

What are the medication related experiences of adults with learning disabilities?

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BACKGROUND & AIM

Learning or intellectual disabilities are terms used to describe an individual who: has significant impairment of intellectual functioning; has significant impairment of adaptive functioning; and where the age of onset was before adulthood¹. People with learning disabilities (LD) are known to have increased medical needs and are known to be prescribed more medication than the general population². Little is known about their experiences with medication³

The aim of this research was to explore the medication related experiences of community dwelling adults with LD using the Patient's Lived Experience with Medicines (PLEM) conceptual model⁴.

METHODS

After the required ethical approval, qualitative, case-study methodology was used to explore the experiences of 10 community dwelling adults with LD in relation to medication. Data was collected through interviews with adults with LD (where possible), interviews with carers and care workers, observation, and review of Care Provider records.

RESULTS

What medication related burden is experienced by adults with LD?

- Medication was seen as a normal part of life
- Routines could be very particular - see Quote 1
- Sometimes medication dictated the daily timetable
- Swallowing difficulties were an issue
- Adverse events were common and often challenging - see Quote 2
- Medication had a positive effect on the adult with LD's social life
- Burden was often transferred to carers and care workers

What are the medication related beliefs of adults with LD?

- Limited by their level of capacity and capability; often transferred to carers and care workers
- Medication is perceived to be beneficial and necessary - see Quote 3

What is the medication taking practice of adults with LD?

- Adults with LD are compliant but regimens have often been optimised

Quote 1: 'He doesn't like change does he?...He likes the normal routine...If that's not followed right down to the tee then it'll knock him and it'll increase his anxieties as well.'

Case06C-Careworker03

Quote 2: 'Kepra [levetiracetam] rage is what they call it because they just become angry and short fuse...I eventually said to the neurologist that I'm prepared to put up with more seizures if she goes back to being a happy bunny because this is no life for anybody, it's just not right.'

Case02N-Carer01

Quote 3: "...they [duloxetine] take the pain away....I don't get depressed so often...I would never be out of my bed. I wouldn't care about myself or nothing.'

Case08C-Ruth

CONCLUSIONS

Through case study methodology this research explored the medication related experiences of community dwelling adults with LD. These experiences are multifaceted and often shared, or transferred to, any carer or care worker. The outcomes of this research could help support the education and training of relevant health care professionals.

References

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Acknowledgments

Thanks to Pharmacy Research UK and NES for sponsoring this research and to PAMIS www.pamis.org for providing the photo in this poster.

Pharmacy Research UK

