Ageing and health status in adults with intellectual disabilities: Results of the European POMONA II study

MEINDERT HAVEMAN1, JONATHAN PERRY2, LUIS SALVADOR-CARULLA3, PATRICIA NOONAN WALSH4, MIKE KERR5, HENNY VAN SCHROIJENSTEIN LANTMAN-DE VAL6, GEERT VAN HOVE7, DASA MORAVEC BERGER8, BERNARD AZEMA9, SERAFINO BUONO10, ALEXANDRA CARMEN CARA11, ARUNAS GERMANAVICIUS12, CHRISTINE LINEHAN13, TUOMO MÄÄTTÄ14, JAN TOSSEBRO15 & GERMAIN WEBER16

1University of Dortmund, Germany, 2Welsh Centre for Learning Disabilities, Cardiff University, Wales, 3University of Cadiz, Spain, 4UCD Centre for Disability Studies, University College Dublin, Ireland, 5Welsh Centre for Learning Disabilities, Cardiff University, Wales, 6Radboud University Nijmegen, the Netherlands, 7University of Ghent, Belgium, 8Institute of Public Health of the Republic of Slovenia, 9CREAI, Languedoc Roussillon, France, 10IRCCS Oasi Maria SS, Troina, Italy, 11Sc Medfam Apolo Srl, Romania, 12Vilnius University, Lithuania, 13UCD Centre for Disability Studies, University College Dublin, Ireland, 14Service Centre of Kuyssamraki, Finland, 15Norwegian University of Science and Technology, Norway, and 16University of Vienna, Austria

Abstract

Background POMONA II was a European Commission public health-funded project. The research questions in this article focus on age-specific differences relating to environmental and lifestyle factors, and the 17 medical conditions measured by the POMONA Checklist of Health Indicators (P15).

Method The P15 was completed in a cross-sectional design for a stratified sample of 1,253 adults with ID across 14 European member states.

Results Older people (55+) were more likely to live in larger residential homes. Rates of smoking and use of alcohol were lower than in the general population but were higher with older age. More than 60% of older adults had a sedentary lifestyle. Cataract, hearing disorder, diabetes, hypertension, osteoarthritis/arthrosis, and osteoporosis were positively associated with advancing age; allergies and epilepsy, negatively associated.

Conclusions Some evidence of health disparities was found for older people with ID, particularly in terms of underdiagnosed or inadequately managed preventable health conditions.

Keywords: ageing, health status, health inequalities

Introduction

In Western countries there is a large and growing proportion of older adults with ID because of higher life expectancy rates. Evidence from the United Kingdom and the United States has indicated significant improvements in the life expectancy of persons with ID (Day & Jancar, 1994; Janicki, Dalton, Henderson, & Davidson, 1999), and, for milder forms of disability, life expectancies are now almost comparable to those in the general population (Bittles et al., 2002; Patja, Iivanainen, Vesala, Oksanen, & Ruoppila, 2000). In the UK, as a consequence, a 53% increase in the number of people with ID between 1960 and 1995 was reported; furthermore, at that time a further increase of 11% was expected for the period 1998-2008 (McGrother, Thorp, Taub, & Machado, 2001).

A large body of research attests to marked disparities in health between people with ID and the general population (e.g., Fisher & Kettl, 2005; Horwitz, Kerker, Owens, & Zigler, 2000; Krahn, Hammond, & Turner, 2006; Pomona, 2008). The poorer health status of people with ID that has been observed is thought to reflect a combination of factors including genetic predispositions to certain
health conditions, less favourable social circumstances, reluctance or inability to utilise generic health services, omission from public health awareness campaigns, and residential circumstances that foster inactivity and poor lifestyle choices.

However, the health disparities gap between people with ID and the general population is narrowing. Throughout the world studies reveal a growing cohort of “healthy” people, mostly with mild ID, who are living to over 70 years of age (Bittles et al., 2002). An active policy of health checks and inoculations, facilitated access to medical treatment and nursing care, safe environments, and nutritious diets, and the discouragement of smoking, alcohol, and illegal drugs might have contributed to this increase in life expectancy.

Due to different study methods used within countries, there is limited knowledge available on a border-crossing international level about age-specific differences in health status for adults with ID considering sociodemographic/environmental factors, lifestyles, and certain medical conditions. The scarcity of comparable data in European public health policy for persons with ID was one of the main reasons why the European Union funded the development (POMONA I), testing, and implementation of a standardised instrument of health indicators for adults with ID (POMONA II, 2005–2008). During POMONA I (2002–2004), partners representing 13 European countries agreed upon a set of 18 key health indicators specifically relevant for people with ID (Pomona, 2008). The POMONA 18-indicator set used the European Community Health Indicators (ECHI) project framework of classifying indicators according to four headings: demographics, health status, determinants, and health systems. The items were either new or adopted from other European Health Interview Surveys. Most questions about medical conditions were focused on just the recent past and did not include age or reason at onset. In each of the 14 countries (Austria, Belgium, Finland, France, Germany, Ireland, Italy, Lithuania, the Netherlands, Norway, Romania, Slovenia, Spain, UK) the Health Interview Survey was conducted directly with the person with ID and a supporter. When information was “unknown” to both of them, it was coded as missing for this item and individual. The evaluation form section of the P15 was sent separately to a person who knew the person with ID well (Veenstra et al., 2010).

