing. Peak bone mass is attained in early adulthood and remains constant into the mid-to-late thirties. Nonetheless, if an individual does not reach optimal bone mass, as is the case for people with Down syndrome (DS), there is an increased risk of developing osteoporosis (Hayes & Batshaw 1993).

Osteoporosis occurs in both genders; however, women are at higher risk of osteoporosis and related fractures because of such factors as lower muscle mass, fluctuation of oestrogen levels and menopause (Melton 2003). Some women with ID and especially those with DS have added risk loading because of late menarche and early menopause (Knickmeyer *et al.* 2006; van Schrojenstein Lantman-deValk *et al.* 2002; Carr & Hollins 1995). It is also recognised that hypogonadism associated with reduction in pubertal growth spurt thus low oestrogen and testosterone levels is prevalent among males with DS (Seeman *et al.* 1983; Hsiang *et al.* 1987; Schuf *et al.* 1997).

Levels of ID can have adverse effect on bone health as those with more severe to profound ID are more likely to present with increased co-morbidities (McCarron *et al.* 2013). Non-ambulatory status has been correlated to higher rates of osteoporosis and fracture (Tyler *et al.* 2000; Baptista *et al.* 2005). Also of note is that this cohort is more likely to experience fracture because of the higher incidence of epilepsy, subsequent AED use and falls (Glick *et al.* 2005). Communication challenges are also prevalent among adults with ID. These challenges make it difficult for people to express their own health needs, discomfort or pain, which in turn can contribute to osteoporotic fracture going undiagnosed. Communication difficulties, especially with comprehension, also contribute to challenges for the person with ID understanding health screening procedures such as DXA. People with ID are very often unfamiliar with DXA and compliance with the specific instructions required for successful scanning do pose problems especially for those with severe or profound ID.

Syndrome-specific risks of poor bone health have also been recognised (Angelopoulou *et al.* 1999; Geijer *et al.* 2014). People with DS are particularly at risk and indeed Angelopoulou *et al.* (1999, 2000) has cited DS as an independent contributory risk factor. People with DS have higher prevalence of endocrine disorders such as hypothyroidism (Jaffe *et al.* 2005). Karlsson *et al.* (1998) in their longitudinal study identified a 33% development of hypothyroidism before the age of 25 years, which in turn can

contribute to poor bone health. McCarron *et al.* (2014) reported that 28% of adults with DS over the age of 40 years had hypothyroidism. As people with DS age, the prevalence of Alzheimer dementia increases rapidly (McCarron *et al.* 2005); the associated epilepsy, increased risk to wander and fall, medications and increased difficulty swallowing combined with the already underlying risks predispose this cohort to further bone compromise.

In addition to complex health conditions, lifestyle factors are also notable contributors to poor bone health. Bone requires stimulation to promote bone turnover; physical inactivity is notable among adults with ID and at a level that does not accrue health benefit (Robertson *et al.* 2000; Beange *et al.* 1999; McCarron *et al.* 2011). Leslie *et al.* (2009) confirm an association with immobility and osteoporosis in adults with ID, which is further supported by Wagemans *et al.* (1998). They note that as a consequence of poor mobility, more than 75% of the cohort had poor bone density despite vitamin D supplementation as a preventative measure. Other contributing behavioural factors include poor dietary habits, which contribute to an overall imbalanced diet and subsequently inadequate vitamin and mineral intake. Poor dietary habits can lead to gastrointestinal disturbance and, coupled with low levels of exercise, can lead to chronic constipation; this in turn affects bone health as chronic constipation can hinder the absorption of vitamins and minerals especially vitamin K in the large bowel, which is crucial in the synthesis of osteocalcin, an element essential in bone mineralisation and calcium ion homeostasis, which is pro-osteoblastic in nature (Weber 2001; Pearson 2007). Further underweight or overweight status is also a reflection of imbalanced diet. Many of these states are prevalent among people with ID (Rimmer *et al.* 2010; Morad *et al.* 2007; Rimmer *et al.* 2007; Yamaki 2005; Emerson 2005).

Consequence of osteoporosis

Osteoporosis is often referred to as the silent thief of bone. The bone demineralisation weakens bone asymptomatically predisposing the bone to an increased risk of fracture, which is the most common outcome of osteoporosis. The most frequently occurring associated fractures are proximal femur, distal radius or vertebral fracture, leading to pain, increased morbidity and loss of independence. Zimmerman *et al.* (1999) reports of the high prevalence of hip fracture among residential settings for the elderly and how this impacts on the quality of life of those who fracture. In fact, Gold (1996) reports that 50% of those over 60 years who present with hip fracture will not regain full independence in their daily activities of living such as washing, dressing or walking unaided.

People with ID are at increased risk for poor bone health, and although some risks are inevitable and unalterable, there are others that may be preventable. The aim of this paper is to identify the prevalence of and associated risk factors for osteoporosis among older adults with ID in Ireland. This opportunity is made possible through the use of the data collected by the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA).

