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**Prevalence, types, and associations of medically unexplained symptoms and signs. A cross-sectional study of 1,023 adults with intellectual disabilities**

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## **Abstract**

### **Background**

Medically unexplained symptoms and signs are common in the general population, and can respond to appropriate managements. We aimed to quantify the types and prevalence of unexplained symptoms and signs experienced by adults with intellectual disabilities, and to determine the associated factors.

### **Method**

In a population-based study, 1,023 adults with intellectual disabilities aged 16 and over had a detailed health assessment which systematically considered symptoms and signs. Descriptive data were generated on their symptoms and signs. Backwards stepwise logistic modelling was undertaken to determine the factors independently associated with unexplained symptoms.

### **Results**

Medically unexplained symptoms and signs were present in 664 (64.9%), 3.8 times higher than in the general population, and 470 (45.9%) had multiple unexplained symptoms or signs. Some were similar to those reported in the general population, such as dyspnoea, dyspepsia, headache, nausea, dizziness. However, others are not commonly reported in the general population, including dysphagia, ataxia, polyuria, oedema, skin rash. Having unexplained symptoms and signs was independently associated with older age, female gender, not having Down syndrome, extent of intellectual disabilities, and more GP visits in the last 12 months. It was not associated with living in deprived areas, type of living/support arrangements, number of hospital visit in the last 12 months, smoking, autism, problem behaviours, or mental disorders.

## **Conclusions**

People with intellectual disabilities have substantial additional unexplained symptoms and signs, some of which are painful or disabling. These findings should inform the content of health checks undertaken for adults with intellectual disabilities, which should not just focus on management of their long term conditions and health promotion.

## **Keywords**

Intellectual disabilities, medically unexplained symptoms and signs, health, health checks

## **Introduction**

People with intellectual disabilities face significant health inequalities. They have a high prevalence of health problems and a shorter life expectancy than the general population (NHS Health Scotland, 2004; Emerson & Baines, 2010). Not only are their levels of health needs higher than the general population, their patterns of health needs are different and their health needs are often unmet (Cooper et al. 2004; Baxter et al. 2006; Emerson & Baines, 2010; Cooper et al. 2014). They are known to experience specific disorders at a higher rate than the general population, such as epilepsy, psychosis, gastro-oesophageal reflux disorder, constipation, sensory impairments (Cooper et al. 2015), but less is known about the symptoms and signs they experience that have no identified medical cause.

Medically unexplained symptoms are a relatively common presentation of the general population in primary health care settings, comprising between 15-19% of consultations (Mumford et al. 1991; Peveler et al. 1997). Examples include

abdominal pain, backache, headache, pelvic pain, functional bowel symptoms, dizziness and fatigue. Although thorough medical investigation of such symptoms results in a high proportion remaining unexplained, there are management approaches which can be helpful, including acknowledgement of the problem, reassurance, identification of stressors, antidepressants, and psychological approaches (Burton, 2003; Schweitzer, 2006). Hence, identification and then intervention for these disorders is important to reduce suffering. Whether medically unexplained symptoms have the same presentations, and are as common, in people with intellectual disabilities is unknown.

Although health checks for the general population have been shown to be ineffective (Krogsbøll et al. 2010), three randomised control trials from Australia and Scotland have demonstrated that health checks may be useful for people with intellectual disabilities who are a high risk population for unmet needs (Lennox et al. 2007; Lennox et al. 2010; Cooper et al. 2014). However it is unclear what these health checks should include for maximum benefit, particularly with regards to symptoms and signs. In England, health checks for people with intellectual disabilities are funded as part of the services that general practitioners can opt into providing for their registered patients; but the content of these health checks is not prescribed. A study of these health checks has found that they tend to focus on management of long term conditions, on which there has also been considerable recent emphasis in the general practitioner contract (Chauhan et al. 2010). This has benefits as it is likely to be associated with longer term health gains, but also brings a potential disadvantage, as this part of the general practitioner contract (the Quality and Outcomes Framework) is an approach directed by evidence on the needs of the general population, rather than those that might be particularly pertinent for people with intellectual disabilities.

This study aims to describe the prevalence of unexplained symptoms and signs experienced by people with intellectual disabilities, through a large-scale, population based study, and to identify the factors independently associated with them. This will help to inform the development of health check materials to include the common symptoms and signs amongst people with intellectual disabilities (in addition to the current approach of management of common long-term health conditions).