To generate comparable health survey data, partners received identical guidelines for sampling in their countries. They were asked to identify approximately 80 potential participants in a geographical health area that met two criteria: the area had to be large enough to guarantee a wide representation of typical living circumstances for adults with ID with diverse levels of ability, and small enough to conduct face-to-face interviews in a reasonable time. Health areas were described according to population size, and by age and gender where possible. Partners aimed to avoid selecting participants by their health or disease; for example, by diagnosis, medical records, or hospital stay. The sample was stratified on age, type of residence, and IQ/adaptational skills.

The sampling process was expected to recruit a total of 1,120 adults with ID. Partners ascertained whether adults with ID were included in a case register in each health area, as these were potentially useful data sources about age, level of disability, and type of residence. Such a register could be used in only two of the 14 health areas. Partners were

The results of this study will be compared with the findings of other studies on this topic. Implications of this study with regard to the existence of health disparities between adults with ID and the general population will be explored and discussed.

**Method**

The POMONA Health Interview Survey and Evaluation Form (P15) comprises items related to demographic characteristics of respondents, health status, health determinants, and health systems. The items were either new or adopted from other European Health Interview Surveys. Most questions about medical conditions were focused on just the recent past and did not include age or reason at onset. In each of the 14 countries (Austria, Belgium, Finland, France, Germany, Ireland, Italy, Lithuania, the Netherlands, Norway, Romania, Slovenia, Spain, UK) the Health Interview Survey was conducted directly with the person with ID and a supporter. When information was “unknown” to both of them, it was coded as missing for this item and individual. The evaluation form section of the P15 was sent separately to a person who knew the person with ID well (Veenstra et al., 2010).

To generate comparable health survey data, partners received identical guidelines for sampling in their countries. They were asked to identify approximately 80 potential participants in a geographical health area that met two criteria: the area had to be large enough to guarantee a wide representation of typical living circumstances for adults with ID with diverse levels of ability, and small enough to conduct face-to-face interviews in a reasonable time. Health areas were described according to population size, and by age and gender where possible. Partners aimed to avoid selecting participants by their health or disease; for example, by diagnosis, medical records, or hospital stay. The sample was stratified on age, type of residence, and IQ/adaptational skills.

The sampling process was expected to recruit a total of 1,120 adults with ID. Partners ascertained whether adults with ID were included in a case register in each health area, as these were potentially useful data sources about age, level of disability, and type of residence. Such a register could be used in only two of the 14 health areas. Partners were
advised on how to secure informed consent directly from participants or by agreement through proxies. A review of partners’ sampling frames revealed (Veenstra et al., 2010) that almost all partners used service providers’ registers to identify samples of potential participants living in residential facilities, the family home, or alone. In the last mentioned circumstances, participants typically received day services from the service provider but were responsible for their own living arrangements. It is known that service registers attract certain biases such as including more severe cases. Partners in some countries identified samples through additional sources. The informed consent and sampling procedures are documented in more detail in earlier publications (Pomona, 2008; Veenstra et al., 2010).

Recruitment of fewer people than expected in the health regions of Ireland, Lithuania, the Netherlands, Norway, and UK was compensated for by additional cases from Finland and Spain. Even in countries that were oversampled, the same strategies for stratification were applied as much as possible. The sampling proportion in 12 countries varied between 4.0 and 6.7%. Spain and Finland’s share of the total sample was 7.9 and 20.9%, respectively.

Data were merged into a single SPSS database and checked for consistency and missing values. Extreme outliers were checked with the relevant partner. The cleaned dataset (N = 1,253) was analysed using SPSS. The procedures run were Pearson’s chi-square and eta-square coefficients for associations between nominal and metric variables. The central variable “age” was analysed in the following bands: 19–34, 35–54, 55–64, and 65 years and older. Due to the relatively small sample sizes in each country, and potential selection bias, it was not possible to explore differences between participating countries or to generalise results at the country level.

Results

Participants’ average age was 41 years (range = 19–90), and 49% were female. As documented in Table 1, the proportion of the sample with various degrees of ability level was mild (22.7%), moderate (28.2%), severe (20.7%), profound (11.8%), and unknown (16.6%). Accommodation type was residential care (47%), family home (34%), independent or semi-independent residence (12%), and nursing home or other facility (7%).

From the total sample of 1,253 participants, 34.8% were aged 19–34 years, 41.2% were 35–54, 15.8% were 55–64, and 8.2% were aged 65 years or older. Age distributions varied between countries. The proportions of people aged 19–34 years differed in this respect from 14.3% (UK) to 58.5% (Italy); 35–54 years from 31.3% (Italy) to 60.0% (UK); 55–64 years from 0.0% (Lithuania) to 26.5% (Finland); and 65 years or older from 2.0% (Lithuania) to 16.7% (Netherlands).

