WHAT CAN PEOPLE WITH INTELLECTUAL DISABILITIES TELL US ABOUT MEDICATION USE?.

Bernadette Flood PhD MPSI
Dr Martin Henman
School of Pharmacy & Pharmaceutical Sciences
Trinity College Dublin
PLAN

• BACKGROUND
• PROJECT
• DIABETES
• FOR THE FUTURE
The healthcare and social environment in which people with intellectual disabilities receive care and are prescribed medication is increasingly complex.

Some people with an intellectual disability face a situation of ‘double jeopardy’ where they are at risk of receiving second rate services from both the disability and health service because they are seen to be the primary responsibility of neither.

MEDICATION USE IS THE **MAJOR THERAPEUTIC INTERVENTION IN THE POPULATION WITH INTELLECTUAL DISABILITIES**
Patient Experience

The experience of all patients in healthcare is an accepted arm of quality.

- People with intellectual disabilities have unique perspectives of healthcare processes that might not be considered by others.
- They may often be ‘hard to hear’ and / ‘hard to see’.
- Improving health care communication reduces health care costs and increases the quality of health care.
• This project facilitated by National Support organisation for people with intellectual disabilities in the Republic of Ireland

• Received approval from the TCD Health Sciences Research Ethics Committee

• Six people with intellectual disabilities consented to be involved

• Semi structured tool. Counsellor present at all interviews.

• Grounded Theory methodology

• Pseudonomy used in following slides
• Person centred care -PCC-is the focus of Irish service delivery when working with and for people with intellectual disabilities.

• GT methodology fits with some of the principles of PCC - it focuses on explaining the person’s main issue of concern and how the person continually resolves this concern.

• GT -allows the generation of new theory from data, as opposed to testing existing theory
SOME THEMES FROM GROUNDED THEORY
It is important that people with intellectual disabilities are included in decisions about their own healthcare of which medication use is a major component.

Exercising autonomy in the medication use process can be difficult and may not ensure the highest quality healthcare for people with intellectual disabilities - who usually are dependent on others for many aspects of their care and access to care.
HEALTH LITERACY

- Seeking medical care,
- taking medications correctly
- following prescribed treatments

requires that people with intellectual disabilities and their carers understand how to access and apply health information.
- Responsibility of health professionals to make information on medication readily available to people with intellectual disabilities and their carers.
- Provision of information to the person and/or their carer does not guarantee that an individual has understood and accepted the information they have received.
Health care professionals do not always understand the complexity of the tasks they ask people with intellectual disabilities and / or their carers to do.
DIABETES

If you have any of these symptoms, see your doctor. For more information about diabetes call Eli Lilly and Company at 1-800-838-3979 or Boehringer Mannheim Corporation at 1-800-658-8772.
<table>
<thead>
<tr>
<th>Participant</th>
<th>Pat</th>
<th>Jamie</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lives at home with parents</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Age</td>
<td>33</td>
<td>32</td>
</tr>
<tr>
<td>Gender</td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>Home address</td>
<td>Outside Dublin</td>
<td>Dublin area</td>
</tr>
<tr>
<td>Tablets Rx</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Diabetic</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Insulin</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Eltroxin RX</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Antidepressant</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Antipsychotic</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Other meds</td>
<td>PPI, Coversyl</td>
<td>Glucophage, Cozaar</td>
</tr>
<tr>
<td>Hypnotic</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Vitamins / Minerals etc</td>
<td>No</td>
<td>Yes – Vit B</td>
</tr>
<tr>
<td>Other products</td>
<td>Arret, Imodium, Solpadiene</td>
<td>No</td>
</tr>
</tbody>
</table>

BF Nat Px Conf 2015
A study of Medicaid expenditure data found that people with Intellectual disabilities were six times more likely to have Type II diabetes than people without intellectual disabilities, as well as having an average of four other chronic health problems.

Ref: Reichard & Stolze, 2011, JIDD:49:30. Diabetes among adults with cognitive limitations compared to individuals with no cognitive disabilities.
• Concern has been expressed concerning the quality of care people with intellectual disabilities and diabetes receive


• Insulin and oral hypoglycaemics are high risk medications.