Methods

Study design and participants

Data was drawn from the first wave of the IDS-TILDA study. This study is a national longitudinal study on the health and well-being of adults with an ID as they age. In summary, 753 participants aged 40 years and over, with varying levels of ID, across a range of living circumstances were randomly selected from the National Intellectual Disability Database (Kelly *et al.* 2009). IDS-TILDA is unique insofar as it is harmonised with the Irish Longitudinal Study on Ageing (TILDA), a larger study investigating ageing in the general Irish population (Kenny *et al.*, 2010). The protocol development was informed by a scientific committee and advocacy groups of people with ID, who reviewed and contributed to questions, amendments and the development of easy-read material to assist in understanding the overall study, assist with obtaining consent and understanding the questions. For detailed study methodology, see McCarron *et al.* (2011).

Ethical considerations

Ethical approval for the study was obtained from the Faculty of Health Sciences, Trinity College Dublin and from all the service providers involved in the study. The initial information pack sent to the participants included easy-read information, an easy-read consent and a family support package. A gatekeeper system was employed to preserve the participant's anonymity, and only on return of the signed consent form did

participant names become known to the study. All data collected is stored in adherence with data protection regulations (Government of Ireland 2003).

Data collection

Data was collected using a pre-interview questionnaire (PIQ) and a face-to-face interview. The PIQ was posted to the participants a week in advance of their face-to-face interview. This facilitated the participant having time to collect the required information and gain support for completion if required. The questions on doctor's diagnosis, medication use and healthcare utilisation were within the PIQ. The face-to-face interview utilised computer-assisted interviewing on encrypted laptops. The data collected included a number of modules encompassing, dietary intake and frequency, activity levels along with social connections and community participation, activities of daily living, mental health and psychological well-being. The participant could complete the interview independently, be supported by a key worker or proxy or have the proxy complete the interview on their behalf. The proxy had to have known the participant for at least 6 months or more. In this study, 40.4% completed the face-to-face interview independently, 20.8% completed with support and 38.8% of the interviews were completed by proxy on behalf of the participants.

Statistical analysis

For the purposes of this paper, statistical analysis was conducted using the Statistical Package for Social Sciences (SPSS) version 22 (IBM Corp. 2013). Preliminary analyses were initially carried out, which 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 independent variables were explored stratified by gender, age, level of ID and living circumstance. In keeping with the theoretical frame presented further on in the text (Fig. 1), all variables were tested for significance; however, only significant values are presented. A *P*-value of 0.05 was considered statistically significant. Bivariate correlation for doctor's diagnosis of osteoporosis was calculated with Pearson's coefficient of correlation. Overall relationship between the dependent variable and the statistically significant risk factors and crude odds ratios (ORs) are explored and identified using binary logistic regression analysis.

Identifying risk factors for poor bone health

Taking into consideration the general and ID specific orthopaedic literature (Kanis *et al.* 2013; Kanis *et al.* 2002; Angelopoulou *et al.* 1999; Geijer *et al.* 2014; Gonzalez-Aguero *et al.* 2011), risks for poor bone health associated with people with ID were identified along

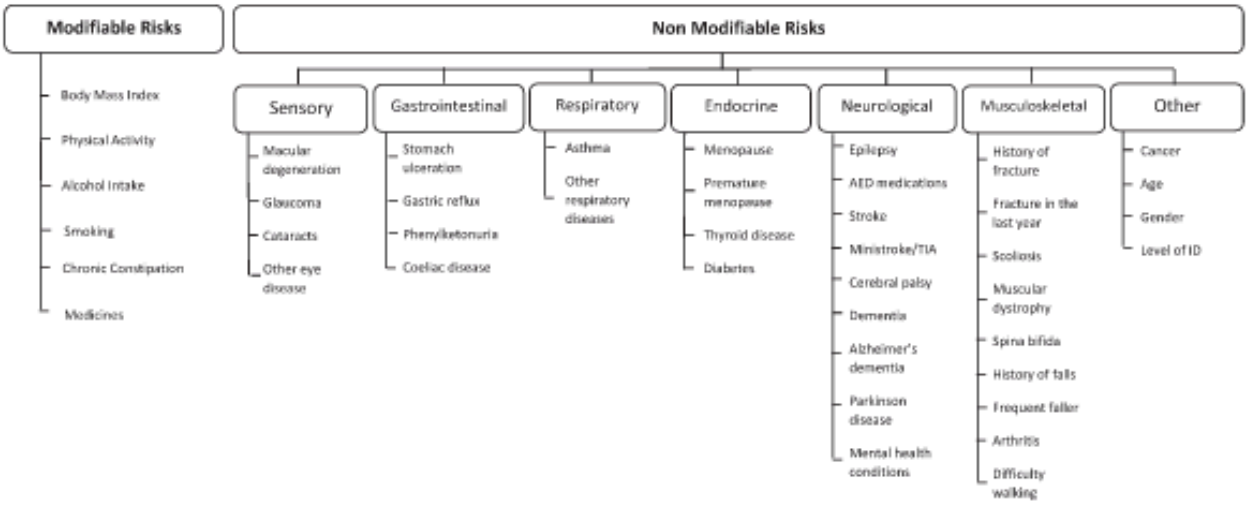

Figure 1 Risk factors for poor bone health.

with the identified risks recognised by the World Health Organisation (World Health Organisation 1994; WHO, 2003) and the associated risks noted by the International Osteoporosis Foundation (IOF); the author compiled a risk factor framework to guide and structure the analysis. These risks were categorised into non-modifiable and modifiable risks with the anatomical systems guiding subcategorisation; see Fig. 1.