Sociodemographic differences

Compared to younger age groups no statistically significant differences were found (chi-square, p > .05) with regard to living in urban or rural regions for older age groups (55–64, 65+). However, fewer elderly people than expected lived amongst the general population (65+ years, 35.3% vs 21.4%; <55 years, p < .005), and more lived alone (>55 years, 17.4% vs 9.6%, p < .001), lived with parents and in families (>55 years, 4.8% vs 36.6%; <55 years, p < .001), and with non-relatives (<55 years, 52.1% vs 41.1%, p < .001). Compared with younger people, older people with ID more often lived in psychiatric hospitals, nursing homes, and other large institutions (>55 years, 11.6% vs 4.3%; <55 years, p < .001).

Table 1. Characteristics of people with ID (%) in the POMONA study (N = 1,253)

<table>
<thead>
<tr>
<th>Age</th>
<th>19–34 (n = 436)</th>
<th>35–54 (n = 516)</th>
<th>55–64 (n = 198)</th>
<th>65+ (n = 103)</th>
<th>Total (N = 1,253)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>45.2</td>
<td>48.6</td>
<td>53.8</td>
<td>62.7</td>
<td>49.4</td>
</tr>
<tr>
<td>Male</td>
<td>54.8</td>
<td>51.4</td>
<td>46.2</td>
<td>37.3</td>
<td>50.6</td>
</tr>
<tr>
<td>Level of cognitive ability</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild ID</td>
<td>22.6</td>
<td>22.9</td>
<td>22.7</td>
<td>21.9</td>
<td>22.7</td>
</tr>
<tr>
<td>Moderate ID</td>
<td>27.8</td>
<td>30.4</td>
<td>23.2</td>
<td>28.1</td>
<td>28.2</td>
</tr>
<tr>
<td>Severe ID</td>
<td>24.5</td>
<td>18.3</td>
<td>17.3</td>
<td>22.9</td>
<td>20.7</td>
</tr>
<tr>
<td>Profound ID</td>
<td>12.0</td>
<td>13.1</td>
<td>10.8</td>
<td>6.3</td>
<td>11.8</td>
</tr>
<tr>
<td>Unknown</td>
<td>13.1</td>
<td>15.3</td>
<td>26.0</td>
<td>20.8</td>
<td>16.6</td>
</tr>
<tr>
<td>Down syndrome</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>19.3</td>
<td>25.1</td>
<td>17.3</td>
<td>7.4</td>
<td>20.3</td>
</tr>
</tbody>
</table>
The results of Table 2 show a systematic relationship between age and social isolation. The older an individual, the less they met with friends and relatives. Whereas about half of the people aged 19–34 met with friends or relatives most days, this was reduced to one third of the people who were older than 65. Only a minority of the youngest age group (11.4%, 19–34 years) met less than once a month or never with friends and relatives, whereas this was a problem for a substantial part of the older people (about 30%) starting with age 55 years.

Of the people aged 19–64 years, 48.1% were unemployed (including special or supported employment). Early retirement is discussed in many European countries as a valuable principle for people with ID because of increasing frailty. However, the proportion of employed people aged 55–64 (55.3%) was relatively high compared to younger age groups. A high proportion (37.7%) was still working at 65 and older. Those in work were often unpaid (70.0%), and this was not restricted to older people; rates of unpaid employment activities were 49.8% for 19–34-year-olds, 39.4% for 35–54-year-olds, and 48.1% for 55–64-year-olds.

A lack of meaningful and age-appropriate programs in residential settings could be a reason why many older people (65+) remain in their structured work environment. A possible positive consequence of this is that the existing social network in the work environment (colleagues and staff) remains in place and offers structure, stability, and resources for communication and social interaction throughout the day. However, it is not known whether work is a positive choice for people, or whether it is the only option available.

**Lifestyle risk factors**

Smoking is a risk factor for both cardiovascular disease and lung cancer. Compared with the general population in the 27 countries of the European Union (World Health Organization Regional Office for Europe, 2010) a low proportion of our sample was daily smokers (6.0% vs 28.3%). Daily smoking is more common in people with ID aged 65 years and older (10.9%) than it is in younger adults (4.8% aged 19–34 years and 5.7% aged 35–54 years). A total of 7.1% of people older than 65 years smoked more than 20 cigarettes a day.

The use of alcohol was more common, but consumption tended to be modest, with 64.9% of the sample not drinking any alcohol, 30.6% consuming one or two glasses of alcohol a day, and 4.5% drinking three or more glasses a day. There are some age-specific differences. More people in the 55–64 and 65+ age groups drank alcohol 5 or more days a week compared to younger people (p < .005). However, heavy drinking (three or more glasses a day) was more prevalent in the younger age groups (19–34, 4.4%; 35–54, 6.0%) than in the older age groups (55–64, 1.5%; 65+, 2.0%).

A lack of regular physical activity and unhealthy eating habits, common factors associated with obesity in the general population, are also prevalent issues for people with ID. More than half (51.8%) of the sample had participated in no or few physical activities. Most of the others (41.4%) performed light activities for about four hours a week. People of 65 years and older spent less time and had less physical ability to perform harder physical activities such as gardening, jogging, recreational, and competitive sports, compared with younger people (see Table 3). Mobility restrictions and lack of stamina in old age could be possible explanations.