## **Methods**

Adults with intellectual disabilities were recruited to the study from part of the Greater Glasgow Health Board area, Scotland. They were aged 16 and over, and identified through an extensive process via primary healthcare services, the Health Board, local specialist intellectual disabilities health services, social work services for people with intellectual disabilities, day services, and local authority funding arrangements for persons receiving paid support of any kind. All of Greater Glasgow's 631 general practitioners were paid a fee for each person registered with them who they identified for the project. Methods are described in greater detail elsewhere (Cooper et al. 2007). Individual consent to participate was taken from each participant. For participants who lacked capacity to consent, consent was taken from the nearest carer, in keeping with Scottish law.

Each participant was assessed by a registered nurse and a general practitioner. The team of six registered nurses had specialist qualifications in working with adults with intellectual disabilities and were trained in the use of the assessment instruments. The three general practitioners had a special interest in working with adults with intellectual disabilities. Each participant's primary health care case notes were reviewed using a semi-structured format, prior to a detailed face to

face assessment. The face to face assessment was conducted with support from the person's paid or family carer. The assessment was conducted using the *C21st Health Check*, which was designed specifically for use with adults with intellectual disabilities, and provides a comprehensive list of symptoms and signs that are systematically enquired about and examined for. A purpose-designed demographic form was used to collect information on demographic factors. Level of intellectual disabilities was determined by scores on the Vineland Scale (Survey Form) (Sparrow et al. 1984), and the *C21st Health Check*. The assessment process took about 4 hours per participant.

Two academic physicians (a general practitioner and an intellectual disabilities psychiatrist) jointly reviewed the symptoms and signs known prior to the assessment and discovered through it, against participants' elicited medical diagnoses, and classified them as either explained or unexplained. They followed the symptom list included in the International Statistical Classification of Diseases, 10<sup>th</sup> Revision (World Health Organisation, 1992), chapter XVIII (symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified). The analysis was conducted using SPSS 22.0. Descriptive data were obtained for the prevalence of symptoms and signs. Associations were investigated using binary logistic regression. The backwards stepwise model was used, with the covariate with the least impact on the outcome variable being removed at each step. Associations were investigated between the dependent variable of presence of unexplained symptoms and signs, and the independent variables of age, gender, level of ability, smoking status, autism spectrum disorders, problem behaviours, mental ill health of any type (excluding autism spectrum disorders, problem behaviours and specific phobias), type of living/support arrangement, Down syndrome, and area based measure of deprivation of person's residence.

## **Results**

Assessments were completed for 70.6% of the eligible population. Of these, valid consent was recorded for 92.7%. This resulted in a sample of 1,023 adults. 562 (54.9%) were men, and 461 (45.1%) were women, with a mean age of 43.9 (range 16-83). 398 people (38.9%) had mild intellectual disabilities, 248 had moderate (24.2%), 193 (18.9%) had severe, and 184(18.0%) profound intellectual disabilities. The cause of intellectual disabilities was Down syndrome for 186 people (18.2%). 390 (38.1%) people lived with a family carer, 467 (45.7%) with paid carer support, 102 (10.0%) lived independently without a carer, and 64 (6.3%) lived in a congregate care setting.

A total of 1,734 individual symptoms and signs were present. 769 (44.3%) of these symptoms and signs were known about and had been presented to the GP prior to the assessment. Of these 1,734 symptoms, 1,386 (79.9%) were medically unexplained and 348 (20.0%) were explained.

The overall prevalence of symptoms and signs (explained and unexplained) was 71.5% (731 people); 664 (64.9%) had at least one medically unexplained symptom or sign, and 263 (25.7%) had at least one explained symptom or sign. Table 1 reports the types of symptoms and signs experienced, and their prevalence. It displays the prevalence of unexplained and explained symptoms and signs individually, with the final column representing the overall prevalence of the symptom or sign (the sum of the previous two columns). The most prevalent unexplained symptoms and signs were ataxic gait/gait disorders (16.9%), dysphagia (12.3%), oedema (11.2%), and skin rash/swelling (10.0%).

- insert table 1 about here -

### *Medically unexplained symptoms and signs*

Table 2 reports the frequency (percentage) of the number of symptoms and signs experienced. It displays the frequency (percentage) of people with each number of unexplained symptoms/signs (Column 2) and explained symptoms/signs (column 3). In column 4, it displays the frequency (percentage) of people with each total number of unexplained or explained symptoms and signs. For example, a person could have 11 total unexplained or explained symptoms in column 4 if they had 5 unexplained symptoms/signs and 6 explained symptoms/signs, or if they had 8 unexplained symptoms/signs and 3 unexplained symptoms/signs; to have no total unexplained or explained symptoms/signs, they would have to have zero unexplained and zero explained symptoms/signs. (Column 4 is therefore not a sum of the preceding two columns.) 470 (45.9%) of people experienced multiple (2 or more) unexplained symptoms and signs.