Body mass index

People reported their height and weight, and body mass index was calculated based on weight in kilogrammes divided by height in metres squared.

Physical activity

People also reported their level of physical activity (PA) classified by mild, moderate and vigorous PA for 10–20 min, more than once a week, once a week, two to three times a month or hardly ever or never. An overall PA variable was then calculated based on the reported amount of time engaging in PA according to the World Health Organisation (World Health Organization 2010) and Irish recommended guidelines (Health Service Executive 2010)of 150 min per week of moderate-to-vigorous intensity PA.

Results

The prevalence of doctor's diagnosis of osteoporosis for this cohort is 8.1% ($n = 61$). A binary logistic regression revealed those in the older age bracket (65+ years) were six times more likely to have a diagnosis than the younger cohort (40–49 years). Among the most prevalent risks identified were female gender, having difficulty walking and having a diagnosis of arthritis. Reported rates of fractures (20%, $n = 152$) were prevalent among this cohort; nevertheless, rates for DXA screening were low at 16.8% ($n = 65$) with just 11.1% ($n = 43$) of those having had screening within the last 2 years.

Demographics

Table 1 presents a detailed description of the overall sample. The cohort comprised 44.9% ($n = 338$) men and 55.1% ($n = 415$) women between the ages 40 and 90 years. Most people noted their level of ID at a moderate level; however, 58 participants failed to identify their level of ID. The majority of people lived in residential-type setting (more than 10 people residing in one accommodation) with well over half, 69% ($n = 435$), of the participants noting that they had some level of difficulty with verbal communication.

Table 1 Demographic profile of participants

Variable		*f*	%	Total
Gender	Male	338	44.9	753
	Female	415	55.1	
Age (years)	40–49	275	36.5	753
	50–64	344	45.7	
	65+	134	17.8	
Level of ID	Mild	166	23.9	695[a]
	Moderate	323	46.5	
	Severe/ Profound	206	29.6	
Living circumstance	Independent/ Family	129	17.1	753
	Community group home	268	35.6	
	Residential setting	356	47.3	
Difficulty communicating	No difficulty	316	42.1	751[b]
	Some difficulty	154	20.5	
	A lot of difficulty	104	13.8	
	Cannot do at all	177	23.6	
Bone screening (DXA)	Within the last 2 years	43	11.1	389*
	Over 2 years ago	22	5.7	
Attended GP services		692	92.1	751
Attended geriatrician		19	2.5	
Medication use	AEDs	287	38.2	
	Ca and vitamin D supplementation	134	17.8	

$N = 753$.

[a]Obs missing 58 (number of participants who did not identify their level of ID).

[b]Two participants did not answer the question on communication.

*This question was introduced post commencement of the overall study ($n = 477$).

AEDs, antiepileptic drugs; DXA, dual-energy X-ray absorptiometry; GP, general practitioner.

Prevalence and identified risks for osteoporosis

In total 8.1% ($n = 61$) of the participants identified that they had a doctor's diagnosis of osteoporosis. With regards to non-modifiable risks, fracture rates and falls

were moderately high at 20.6% ($n = 152$) and 26.7% ($n = 200$), respectively, with a further 27% ($n = 214$) reporting some level of mobility difficulties and 30.5% ($n = 225$) reporting epilepsy with 38.2% ($n = 287$) prescribed antiepilepsy medications [antiepileptic drugs (AEDs)]. In addition, 57.8% ($n = 238$) of women reported having experienced the menopause with a mean age of onset for 98 participants at 47.02 years, (SD ±5.63). Among the modifiable factors identified were low physical activity levels with over 70% not engaging in the recommended minutes per week; few people reported they currently or previously smoked (15.4%, $n = 116$), with very low numbers of people reporting alcohol use at levels to incur bone interference ($n = 20$). Levels of obesity were high with over 60.7% ($n = 174$) reporting being overweight or obese with a small number of participants reporting underweight status (1.9%, $n = 6$) Finally 17.3% ($n = 130$) reported chronic constipation (see Table 2 for details of all risks identified).