A substantial proportion (26.6%) had mobility limitations: 6.0% could not walk, 9.2% used a wheelchair or a frame, 3.7% could walk only a few metres, and 7.7% could walk less than 200 metres. Mobility restrictions for older adults with ID (65+) were significantly higher than young adults (19–34, p < .005): 15.2% versus 9.5% used a wheelchair; 15.2% versus 5.1% could walk less than 200 metres.

**Prevalence of medical conditions and ageing**

The P15 asked only about cataracts relating to problems with vision. From all adults included in

<table>
<thead>
<tr>
<th>Frequency of social visits</th>
<th>19–34 yrs</th>
<th>35–54 yrs</th>
<th>55–64 yrs</th>
<th>65+ yrs</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>On most days</td>
<td>50.1</td>
<td>39.2</td>
<td>35.6</td>
<td>33.3</td>
<td>42.0</td>
</tr>
<tr>
<td>Once or twice a week</td>
<td>19.6</td>
<td>22.7</td>
<td>17.5</td>
<td>19.2</td>
<td>20.5</td>
</tr>
<tr>
<td>Once or twice a month</td>
<td>18.9</td>
<td>20.1</td>
<td>17.0</td>
<td>17.2</td>
<td>18.9</td>
</tr>
<tr>
<td>Less than once a month</td>
<td>5.1</td>
<td>14.3</td>
<td>23.2</td>
<td>23.2</td>
<td>13.2</td>
</tr>
<tr>
<td>Never</td>
<td>6.3</td>
<td>3.8</td>
<td>6.7</td>
<td>7.1</td>
<td>5.4</td>
</tr>
<tr>
<td>Total</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>
the sample 6.3% had cataracts and 12.7% of adults aged 65 years and over. Age also generates hearing problems. The proportion of adults with ID who had problems hearing with a hearing aid in a normal conversation between three people or more increased significantly with age (from 3.7% for people aged 19–34 to 11.9% for those aged 65 years and older). The overall prevalence of this hearing problem was 6.2% (see Table 4).

Thyroid disease is another common medical problem for people with ID, with 8% of the sample diagnosed as having hypo- or hyperthyroidism. Occurrence of thyroid disease in this sample was not age related.

The proportion of people diagnosed with diabetes mellitus increased with age, from 1.6% of people aged 19–34, to 10.8% of people aged 65 or older.

Little is known about the prevalence and agesspecific distribution of respiratory tract infections such as chronic bronchitis and emphysema. In the present study, 7.4% of the sample had respiratory tract infections. There was no statistically significant correlation with age. Asthma was reported for 6.3% of the sample and was quite evenly distributed over the younger and older age groups. Allergies (excluding allergic asthma) were more common in younger people aged 19–34 years (24.9%) but were

---

**Table 3. Lifestyle risk factors in people with ID according to age (%)**

<table>
<thead>
<tr>
<th>Age</th>
<th>19–34</th>
<th>35–54</th>
<th>55–64</th>
<th>65+</th>
</tr>
</thead>
<tbody>
<tr>
<td>Smoking</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>91.5</td>
<td>90.0</td>
<td>90.4</td>
<td>85.1</td>
</tr>
<tr>
<td>Now and then</td>
<td>3.7</td>
<td>4.3</td>
<td>3.0</td>
<td>4.0</td>
</tr>
<tr>
<td>Daily</td>
<td>4.8</td>
<td>5.7</td>
<td>6.6</td>
<td>10.9</td>
</tr>
<tr>
<td>Alcohol use</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>71.2</td>
<td>61.5</td>
<td>60.5</td>
<td>60.0</td>
</tr>
<tr>
<td>Less than twice a month</td>
<td>23.0</td>
<td>26.1</td>
<td>29.1</td>
<td>27.0</td>
</tr>
<tr>
<td>1–2 days a week</td>
<td>4.0</td>
<td>8.5</td>
<td>4.1</td>
<td>10.0</td>
</tr>
<tr>
<td>3–6 days a week</td>
<td>0.7</td>
<td>1.8</td>
<td>2.6</td>
<td>3.0</td>
</tr>
<tr>
<td>Every day</td>
<td>1.2</td>
<td>2.2</td>
<td>3.6</td>
<td>0.0</td>
</tr>
<tr>
<td>Physical activity</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sedentary</td>
<td>52.4</td>
<td>49.0</td>
<td>53.3</td>
<td>60.9</td>
</tr>
<tr>
<td>Light activities 4 hours a week</td>
<td>36.8</td>
<td>45.4</td>
<td>42.8</td>
<td>37.0</td>
</tr>
<tr>
<td>Gardening, jogging, recreational sports 4 hours a week</td>
<td>9.0</td>
<td>5.0</td>
<td>2.8</td>
<td>1.1</td>
</tr>
<tr>
<td>Hard training, competitive sports more than once a week</td>
<td>1.8</td>
<td>0.6</td>
<td>1.1</td>
<td>1.1</td>
</tr>
</tbody>
</table>