- insert table 2 about here -

Table 3 presents the factors independently associated with the presence of unexplained symptoms and signs. 14 participants (1.4%) had missing data and were excluded from the analysis. The presence of unexplained symptoms and signs was independently associated with: older ages but not after age 75 years, female gender, not having Down syndrome, a higher number of general practitioner visits in the last 12 months, and having profound intellectual disabilities. It was not associated with living in areas of neighbourhood deprivation, type of living/support arrangements, smoking status, autism spectrum disorders, problem behaviours, mental disorders, or number of hospital visits in the last 12 months.

- insert table 3 about here -

## **Discussion**

In this study, the prevalence of medically unexplained symptoms and signs in adults with intellectual disabilities was 64.9%, and 45.9% had multiple unexplained symptoms or signs, which is much higher than that encountered in the general population. Hence, in addition to having a high prevalence of diagnosed health problems, the majority of adults with intellectual disabilities experience symptoms and signs that are medically unexplained. A number of these are painful and/or disabling, and drawing on findings about medically unexplained symptoms in the general population, many might be improved if properly managed (Burton, 2003; Schweitzer, 2006). Despite the very high prevalence, this is surprisingly an area of health need that has not previously attracted attention for adults with intellectual disabilities.

This level of medically unexplained symptoms and signs is 3.8 times higher than that reported in the general population (Mumford et al. 1991; Peveler et al. 1997). The assessment uncovered symptoms and signs that had not been previously attended to by the persons GP, even though the individuals with medically unexplained symptoms and signs were more frequent attenders to their GPs than those without such symptoms. Prior to the assessment, the rate of medically unexplained symptoms and signs known to the GPs was 1.7 times higher than that seen in for the general population.

Some of the unexplained symptoms and signs we found are similar to those commonly reported in the general population, such as dyspnoea, dyspepsia, headache, nausea, dizziness (Mumford et al. 1991; Peveler et al. 1997). However, others are not commonly recognised in the general population, including dysphagia, ataxia, polyuria, oedema, skin rash. This might suggest a

lower level of medical care for the adults with intellectual disabilities with regards to these conditions, or alternatively reflects differences in their patterns of presentation. In either case, it highlights that the role of health checks should not be just in the management of long term conditions and health promotion, but in actively reviewing symptoms and signs, offering further investigation where indicated, and providing supportive management for medically unexplained symptoms. Our findings also offer some guidance to the types of symptoms and signs that should routinely be incorporated into enquiries and examinations conducted in health checks for adults with intellectual disabilities.

In keeping with findings in the general population, females and frequent general practice attenders were more likely to have unexplained symptoms and signs. Contrary to the general population, older rather than younger, people were more likely to have these symptoms, but not over the age of 75 years (although there were only 16 adults with intellectual disabilities in this oldest age category). There was a gradient in odds ratio across the levels of intellectual disabilities, though this was only statistically significant at the level of profound intellectual disabilities. The complexity of health needs of people with profound intellectual disabilities might contribute to them having higher levels of unexplained symptoms and signs than adults at other levels of intellectual disabilities. The association between not having Down syndrome and unexplained symptoms/signs may be due to the lower overall levels of mental health problems in Down syndrome (Mantry et al. 2008), and a higher awareness of health professionals and carers of the physical complications of Down syndrome.

Strengths of the study are the systematic, comprehensive, and detailed assessment of health symptoms and health conditions, the comprehensive case ascertainment, large sample size, and high participation rate. A limitation of the study is the low R-squared value (17.4%) of the regression model. This indicates

that the model does not explain a great deal of the variability in the presence of unexplained signs and symptoms.