Association of risks and doctor's diagnosis of osteoporosis

These risks were then examined in relation to those who had confirmed a doctor's diagnosis of

Table 2 The prevalence of risk factors for poor bone health and increased fracture risk

Non-modifiable			*f*	%	**Total**
Musculoskeletal	Doctor's diagnosis of osteoporosis		61	8.1	752
	History of fracture		152	20.6	738
	History of falls		200	26.7	748
	Frequent faller		107	16.3	655
	Arthritis		81	10.8	749
	Mobility (walking 100 yards)	No difficulty	537	71.5	751
		Some difficulty	82	10.9	751
		A lot of difficulty	52	6.9	751
		Cannot do at all	80	10.7	751
Neurological	Epilepsy		229	30.5	752
	Anticonvulsant drug use		287	38.2	752
	Cerebral palsy		43	5.7	752
Endocrine	Menopause	Experienced menopause	238	57.8	412
	Mean age at menopause*	47.02 years, (SD ±5.63)			93
	Thyroid disease		110	14.5	752
	Diabetes		61	8.2	747
Gastrointestinal	Gastroesophageal reflux		59	7.8	752
Sensory	All eye diseases~		21	27.1	749
Mental health condition			355	47.5	747
Modifiable					
	BMI	Healthy weight	217	37.2	584
		Overweight/Obese	174	60.7	584
	Chronic constipation		130	17.3	752
	Smoking	Current or past smoker	116	15.4	753
	Medicines	Hypnotics and sedatives	100	13.3	752
		Antidepressants	204	27.1	752
		Anxiolytics	167	22.2	752
	Physical activity	Meets RDA	223	29.7	753
		Does not meet RDA	528	70.3	

Only conditions with a prevalence above 5% are presented, those excluded were scoliosis, CVA, TIA, respiratory conditions, stomach ulceration, PKU, coeliac, all cancers, being underweight, history of alcohol >2 U 3–4 times a week and corticosteroids.

*140 participants did not know their age at menopause

~All eye diseases include macular degeneration, cataracts, glaucoma and other eye conditions

BMI, body mass index; CVA, cerebrovascular accident; PKU, phenylketonuria; RDA, recommended daily allowance; SD, standard deviation; TIA, transient ischemic attack.

Table 3 Associations between doctor's diagnoses of osteoporosis and risk factors

		Doctor's diagnoses of osteoporosis		
	Yes/No	%	*n*	*P*-value
Gender				<0.0001
Male		3.0	337	
Female		12.3	415	
Age (years)				<0.0001
40–49		2.9	274	
50–64		9.0	344	
65+		16.4	134	
Level of ID				0.455
Mild		6.6	11	
Moderate		7.1	23	
Severe/ Profound		9.7	20	
Living circumstance				0.156
Independent/Family		6.2	8	
Community group home		6.3	17	
Residential setting		10.1	36	
Type of ID – Down syndrome		9.5	14	0.455
Non-modifiable risk factors				
History of fracture	Yes	13.2	151	0.008
	No	6.7	586	
Arthritis	Yes	22.2	81	<0.0001
	No	6.6	656	
Difficulty walking 100 yards	Yes	14.6	213	<0.0001
	No	5.6	537	
Epilepsy	Yes	13.5	229	<0.0001
	No	5.6	518	
Antiepileptic drug	Yes	11.8	287	0.003
	No	5.8	464	
Has gone through the menopause	Yes	15.1	238	0.016
	No	6.4	125	
Eye disease	Yes	14.7	163	0.001
	No	6.3	584	
Modifiable risk factors				
Chronic constipation	Yes	15.4	130	0.001
	No	6.6	622	

Candidate variables that violated assumptions of χ^2 test for associations because of expected cell count <5 and are not included were memory impairment/Alzheimer's disease, diabetes, gastroesophageal reflux, smoking, hypnotics and sedatives and antidepressants. All other candidate variables not presented did not achieve statistical significance.

osteoporosis ($n = 61$). As outlined in Table 3, the most significant association with osteoporosis was older age ($P < 0.0001$), female gender ($P < 0.0001$), difficulty walking ($P < 0.0001$) and a history of arthritis ($P < 0.0001$). Strong statistical associations were also observed for those who had a diagnosis of epilepsy and were on AEDs ($P < 0.0001$).

Binary logistic regression

A binary logistic regression was conducted to examine the influencing factors for doctor's diagnosis of osteoporosis; all odds ratios presented are crude ORs. There is a definitive age gradient observed with those in the older age group almost six times more likely to have a diagnosis of osteoporosis than those in the younger age group (OR = 6.53; 95% confidence interval (CI) 2.82–15.110). Women are over four times more likely to have a diagnosis (OR = 4.58; 95% CI 2.29–9.17) as were those with arthritis (OR = 4.07; 95% CI 2.21–7.48). Other significant factors can be observed in Table 4.

Consequences of osteoporosis

A foreseeable consequence of osteoporosis is fracture; an outline in Table 5 provides the profile of those who reported a history of fracture (20.6%, $n = 152$).