**Table 4. General and age-specific prevalence rates of health problems (%)**

<table>
<thead>
<tr>
<th>Age</th>
<th>19–34</th>
<th>35–54</th>
<th>55–64</th>
<th>65+</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cataract (+)</td>
<td>3.2</td>
<td>5.8</td>
<td>11.2</td>
<td>12.7</td>
</tr>
<tr>
<td>Hearing with difficulty what is said between 3 people (+)</td>
<td>3.7</td>
<td>6.0</td>
<td>9.5</td>
<td>11.9</td>
</tr>
<tr>
<td>Hypo-hyperthyroidism</td>
<td>5.3</td>
<td>9.7</td>
<td>10.7</td>
<td>5.9</td>
</tr>
<tr>
<td>Diabetes (+)</td>
<td>1.6</td>
<td>4.5</td>
<td>6.6</td>
<td>10.8</td>
</tr>
<tr>
<td>Chronic bronchitis/emphysema</td>
<td>7.6</td>
<td>8.9</td>
<td>2.5</td>
<td>7.8</td>
</tr>
<tr>
<td>Asthma</td>
<td>6.5</td>
<td>6.0</td>
<td>7.1</td>
<td>4.9</td>
</tr>
<tr>
<td>Allergy (−)</td>
<td>24.9</td>
<td>21.2</td>
<td>18.3</td>
<td>8.8</td>
</tr>
<tr>
<td>Hypertension (+)</td>
<td>5.8</td>
<td>9.5</td>
<td>16.8</td>
<td>30.4</td>
</tr>
<tr>
<td>Heart attack</td>
<td>1.4</td>
<td>1.8</td>
<td>2.0</td>
<td>4.9</td>
</tr>
<tr>
<td>Stroke, cerebral haemorrhage</td>
<td>1.2</td>
<td>1.6</td>
<td>2.0</td>
<td>2.0</td>
</tr>
<tr>
<td>Osteoarthritis/arthritis (+)</td>
<td>3.9</td>
<td>7.6</td>
<td>15.2</td>
<td>12.7</td>
</tr>
<tr>
<td>Osteoporosis (+)</td>
<td>5.3</td>
<td>3.9</td>
<td>6.6</td>
<td>11.8</td>
</tr>
<tr>
<td>Gastric/duodenal ulcer</td>
<td>4.6</td>
<td>4.7</td>
<td>6.1</td>
<td>5.9</td>
</tr>
<tr>
<td>Malignant tumour</td>
<td>1.6</td>
<td>2.5</td>
<td>3.0</td>
<td>2.9</td>
</tr>
<tr>
<td>Constipation</td>
<td>26.7</td>
<td>26.1</td>
<td>26.9</td>
<td>26.5</td>
</tr>
<tr>
<td>Migraine/frequent headache</td>
<td>16.8</td>
<td>17.9</td>
<td>14.2</td>
<td>7.8</td>
</tr>
<tr>
<td>Epilepsy (−)</td>
<td>30.2</td>
<td>29.2</td>
<td>26.6</td>
<td>15.0</td>
</tr>
</tbody>
</table>

*Note.* (−) negative or (+) positive statistical association (eta-square coefficients, $p < .05$) with advancing age.
significantly reduced (8.8%) in adults aged 65 years and older.

The data on hypertension were age-related and showed a significant increase from 5.8% of people aged 19–34 to 30.4% of people aged 65 and older.

Compared with younger adults, higher proportions of heart attack were found in people aged 65 and older. The increase with age was systematic but not statistically significant.

The overall prevalence of stroke and cerebral haemorrhage was 1.5%. The slight increase with age was not statistically significant. More older than younger adults were affected by osteoarthritis/arthritis/rheumatism (3.9% for people aged 19–34, compared with 15.2% and 12.7% for people aged 55–64 and 65+, respectively).

A statistical significant increase with age was found for osteoporosis, with the lowest rate (3.9%) for the 35–54 age group and the highest rate (11.8%) for people aged 65 and older. The overall prevalence of gastric or duodenal ulcer was 5%. The rate of malignant tumours (including leukaemia and lymphoma) was 2.9% higher amongst people aged 65 and older compared to younger adults.

Constipation was reported for 26.5% of the sample and was not age related. Severe and/or frequent headache/migraine was less common in adults aged 65 and older.

The overall prevalence of epilepsy was 28.0%.

Table 4 shows an inverse statistically significant relation of epilepsy with age. People aged 65+ were diagnosed with 15.0% of cases—about half as often as having seizures compared to persons from younger age groups.

Discussion

How healthy are older adults with ID with regard to lifestyle factors?

There is little evidence about smoking rates among older adults with ID. Lower smoking rates compared with the general population have been noted among adults with severe ID, and equivalent or higher rates among people living in the community and not in institutions, and adults with mild ID (Draheim, McCubbin, & Williams, 2002; McGilli-cuddy, 2006; Welsh Office, 1996). In the Welsh study, people with ID were less likely to smoke (19.2% smokers/ex-smokers) than the general adult population (63.1% smokers/ex-smokers). In our study, smoking was more common in older adults with ID. Also, individuals of the oldest age group smoked the most cigarettes. Cohort effects could be one explanation for this. Alcohol intake did not differ much between elderly adults with ID and younger adults.