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**Table 1 – Prevalence (%) of types of symptoms and signs**

<b>Symptom</b>	<b>Unexplained (n=1,023)</b>	<b>Explained (n=1,023)</b>	<b>Total (n=1,023)</b>
Dyspnoea/wheezing	89 (8.7%)	42 (4.1%)	131 (12.8%)
Chest pain	39 (3.8%)	0	39 (3.8%)
Purulent sputum	1 (0.1%)	2 (0.2%)	3 (0.3%)
Haemoptysis	2 (0.2%)	0	2 (0.2%)
Nausea and vomiting	46 (4.5%)	21 (2.1%)	67 (6.6%)
Abdominal pain	38 (3.7%)	41 (4.0%)	79 (7.7%)
Dyspepsia	83 (8.1%)	14 (1.4%)	97 (9.5%)
Dysphagia	126 (12.3%)	21 (2.1%)	147 (14.4%)
Abdominal mass	3 (0.3%)	3 (0.3%)	6 (0.6%)
Jaundice	2 (0.20%)	0	2 (0.2%)
Change in bowel habit	1 (0.10%)	1 (0.1%)	2 (0.2%)
Neurological symptoms	22 (2.2%)	5 (0.5%)	27 (2.6%)
Headache	74 (7.2%)	3 (0.3%)	77 (7.5%)
Involuntary tremor and movement disorders	59 (5.8%)	13 (1.3%)	72 (7.0%)
Ataxic gait/gait disorders	173 (16.9%)	133 (13.0%)	306 (29.9%)
Disorders of micturition	34 (3.3%)	1 (0.10%)	35 (3.4%)
Haematuria	41 (4.0%)	0	41 (4.0%)
Polyuria	87 (8.5%)	0	87 (8.5%)
Other disorders of micturition (excluding incontinence)	32 (3.1%)	4 (0.4%)	36 (3.5%)
Dizziness/syncope	42 (4.1%)	1 (0.1%)	43 (4.20%)
Rhythm disorder	1 (0.1%)	1 (0.1%)	2 (0.2%)
Blood pressure	82 (8.0%)	1 (0.1%)	83 (8.1%)

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Cyanosis	1 (0.1%)	0	1 (0.1%)
Oedema	115 (11.2%)	2 (0.2%)	117 (11.4%)
Anorexia	60 (5.9%)	19 (1.9%)	79 (7.7%)
Malaise and fatigue	18 (1.8%)	2 (0.2%)	20 (2.0%)
Skin Rash/swelling	103 (10.0%)	13 (1.2%)	116 (11.3%)
Other	4 (0.4%)	0	4 (0.4%)
Other pain	8 (0.8%)	5 (0.5%)	13 (0.8%)
<b>Any symptom or sign</b>	<b>664 (64.9%)</b>	<b>263 (25.7%)</b>	<b>731 (71.5%)</b>

**Table 2 – Prevalence (%) of number of symptoms and signs**

<b>Number of symptoms and signs</b>	<b>Unexplained (n=1,023)</b>	<b>Explained (n=1,023)</b>	<b>Unexplained or Explained (n=1,023)</b>
0	359 (35.1%)	760 (74.3%)	292 (28.5%)
1	294 (28.7%)	200 (19.6%)	256 (25.0%)
2	176 (17.2%)	44 (4.3%)	208 (20.3%)
3	108 (10.6%)	18 (1.8%)	135 (13.2%)
4	45 (4.4%)	0	66 (6.5%)
5	24 (2.3%)	0	36 (3.5%)
6	9 (0.9%)	1(0.1%)	16 (1.6%)
7	3 (0.3%)	0	7 (0.7%)
8	4 (0.4%)	0	1 (0.1%)
9	1 (0.1%)	0	2 (0.2%)
10	0	0	2 (0.2%)
11	0	0	2 (0.2%)

**Table 3 – Factors independently associated with the presence of unexplained symptoms and signs**

<b>Variable</b>	<b>Odds ratio</b>	<b>(95% CI)</b>	<b>β</b>	<b>P</b>
<b>Age</b>				
16-24	Reference			
25-34	1.689	(1.030-2.770)	.524	.038
35-44	1.488	(0.948-2.336)	.398	.084
45-54	2.432	(1.521-3.889)	.889	.000
55-64	2.135	(1.298-3.510)	.758	.003
65 -74	3.569	(1.765-7.217)	1.272	.000
75+	2.894	(0.760-11.026)	1.063	.119
<b>Gender</b>				
Male	Reference			
Female	1.687	(1.280 – 2.223)	0.523	.000
<b>Level of intellectual disabilities</b>				
Mild	Reference			
Moderate	1.261	(0.894-1.779)	.232	.187
Severe	1.422	(0.971-2.082)	.352	.071
Profound	1.551	(1.049-2.295)	.439	.028
<b>Down syndrome</b>	.643	(0.457-0.904)	-0.442	.011
<b>GP visits in last 12 months</b>	1.054	(1.022-1.086)	.052	.001

R squared = 17.4%

(-2Log Likelihood (original)/Model Chi squared = 1225.853/70.607=17.4%)