• Insulin must be stored and injected properly.
<table>
<thead>
<tr>
<th>Issues</th>
<th>PAT = Index Case</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health literacy / Vulnerability</td>
<td>Had a ‘hypo’ previous weekend in shopping centre. Had to get glucagon ‘into backside’. Reported numerous ‘hypos’.</td>
</tr>
<tr>
<td>Diabetes distress/ Autonomy</td>
<td>Hates diabetes. Hates ‘everything about it’ Just takes tablets because ‘I do not want to die’ Mentioned numerous times during interview</td>
</tr>
<tr>
<td>Autonomy</td>
<td>Appeared to have responsibility for own ‘self care’</td>
</tr>
<tr>
<td>Medicine Information</td>
<td>Stored insulin in drawer bedroom – not in fridge. Brought 13 + 4 insulin pens into interview and 3 glucagon hypokits</td>
</tr>
<tr>
<td>Health Literacy/ Monitoring</td>
<td>Takes tablets with xxx YOGURT DRINK – very high in sugar. Each 100g pot contains 13g of liquid sugar. One xxx - 25% -33% of the amount of free sugar advised per day. 2 Glucose diaries – very few entries.</td>
</tr>
<tr>
<td>Health Literacy / Autonomy / Medicine Information</td>
<td>Medicines in Monitored Dosage System[MDS] – used erratically - complex Medicines dispensed by 2 separate pharmacies – 2 different systems. If does not want to take tablets ‘just don’t take them’</td>
</tr>
</tbody>
</table>
• DD is a general term that refers to the emotional burdens, stressors and frustrations that stem from managing diabetes (Fisher et al., 2012, Egede and Dismuke, 2012).

• Distress is associated with poor clinical outcomes in many patients (Gonzalez et al., 2011).
A survey which included 500 patients with diabetes has identified that 33% of patients have some level of dread associated with daily insulin injections and 57% of patients intentionally skip insulin injections.

High Risk/Alert Medications

- Insulin and oral hypoglycaemics are high risk / alert medications

- Have a heightened risk of causing significant patient harm when they are used in error
- The consequences of an error are more devastating to patients

INSULINS and Glucagon

**Insulin:**
When in use or carried as a spare may store for 4 weeks <30 degrees C. Before opening should be stored in fridge 2-8 degrees C.

**Glucagon:**
Can store GlucaGen HypoKit at room temperature (25°C) for up to 18 months within the shelf life period...should label with removal date.
Interventions to reduce emergency hospital admissions for diabetes

• Health professionals should get **insight** into challenges faced by people with intellectual disabilities and diabetes to encourage them to work together more effectively and provide appropriate support.

MONITORED DOSAGE SYSTEM
May be very common...between one-third and a half of all medicines prescribed for long-term conditions are not taken as recommended.

Non-adherence......

• Is not the patient’s problem.
• Is a fundamental limitation in the delivery of health care
• Indicates failure to fully agree the prescription in the first place or to identify and provide the support that patients need later on
Self Care & Diabetes

• Strategies to self-manage diabetes - a nominated buddy to encourage their exercise, and having to provide advice and reminders.

• Advice and support ongoing.
Medication Risk

At the top of the pyramid are people with intellectual disabilities who

• have multiple co morbidities
• are prescribed multiple medications
• are prescribed high risk medications that may require calculation
• prescribed high cost medications
• have poor health literacy
• Services and clinicians such as pharmacists may fail to adequately address communication issues and to understand the complex social networks on which people with intellectual disabilities often rely.

• When there is little understanding of the social networks and communication difficulties in the vulnerable population with intellectual disabilities, mainstream services can have difficulty in instituting successful treatment and management packages.
• Pat appeared to have responsibility for his own self care and medication use.

• His ‘right’ to autonomy was recognised but there would be concerns about the ‘respect’ shown to him as a person deserving of the highest quality of healthcare and the ‘responsibility’ of the healthcare system to protect his ‘right to health’.
Concentration by clinicians, service providers and carers on rights alone without regard to respect and responsibility can place people with intellectual disabilities in the position of making potentially unwise and unhealthy decisions in relation to medication use / non-use and other healthcare decisions.
FOR THE FUTURE
With the move towards ............

community and primary care based services there will be greater reliance of people with intellectual disabilities and society ......

on care providers and families supporting people with intellectual disabilities with their medication use and general healthcare.
Support Staff

Concern has been expressed in England that people with mild, moderate or severe intellectual disabilities with multi-morbidity may be cared for by support staff (if they receive care or support at all) that are ill-equipped to effectively help them coordinate, manage and proactively address their health needs (Heslop et al., 2014b).
How to deliver integrated safe care for people who take medication with

long-term illness e.g. diabetes

complex needs e.g. intellectual disabilities

health literacy problems ????????
Acknowledgements

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• Support organisation staff and management
• Dr Martin Henman, TCD
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