Table 4 Binary logistic regression for osteoporosis diagnosis

Risk factors		Crude OR	*P*-value	CI
Gender	Male	1	1	
	Female	4.582	<0.0001	2.289–9.172
Age	40–49	1	1	
	50–64	3.293	0.003	1.488–7.287
	65+	6.531	<0.0001	2.823–15.110
History of fracture		2.141	0.009	1.209–3.793
Arthritis		4.073	<0.0001	2.217–7.483
Epilepsy		2.547	0.001	1.501–4.320
AEDs		2.175	0.004	1.282–3.690
Difficulty walking		2.879	<0.0001	1.695–4.889
Experienced menopause		2.606	0.019	1.172–5.796
Eye disease		2.553	0.001	1.478–4.408
Chronic constipation		2.576	0.001	1.454–4.566

AEDs, antiepileptic drug; CI, confidence interval; OR, odds ratio.

Table 5 History of fracture in association with risk factors

Variables		History of fracture	*f*	%	Number in sample	*P*-value
Gender						0.965
	Male		68	20.7	329	
	Female		84	20.5	409	
Age (years)						0.395
	40–49		47	17.8	264	
	50–64		74	21.8	340	
	65+		30	22.6	133	
Level of ID						0.830
	Mild		36	22.0	164	
	Moderate		63	19.9	317	
	Severe/Profound		39	19.6	199	
Living circumstance						0.488
	Independent/family		31	24.2	128	
	CGH		50	19.0	263	
	Residential setting		71	20.5	347	
Type of ID						0.018
	Down syndrome		19	13.4	142	
	Non-Down syndrome		133	22.3	596	
Other risk factors						
	Doctor's diagnosis of osteoporosis	Yes	20	33.9	59	0.008
		No	131	19.3	678	
	Epilepsy	Yes	64	28.4	225	<0.0001
		No	87	17.2	507	
	Antiepileptic drug	Yes	80	28.5	281	<0.0001
		No	72	15.8	456	
	History of falls	Yes	65	43.0	197	<0.0001
		No	86	16.0	537	
	Frequent fallers	Yes	39	31.2	105	<0.0001
		No	86	16.0	537	
	Cerebral palsy	Yes	16	10.6	42	0.004
		No	135	19.4	695	
	Difficulty walking	Yes	67	31.8	211	<0.0001
		No	85	16.2	526	

CGH, community group home.

Proportionately, slightly more people with ID in the older age group (65+ years) reported having a history of fracture than those in the younger (40–49 years) or middle age group (50–64 years) at 22.6 % versus 17.8% and 21.8%, respectively. Of those who reported fracture, 12.5% ($n = 19$) had DS with 8.9% fracture rate difference between those with and without DS (13.4% versus 22.3%). There was no gender difference with fractures reported at 20.7% in men versus 20.5% in women. The highest reported type of fracture was hip fracture at 12.6% ($n = 19$), with no reports of vertebral fracture; similarly, hip fracture was the highest reported type of fracture for those with DS (23%, $n = 5$). Proportionately, there were slightly more ,fracture reports among those with mild level of ID and those living at home (22.0% and 24.2%) respectively.

Having epilepsy, being on AEDs, having difficulty walking and having a diagnosis of cerebral palsy were the most strongly associated factors with having experienced a previous fracture ($P < 0.0001$). In this study, the reported prevalence for epilepsy was 30% ($n = 229$), and of those, 4 in 10 reported a history of fracture, and the associated risk of epilepsy with osteoporosis was strongly significant ($P < 0.0001$); reported AEDs medication usage was 38% ($n = 287$)

also significantly associated with fracture ($P < 0.0001$). For those who had a diagnosis of epilepsy, 13.5% ($n = 31$) reported a diagnosis of osteoporosis. As would be expected, being a frequent faller or having a history of falling ($P < 0.0001$) and osteoporosis ($P = 0.008$) were also strongly associated with a history of fractures.

Prevention and diagnosis

Almost one-sixth of people (17.8%, $n = 136$) were taking calcium/vitamin D supplementation; the majority were female (74.3%, $n = 101$), were within the middle age bracket of 50–64 years (47.8%, $n = 65$) and predominantly lived in residential-type setting (63.7%, $n = 86$). For those who had a doctor's diagnosis of osteoporosis, 70.5% ($n = 43$) were prescribed calcium/vitamin D, which means 3 in every 10 with a diagnosis of osteoporosis were not prescribed these preventative measures. Of all those who had experienced a fracture over three quarters, 75.7% were not prescribed vitamin D, calcium or a combination. In total, over 38% ($n = 284$) did not drink milk, one of the best sources of dietary calcium.

The majority of participants (92.1%, $n = 692$) reported they attended general practitioner services in the last year; however, very few (2.5%, $n = 19$) reported utilising specialist like geriatrician services, and the majority of whom were over the age of 65 years ($n = 12$). Interestingly, 92.5% of the men and 86.0% of the women did not have a DXA within the last 2 years; similarly, over 86% of those over 50 years had not attended for DXA and 81% of those over 65 years. The most statistically significant factor associated with non-attendance for DXA was difficulty mobilising ($P = 0.004$). See Table 6 for profile of those prescribed vitamin D and/or calcium and factors associated with non-attendance for DXA screening.

