Management and quality indicators of diabetes mellitus in people with intellectual disabilities

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Diabetes Background

- Diabetes mellitus affects approximately 1 in 20 people across Europe and accounts for an uneven use of healthcare resources (International Diabetes Federation, 2007)

- WHO (2006) states rates of diabetes worldwide will increase from 177 million in 2000 to 366 million by 2030, a global prevalence rate of 6.3%

- The chronic complications of diabetes include; blindness, renal failure, amputation and cardiovascular problems (stroke and myocardial infarction)

- People with diabetes experience greater morbidity and mortality than the general population
Diabetes Background

- T1D is caused by an autoimmune disorder that develops when the body’s immune system attacks and destroys the cells that produce insulin.

- T2D develops when the body does not produce enough insulin to maintain a normal blood glucose level, or when the body is unable to effectively use the insulin that is produced.

- Specific risk factors for the development of T2D are having a sedentary lifestyle, little exercise, poor nutrition (high fat and low fibre), obesity, high blood pressure and cholesterol, increasing age, family history of diabetes and ethnicity (Turner et al., 1998, Mokdad et al., 2001).
Anwar et al. (2004) found that T1D was more prevalent in individuals with Down syndrome: 10.6%

Turner syndrome, Klinefelter syndrome, Prader-Willi syndrome, Noonan syndrome and Williams syndrome have also been found to be associated with endocrine conditions such as T1D (Hoybye, 2004, Botero & Fleischman, 2006)

People with ID are more likely to have risk factors for T2D (Havercamp et al., 2004, Merrick & Morad, 2010, Shireman et al., 2010, Taggart et al., 2012)

Prevalence figures found to vary from 7.1% to 14% depending on the sample used (McDermott et al., 2006, Shireman et al., 2010, Lunsky et al., 2011). Diabetes UK (2009) estimated that 270,000 people with ID have T2D in the UK
Rarely have studies examined the extent to which people with ID diabetes is managed or whether the quality indicators for diabetes care are met (Beange et al., 1995)

Lennox et al. (2007) found a considerable number of people with ID living in the community who had diabetes and were obese: neither identified nor managed

Shireman et al. (2010) found that of adults with ID and diabetes in Canada 52% had annual blood glucose checks, 44% had cholesterol levels measured, 29% were screened for diabetic retinopathy and 19% for microalbuminuria

People with ID have had few opportunities to actively engage in appropriate diabetes education or health screening (Taggart et al; 2012)
The aim of this study was to examine the demographics, the health and quality of diabetes care indicators amongst a sample of people with ID and diabetes.
Methodology

- **Design:** This is a quantitative study using a postal survey design employing an anonymised questionnaire

- **Sample:**
  - All PWID known to ID services
  - All five H&SCT’s in NI

- **Procedure:** Contact all Community ID Teams and residential managers

- **Questionnaire:** research team developed
  - Research governance and research ethics completed

- **Funding:** None

- **Date:** Aug 2010 – Aug 2011
67% had T2D whereas 33% had T1D

T2D were significantly older (mean = 57.3 yrs, range 6–77 years) compared with T1D (mean = 46.6 yrs, range 26–95 yrs)

23% had Down syndrome compared to 8% of those with T2D (chi sq = 8.15, df = 1, p < 0.01)

Significantly more people with Autistic Spectrum Disorder (ASD) had T1D (13%) compared to 5% with T2D (chi sq = 4, df = 1, p < 0.05)

Less than a half of the people had a borderline/mild ID, a third had a moderate ID (37%) and 19% had a severe/profound ID

40% lived within a supported living/residential accommodation, 31% lived within their own home independently or with their partner (31%) and 23% lived within their family home/with parent(s)
<table>
<thead>
<tr>
<th>Total BMI</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Underweight (&lt; 18.5)</td>
<td>1</td>
<td>0.9%</td>
</tr>
<tr>
<td>(18.5 - 24.9)</td>
<td>22</td>
<td>21.3%</td>
</tr>
<tr>
<td>Overweight (25 - 29.9)</td>
<td>26</td>
<td>20%</td>
</tr>
<tr>
<td>Obese (30 - 39.9)</td>
<td>37</td>
<td>35.9%</td>
</tr>
<tr>
<td>Morbidly Obese (40 plus)</td>
<td>17</td>
<td>16.5%</td>
</tr>
</tbody>
</table>
78% had their lipid/cholesterol levels checked yearly

77% had an annual eye examination

59% of the sample had their HbA1c monitored yearly

A significant difference was found between weight change and BMI, with those people within the morbidly obese category more likely to increase their weight (65%) (chi sq= 6, df= 2, p< 0.05)

10% of this population had attended an A&E facility in the last 12-months for a diabetes related condition
This study confirmed a higher rate of T1D in people with Down syndrome compared to previous studies as cited by Anwar et al. (2004), likewise, more people with ASD also had T1D.

This study found that over half of this sample was overweight/obese and more disturbingly 17% were morbidly obese.

Results showed that the national standards for good diabetes management (NICE, 2011), NSFD, 2007, DUK, 2011) were only partially met due to a lack of regular screening of Hb1Ac, BMI, BP and lipids/cholesterol.
In terms of diabetes self-management and glycaemic control, over half of this population were reported to have HbA1c >6.

If blood glucose is high, individuals are likely to experience a range of physical symptoms of hyper-glycaemia such as increased thirst, difficulty concentrating, headaches, blurred vision, frequent urination, fatigue, weight loss and mental health symptoms (mood change, agitation, withdrawal, verbal and physical aggression).
Implications

- Processes need to be agreed to enable those people with an ID to be screened to identify their risk of developing T2D or indeed to diagnose if they have developed diabetes.

- A strong argument exists in favour of screening for subjects who are at increased risk for diabetes. Lindster & Tuomilehto (2003) in Finland developed the Diabetes Risk Score (DRS).

- High obesity rates: this study suggest opportunities for targeting this high risk group within the ID population for lifestyle and behaviour modification.
Implications

- Hyper-glycaemia symptoms may be masked by the persons’ ID (‘diagnostic over-shadowing’), communication difficulties, the medication they are prescribed and/or also challenging behaviours displayed.

- Therefore, the person may not get the medical attention they merit as staff may not recognise their symptoms related to diabetes particularly if diabetes has not been diagnosed.

- Half of the informants failed to report the requested information, this is a cause for concern.

- This calls into question, whose responsibility it is to monitor and manage diabetes in people with ID?
Implications

- Government policies place a strong ethos upon self-management at the heart of living with diabetes; however this further poses challenges for this population and those who provide care for them.

- Greater emphasis needs to be placed upon collaborative working and education between ID, primary healthcare and diabetes staff in order to meet these quality indicators and improve the quality of life of this population (Taggart et al., 2012).
Thank-you

QUESTIONS:

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