A lack of regular physical activity and unhealthy eating habits, common factors associated with obesity in the general population, are also prevalent issues for people with ID (Braunschweig et al., 2004; Draheim, Williams, & McCubbin, 2002; Emerson, 2005; Fernhall & Pitetti, 2001; Graham & Reid, 2000). In other studies, age appears to be negatively associated with physical activity in adults with ID (Emerson, 2005; Robertson et al., 2000).

Low levels of physical activity combined with high-energy diets probably play a major role in the development of obesity, cardiovascular disease, Type 2 diabetes, constipation, osteoporosis, incontinence, and arthritis in older adults with ID. The standard recommendation is that engaging in 30 minutes of moderate intensity physical activity (or 10,000 steps throughout a day) on most, preferably all, days of the week (World Health Organization [WHO], 2004) serves as a preventative health measure. Very few people with ID meet these activity guidelines (Stanish, Temple, & Frey, 2006). In the United States, less than one third of the ID population engages in sufficient physical activity to accrue health benefits (Centers for Disease Control and Prevention, 2005). Similar findings have been reported in three studies from England using the criteria of at least 12 bouts of 20 minutes of moderate to vigorous activity occurring over 4 weeks (Emerson, 2005; Messent, Cooke, & Long, 1998; Robertson et al., 2000). The proportion of participants meeting this criterion ranged from 4 to 20% (Stanish et al., 2006). The results from the POMONA study are in the same range. About 7% of this sample had participated in at least 4 hours a week of more intensive physical activity.

The negative association between age and physical activity in our study is consistent with other studies (Emerson, 2005; Robertson et al., 2000). Only a minority (2.2%) of people aged 65 and older in the current study had taken part in more than 4 hours of intense physical activity a week.

Considering that 60% of global populations do not meet the minimum physical activity guidelines (WHO, 2004), it is difficult to conclude whether adults with ID are any less motivated to be active than those without ID. However, motivation towards physical activity cannot explain all differences. Activity and exercise levels remain very limited in those people who were non-ambulatory (e.g., some people with cerebral palsy) who are permanently reliant on using wheelchairs for mobility, have vision problems, are afraid of falling and having fractures, or have musculoskeletal conditions.
Are there indications that some disease categories are over- or under-represented in older adults with ID compared to the general population?

Compared to lifestyle factors, health problems and diseases are better documented in epidemiological studies for people with ID; however, information about the health status of older adults is still limited. Problems with seeing and hearing affect mobility and have serious consequences for quality of life. Vision problems (e.g., refractive errors, strabismus, cataracts, and keratoconus) are more common among individuals with ID than those without ID (Carvill, 2001; Kapell et al., 1998; Warburg, 2001a). In the general population, there is a significant increase in vision problems in people with advancing age (Janicki et al., 2002; Merrick et al., 2004).

Both the overall rate for cataracts and the age-specific rate for people with ID of age 65 and older, are quite low in our study compared with other studies (Congdon, Friedman, & Liemtan, 2003; Foran, Wang, & Mitchell, 2003; Friedman, Congdon, Kempen, & Tielsch, 2002; Kerr et al., 2003; Kleinste et al., 2003; The Eye Diseases Prevalence Research Group, 2004; van Splunder, Stilma, Bernsen, & Evenhuis, 2004; van Splunder, Stilma, & Evenhuis, 2003; Warburg, 2001b). British administrative data suggest prevalence estimates of cataracts as high as 28% among individuals with ID (Kerr et al., 2003), while a study of individuals with ID aged 60 and older in Dutch residential homes found that 69% had cataracts (Evenhuis, 1995). There are indications that in the POMONA study many cases of cataracts in people with ID were missed because of its observational design. Studies with new diagnostic intervention (screening) will show much higher results (Haveman, 2004).

Compared to our results, other studies also show higher overall rates of hearing impairment (Beange, Lennox, & Parmenter, 1999; Evenhuis et al., 2001; van Schrojenstein Lantman-de Valk, Metsemakers, Haveman, & Crebolder, 2000; Welsh Office, 1996), with a strong increase in the prevalence of hearing impairments with advancing age (Janicki et al., 2002; Merrick et al., 2004). Evenhuis, Theunissen, Denkers, Verschure, and Kemme (2001) found a prevalence of hearing impairment of 21% in a Dutch residential sample of people with ID, and Aerts-Neggers, Schoonbrood-Lenssen, and Maaskant (2003) reported that over half of the clients of three Dutch vocational centres for people with ID showed hearing impairments. Risk groups for hearing impairment were people with Down syndrome and people older than 60. Many people with hearing impairments had not been diagnosed previously and most were treatable to some extent. In the current study it appears that the information given by people themselves, staff, and family is an underestimation of the true prevalence of hearing problems in people with ID.

Evidence from several studies show that people in daily contact with older adults with ID (family members and staff) are insufficiently sensitive, experienced, and trained to manage effectively the serious regression of vision and function of their older clients. Older adults with severe and profound multiple disabilities and people with Down syndrome, in particular, have many problems with vision. Van Splunder, Stilma, Bernsen, and Evenhuis (2006) concluded that all persons with severe and profound ID and all older adults (40+) with Down syndrome should be considered as visually impaired until proven otherwise; arguably, this presumption applies also to the presence of hearing impairment.