Discussion

Despite advances in diagnosis and prevention of osteoporosis, this study shows that people with ID present with many risks similar to the general population that increase the likelihood of reporting a diagnosis of osteoporosis. However, for people with ID, there are also additional risks such as epilepsy, AEDs prescription, early menopause among the women and genetic factors such as DS. Commonly identified risk factors observed among the general population, such as smoking, alcohol and corticosteroid use, are not consistently observed at rates to warrant concern.

Bone health is fundamental to ageing well, and the maintenance of good bone health plays a vital role in achieving a healthy old age (World Health Organization 2002). In this study, just 8.1% presented with osteoporosis; however considering the insidious nature of the condition and the high worldwide prevalence (Kanis *et al.* 2012; Odén *et al.* 2015), the figure in this study is most likely an underestimation, especially considering estimated prevalence among people with ID varies from 17.1% (Zylstra *et al.* 2008) to 43.9% (Bastiaanse *et al.* 2014) in other reported studies. However, caution must be exercised when considering these figures as prevalence can vary considerably depending on the methodology and definition applied. Nevertheless, it is reported that people with ID present with increased risk of low bone mineral density (Aspray *et al.* 1998; Center *et al.* 1998; Baptista *et al.* 2005; Jaffe *et al.* 2005) and that osteoporosis continues to be under diagnosed and undertreated in the older population (Jasien *et al.* 2012), which supports the results of this study. This is not surprising then considering that Srikanth *et al.* (2011) report that the one area often neglected in physical health exams for people with ID is bone health status.

Worldwide osteoporosis is of concern especially for women (Compston *et al.* 2013). Meunier *et al.* (1999) recommend assessment of all women on cessation of menstruation. Over 57% of the women had experienced the menopause by an average age of 47 years, lower than the 52 years reported by the Health Service Executive (2008), and women in this study were found to be four times more likely to have a diagnosis, yet 86% of the women were not screened for osteoporosis. Such lack of investigation exposes the women with ID to an increased likelihood of experiencing fracture, an absolutely preventable consequence of osteoporosis, potentially leading to devastating consequences for quality of life, independence and physical and psychological well-being. However, in saying that, assessment can be fraught with difficulties for people with ID (McCallion & McCarron 2004). From fear of unfamiliar procedures, difficulty understanding

Table 6 Factors associated with non-attendance for DXA and profile of those on vitamin D/calcium prescription

Variables		Did not attend for DXA* in the last 2 years					Prescribed vitamin D/calcium				
		Yes/No	*f*	%	Number in sample	*P*-value	*f*	Yes/No	%	Number in sample	*P*-value
Gender						0.043					0.0001
	Male		161	92.5	174		35		10.4	336	
	Female		185	86.0	215		101		24.2	417	
Age						0.010					<0.0001
	40–49		141	94.6	149		29		10.6	274	
	50–64		151	86.8	174		65		18.9	344	
	65+		54	81.8	66		42		31.3	134	
Level of ID						0.827					0.350
	Mild		90	88.2	102		25		15.1	166	
	Moderate		151	89.9	168		66		20.4	323	
	Severe/Profound		80	90.9	88		38		18.4	206	
Living circumstance						0.120					<0.0001
	Independent/family		84	94.4	89		9		7.0	129	
	CGH		136	88.9	153		40		15.2	264	
	Residential setting		126	85.7	14		86		24.2	356	
Other factors											
	Doctor's diagnosis of osteoporosis	Yes	11	39.3	28	0.0001	43	Yes	70.5	61	0.0001
		No	335	92.8	361		93	No	13.5	691	
	Difficulty walking	Yes	76	80.9	94	0.004	53	Yes	24.8	214	0.002
		No	269	91.5	269		82	No	15.3	537	
	AEDs	Yes	113	84.3	255	0.035	76	Yes	26.5	287	<0.0001
		No	233	91.4	134		60	No	12.9	465	
	History of fracture	Yes	64	83.1	77	0.073	37	Yes	24.3	152	0.026
		No	279	90.3	309		97	No	16.6	586	
	Epilepsy	Yes	88	84.6	104	0.100	71	Yes	31.0	229	<0.0001
		No	258	90.5	285		65	No	12.5	518	
	Menopause	Yes	97	82.9	117	0.103	76	Yes	31.9	238	<0.0001
		No	64	91.4	70		19	No	15.2	125	
	History of falls	Yes	86	91.5	94	0.362	49	Yes	24.5	200	0.007
		No	259	88.1	294		87	No	15.9	548	

*This question was introduced post commencement of survey
AED, antiepileptic drug; DXA, dual-energy X-ray absorptiometry.

complex test such as DXA, inaccessibility of equipment and environments, to difficulty in expressing their own health needs, all hinder or prevent people with ID engaging in assessment. These difficulties may form the basis of why it is noted that overall, people with ID are less likely to have routine screening (Michael 2008) despite experiencing poorer health. Non-attendance at DXA screening is very evident in this study regardless of age or level of ID. Perhaps, challenges experienced account for the low attendance especially considering that having a mobility difficulty was the most statistically significant factor ($P = 0.004$) for not attending for DXA. Lying in a specific position for a certain length of time poses challenges along with following precise instruction requiring a level of understanding that may be all too difficult for some people with ID. Therefore, what is deemed as the gold standard for diagnosis (DXA) may not be suitable for people with ID. Perhaps, these gold standards need to be rethought for people with ID and alternatives, such as the QUS, investigated and employed. Those who lived at home were also more likely not to engage in DXA screening; however, this could possibly be because those at home were generally younger. Overall, levels of DXA scans were low, a finding similar to Dreyfus *et al.* (2014) who suggest the need for service provider awareness. Screening recommendations vary considerably, and there are no specific recommendations for people with ID in Ireland. Because of policy change (Health Service Executive 2011), large residential-type living and service delivery are changing, and people with ID are moving to integrated community living. Here, they are accessing community primary healthcare professional who may be delivering care to people with ID for the first time. Considering that some people with ID require a proxy to identify healthcare needs, educating physicians and caregivers are critical in light of the increased risk of osteoporosis in this population.

People with ID very often have more complex health needs and frequently present with older age conditions at a much younger age. These presentations could benefit from comprehensive assessment by specialist geriatric services that are skilled in the multidimensional diagnostic process, which contributes to the development of co-ordinated and integrated plans of care. However, these services are commonly chronologically determined, with those aged 65 years and over only having access. This immediately excludes those below this age despite presenting with older age conditions and may account for the small numbers in this study (2.5%) accessing such specialist services. It is unfortunate as perhaps if these services were expanded to include younger age groups of people with ID, accessing such co-ordinated multidisciplinary assessment earlier could facilitate earlier identifications of potential risk of older age conditions and comprehensive care pathways instigated.

The deterioration of the bone tissue associated with osteoporosis is reported to lead to increased bone fragility and risk of fracture particularly of the hip, vertebrae and wrist (International Osteoporosis Foundation (IOF) 2012). Hip fracture rates are reported just over three times higher at 12.9% than those reported by the general population study TILDA at 3.6% (Cronin *et al.* 2011). Hip fractures can have devastating consequences on quality of life and independence and deplete an already compromised functional ability, which is the case for many people with ID. Often, the strict rehabilitation regimes are difficult for people with ID to follow, and compliance becomes an issue, resulting in further loss of independence. The rates of fracture among those with DS is also substantially higher than those of the general population highlighting the need for robust assessment of those with DS, which Angelopoulou *et al.* (1999) note as an independent risk for osteoporosis. It would be prudent for healthcare professionals to consider history of fracture when planning fracture prevention strategies in light of the potential of an increased likelihood of future fractures where history of fracture exists (Holloway *et al.* 2015). One of the most intriguing findings in this study is the fact that there is very little difference in the fracture rates between men and women. Previous studies (da Silva *et al.* 2010; Baptista *et al.* 2005) have also identified high prevalence of low bone density among men especially those with DS, and the findings here further confirm the misconceptions that there is greater prevalence in women, which necessitates further investigations.

In this study, the high reported prevalence of epilepsy (30.5%) and AED medication use (38.2%) along with substantial levels of reported history of fracture is concerning considering that the reported

levels of osteoporosis are relatively low. It is known that AED medication interferes with bone metabolism, thus compromising bone health. It is commonly assumed that fracture rates increase because of seizural activity, which does expose the person to increased falls risk (Sato *et al.* 2001); however, fracture rates have been shown to increase independently of seizure activity (Mattison and Gilda, 2004). It is quite probable that in this study, osteoporosis is underdiagnosed and the bone compromise is increased in the presence of AED medication leading to increased fracture risk.

Bone is living tissue that requires stimulation to promote bone turnover and resorption making PA an important factor to prompt this process. In this study, for 70.3% ($n = 528$) of people, PA levels were not at a level sufficient to accrue health benefit. Moreover, ambulation has been reported to play a significant role in helping limit the development of osteoporosis among people with ID (Tyler *et al.* 2000; Zylstra *et al.* 2008), and in this study, those reporting difficulty with walking were three times more likely to report a doctor's diagnosis of osteoporosis (OR 2.9, $P < 0.0001$, CI 1.695–4.889). Of those with mobility difficulty, almost 1 in 5 ($P < 0.0001$) reported a diagnosis of osteoporosis, and 3 in 10 reported a history of fracture ($P < 0.0001$). Engaging in PA is challenging for the best of us; it requires motivation and encouragement to participate and commitment to stay engaged sufficiently as to make it part of one's lifestyle and promote change. Those who can engage in PA ought to be encouraged to do so, which requires effort and education for service providers, carers and the person themselves. Difficulty with mobilising presents challenges for a substantial cohort in this study (28.5%, $n = 214$). People with difficulty or who are not able to mobilise at all are dependent on secondary assistance. Educational programmes for carers and alternative activities to promote muscle strength and resistance that will stimulate bone turnover ought to be devised. Considering the low levels of exercise identified among this cohort and the positive consequences of introducing or increasing exercise regimes in people's lives, it is recommended that consideration should be given to improving lifestyle behaviours such as the introduction of physical activity programmes. These would also have the additional benefit of improving the overall muscular status of the person, improving balance and contributing to a reduction in the potential for falls. It is interesting that those who reported eye disease were over two and half times more likely to report osteoporosis (OR 2.553, $P = 0.001$, CI 1.478–4.408). Eye disease has no direct correlation with osteoporosis, however, is associated with falls risk and is highly prevalent among older adults with ID; in fact, previously, McCarron *et al.* (2013) established a 71% prevalence of multimorbidity with eye disease identified as one of the highest occurring conditions. Therefore, physical activity could also potentially contribute benefit to those who present with multimorbidity who may possibly be frailer. Another emerging condition, chronic constipation, was also significant in the presence of osteoporosis. A possible explanation is perhaps that this is reflective of an imbalanced diet and may be reflective of inequity in the overall diet of the participant; chronic constipation could possibly affect vitamin and mineral absorption and having an effect on appetite further contributing to dietary imbalance and if left long-term effect bone health.