For adults with ID, routine screening for age-related visual and hearing loss at 45 years and every 5 years thereafter by an experienced ophthalmologist or audiologist has been recommended (Evenhuis & Nagtzzaam, 1998). If possible, this should be done. An extra vision check at age 30 has been recommended for adults with Down syndrome. Screening of the hearing function of adults with Down syndrome is recommended every 3 years throughout life (International Association for the Scientific Study of Intellectual Disability [IASSID], 2002).

There are some limitations regarding the interpretation of the results of the POMONA study. It is not possible to generalise the results of this study to the health status of the population of adults with ID in Europe or for European member states. The samples are drawn from pilot areas and are too small and unrepresentative to be conclusive at either the country or EU level. This study generated data that is exploratory in nature and can give some indications about the health status of older adults with ID. For measuring differences in the health status of older adults between countries and for a better insight into national and structural barriers to adequate service delivery, larger and more representative samples at the country level are needed. The results presented are cross-sectional. The percentages given are not a true lifetime rate and would be higher if they included longitudinal data, including deceased persons. For all included health conditions, the POMONA study did not offer standardised testing or screening but measured existing medical knowledge. Moreover, not all participants were screened recently, and not all caregivers (family or staff) will be totally aware of the disorders being diagnosed in their family members/clients. The observational and...
cross-sectional design of POMONA could have resulted in a considerable underestimation of the true prevalence of these conditions.

Thyroid disease was not age related in this sample. The overall prevalence rates of thyroid disease were somewhat higher (12%) in a population study in Australia (Beange, McElduff, & Baker, 1995) compared to our rates (8.0%). These rates and those in the current study were higher than the self-reported rate in the Australian population of 0.1%. People with Down syndrome are particularly affected.

An Australia-wide general population study (Dunstan et al., 2001) found a prevalence figure for diabetes of 7.5% in the adult population. In the general population, rates of diabetes have been found to increase with age (DECODE Study Group, 2003). The same trend occurred in our study with regard to adults with ID. Compared to other studies, however, overall (4.3%) and age-specific prevalence rates (65+, 10.8%) were rather small. One in four of the 80-year-olds had Type 2 diabetes. Some researchers suggest that there is a significant chance that Type 2 diabetes is systematically underestimated amongst older adults with ID (Janicki et al., 2002; Merrick et al., 2004). Underreporting and the low proportion of very old people with Type 2 diabetes could also be an important explanation for the low rate of cases found in the current study.

Data in the literature on rates of hypertension for adults with ID is somewhat conflicting. Some studies noted lower rates of hypertension (Draheim, McCubbin & Williams, 2002; Janicki et al., 2002; McDermott, Platt, & Krishnaswami, 1997), whereas Henderson et al. (2008) demonstrated similar rates of hypertension in adults with ID living in the community compared to the general population. Few studies reported age-specific hypertension rates. In the current study, as with Cooper (1998), rates of hypertension were found higher amongst older adults (65+, 30.4% vs 18–34, 5.8%) with ID.

People with ID have been reported as having lower levels of arthritis and back pain compared to the general population (Welsh Office, 1996). However, arthritis and arthrosis are likely to be systematically underassessed in adults with ID (Haveman et al., 2009). The current data show an age-related increase in the number of people affected by osteoarthritis or arthrosis.

Research suggests that older adults with ID are more likely to have higher levels of osteoporosis and fractures as a result of decreased mobility than the general population (Center, Beange, & McElduff, 1998; Glick, Fischer, Heisey, Leveson, & Mann, 2005; Lohiya, Crinella, Tan-Figueroa, Caires, & Lohiya, 1999). Consistent with such findings, a statistically significant increase of osteoporosis with age has been found in the current study.

A high occurrence of Helicobacter pylori (HP) has been reported in older adults with ID (Böhmer, Klinkenberg-Knol, Niezen-de Boer, & Meuwissen, 1997; Clarke, Vermuri, Gunatiakte, & Tewari, 2008; Kennedy, 2002; Morad, Merrick, & Nasri, 2002; Wallace, Webb, & Schluter, 2002). HP causes gastritis in 100%, peptic ulcer in 6–20%, and gastric cancer in about 1% of those adults who are chronically infected (Howden, 1996).

A consequence of the increasing life expectancy of people with ID is that chronic conditions such as cancer are becoming more common. The distribution of cancer is different to that of the general population, with a high proportion of cancers that affect the intestinal tract, and fewer affecting the lungs, breast and prostate (Cooke, 1997; Jancar, 1990). Finnish researchers found cancer incidence comparable to the general population in spite of low smoking levels (Patja, Eero, & Ivanaïnen, 2001). The prevalence rate of malignant tumours in the current study shows higher rates with advancing age, but types of cancer were not specified.