Another contributing factor to poor bone health identified in this study are the low levels of vitamin D supplementation. Ireland is a northern hemisphere country and, as such, does not experience sufficient sunlight to promote adequate natural vitamin D synthesis; therefore, the Food Safety Authority of Ireland has recommended supplementation for all citizens. However, it was evident in this study that very few people (17.8%, $n = 136$) were on vitamin D supplementation. It is concerning that 3 in every 10 people with a diagnosis of osteoporosis were not prescribed this first line preventative and that over three quarters of those who had a history of fracture were not on vitamin D, calcium or a combination. It is known that having a history of fracture is a risk for future fracture and considering that over 38% did not drink milk, supplementation ought to be investigated. By comparison, in the data reported by TILDA for the general population, calcium and vitamin D was the most commonly reported food supplement, used by 31.4% of those who used food supplements (Peklar *et al.* 2013).Vanlint & Nugent (2006) note vitamin D insufficiency is more prevalent among people with ID than the general population. However, Hirani & Primatesta (2005) report vitamin D deficiency at alarming levels among the general older population living in nursing homes. This is particularly

concerning for people with ID who may have lived most or part of their lives in an institutional setting. Further, the levels of AED use noted in this study are likely to have a negative impact on vitamin D levels. Despite the evidence of higher levels of supplementation among the TILDA participants, their initial survey did not include people living in nursing homes (Barrett *et al.* 2011).

For people with ID, both receptive and expressive communication challenges pose difficulty (Kevan 2003). Over half of the cohort (58%, $n = 435$) had difficulty in communicating, with almost half of those (23.6%, $n = 177$) reporting not being able to verbally communicate at all. McCarron *et al.* (2011) note that people with ID have some of their greatest challenges communicating with the health profession. McCarron *et al.* (2011) also noted that people with ID too rarely receive easy-read information on their health or engage in health promotion contributing to reduced healthcare access for people with ID and health conditions going unrecognised and under treated (Bergström *et al.* 2014; McCarron *et al.* 2011; Kerr 2004). The vast majority of people with ID are dependent on others to manage their health need. If these carers themselves are unaware of the unique risks of osteoporosis very often, barriers to healthcare are widened, and inequalities increase (Cooper *et al.* 2004).

This study supports further investigation of the bone health of people with ID and warrants systematic objective measurement of bone status utilising alternate methods focused specifically for people with ID.

Strengths and limitations

Undoubtedly, the greatest strength of this study is the number of participants who contributed to the data. This study is based on the participants self-report of their doctor's diagnosis of osteoporosis from their clinical files, and whilst opportunity was afforded to participants to access their medical files for accuracy, no objective measures were conducted by the researcher. This study however confirms that the inclusion of objective measurement could contribute further to identifying specific risks among older adults with ID. Because of small numbers, specific variables such as cerebral palsy and scoliosis, which in all likelihood contribute to the presence of osteoporosis, were excluded for some analysis. Finally, the question on DXA screening was introduced post commencement of the study; however on correlation analysis, pairwise analysis command was utilised; thus, only completed cases are represented.

Conclusion

Despite high levels of risk, the reported level of doctor's diagnosis of osteoporosis was low, and considering the insidious nature of osteoporosis, one could only suspect that there is a hidden and undiagnosed level of osteoporosis among this cohort. The clinical outcome of poor bone health is fracture, an event that results in unnecessary pain, physical disability and economic consequence impacting on people's daily living activities, quality of life and ultimately quality of life years lived. The findings here support a need for robust risk assessment, for regular checks and for clinical practitioners to not only seek the obvious risk factors but also consider the specifics for ID. Further, although some risks are unalterable and inevitable such as AEDs required for epilepsy or the fact that the person has DS, there are amenable factors that require attention. Addressing inactivity, vitamin D supplementation, dietary balance and risks for falls recommendations may contribute to the amelioration of this silent and, if left unhindered, debilitating disease. Further exploration of bone health is required to establish a robust picture of the skeletal status of people with ID, and with some creative vision, osteoporosis does not have to be inevitability of old age for any citizen.

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