Constipation has been reported more frequently for adults with ID compared with the general population (Lembo & Camilleri, 2003; Talley, Jones, Nuylts, & Dubois, 2003). The results of the current study were similar to those of Van Winckel, Vander Stichele, Bacquer, and Bogaert (1999), who reported that 26.4% of people with ID in Belgian residential care homes regularly used laxatives, and less when compared to the study of Böhmer, Taminiau, Klinkenberg-Knol, and Meuwissen (2001), with 69.3% of people in Dutch residential care centres regularly using laxatives. Morad, Nelson, Merrick, Davidson, and Carmeli (2007) reported a significantly lower rate of constipation (8%) for adults aged 40 and older in residential homes in Israel. Type of diet, differences in mobility, and type of measurement of constipation in those studies could explain the different outcomes.

In all studies, including the current one, old age was not associated with high rates of constipation. The normal ageing process itself seems not to be a risk factor for constipation. Age-related conditions, however, such as immobility, cerebral palsy, neurological disease, specific drugs and physical inactivity, can contribute to its occurrence.

A number of studies have found a higher prevalence of epilepsy among people with ID compared with the general population. Epilepsy occurs among people with ID in the order of 20–50 times more frequently than in the general population (van Schrojenstein Lantman-de Valk et al., 2000). There...
is no evidence that overall prevalence of seizures increases with age as documented for the general population, mainly due to cerebrovascular disease and dementia (Wallace, Shorvon, & Tallis, 1998). As in the general population (Amatniek et al., 2006; Hesdorffer, Hauser, Annegers, Kokmen, & Rocca, 1996), seizures may develop in people with Down syndrome as they age, together with the manifestation of dementia (Collacott, 1993). In our study, prevalence of epilepsy was lower for adults of 65 years and older compared with younger age groups. A possible partial explanation of this phenomenon is that epilepsy is a contributory cause of death in younger age, and that the likelihood of reaching age 65 and beyond is small for persons with Down syndrome having dementia and epilepsy.

For some disease categories measured in the current study little or no comparative data exist. In analysing the publications from 1999 to 2008 no publications about prevalence of chronic bronchitis, asthma, allergies, and migraine/frequent headaches in the population of older adults with ID could be found (Haveman et al., 2009). There are indications that the prevalence of stroke in people with ID is comparable to rates found for the general population (Junghøjlsing et al., 2008).

Are there health disparities between older adults with and without ID?

In this European study we found statistically significant differences in size and type of residential facility and frequency of contacts with friends and relatives between older and young adults with ID. Older adults were more likely to live in bigger institutions and were more socially isolated, whereas younger adults were more likely to live in smaller community-based settings and had more frequent contact with friends and relatives. Covariate analysis showed that the strength of the statistical association between age and living environment did not change for both findings when controlling for the influence of severity of disability. In a time in which the UN Convention on the Rights of Persons with Disabilities is accepted by law in most countries as part of social policy, it seems that the gap between de jure and de facto is still large, especially with regard to inclusion of older adults with ID.

In theory, people with ID living in European countries have equal access to essential health care services. Countries, and regions within countries, however, vary in their models of health care delivery for people with ID (Pomona, 2008). The barriers that exist in providing care to people with ID vary by region and type of health care system. It is important that health care providers and policy makers acknowledge that many people with ID have special needs that may require the modification of standard health care practices and service models, and that these needs emerge with advancing age.

Some evidence of health disparities for older people with ID was found in the current study, particularly with respect to a number of preventable health conditions, which usually remain underdiagnosed, diagnosed late, or are inadequately managed. Similar results were reported by Webb and Rogers (1999), Baxter et al. (2006), and in a review study by Haveman et al. (2009). Health disparities between older people with ID and their peers in the general population have been documented with regard to communication, mobility, oral health, vision and hearing, neurological disorders (epilepsy and Alzheimer disease), pain, osteoporosis, and gastrointestinal problems (e.g., Helicobacter pylori, gastro-oesophageal reflux disease, constipation). Many health problems of older adults with ID remain unrecognised by people themselves, their family members, staff, and medical professionals. A more active, systematic, and regular approach to monitor and measure preventable and more common medical problems would be helpful for this group of people in all countries.

Several approaches have been developed to encourage regular health checks that are targeted to the health needs of young and old adults with ID such as the Cardiff Checklist (Baxter et al., 2006), Comprehensive Health Assessment Program (CHAP, Lennox, & Eastgate, 2004), the Self-Report Health Status Measure (Ruddick & Oliver, 2005), and the Health Assessment Instrument (Fender, Marsden, & Starr, 2007; Starr & Marsden, 2008). In countries without regular and comprehensive health assessments for older people with ID, the implementation of such systematic methods are highly recommended to detect any health condition at a very early stage for treatment.

In other countries, however, ageing people with ID should not be excluded from standard health checks for the elderly and from healthcare programs provided for this age group. The inclusion of people with ID in health surveys, healthy lifestyle studies, and generic ageing intervention programs may improve our knowledge of differences and similarities in health status, lifestyle, and met and unmet needs in people with or without ID. For the persons themselves, it means that they feel they are treated the same way and have the same rights as other citizens in society.

Author note

The POMONA project was carried out with financial support from the European Commission (Agreement 2004130).
References


