Theory-based interviews with adults with learning disabilities & their carers: An iterative process

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Background

- Adults with mild-moderate learning disabilities (ID) tend to have poorer diets, lower physical activity and greater sedentary behaviour than those in the general population [1,2].
- There have been several previous intervention studies, most using social cognitive theory (SCT), with mixed results. However, not all have aimed to increase self-efficacy as this can be difficult to achieve [3, 4, 5].
- There is a relative lack of research examining perspectives of adults with mild-moderate ID and their carers on what may aid health promotion efforts and theory-based approaches to do so have been lacking.
- This study used an SCT-based approach to address this and inform future intervention efforts.
- Due to cognitive difficulties experienced by adults with ID, an adapted interview protocol was developed to facilitate gathering of data.

Objectives:

- To understand perspectives of adults with mild-moderate ID and carers of what may aid healthy eating, physical activity and reducing sedentary behaviour with this group, using a social cognitive theory-based approach.
- To assess feasibility of using a theory-based approach with adults with ID and how this can be adapted to facilitate their participation.

(Social Cognitive Theory, [6, 7])

Method

N = 24 (12 adults with mild-moderate ID, 12 carers. The latter were support workers, family relatives and managers of social care and day services).

Inclusion: Adults with ID who were 18+ years old, able to give informed consent, have sufficient communication skills to answer basic questions verbally.

Carers supporting adults with mild-moderate ID (directly or indirectly) for 3+ months, provided support within 3 months or close family relative of an adult with ID

Exclusion criteria: Adults with ID who were primarily non-orally fed (e.g. PEG feeding) or terminally ill.

Recruitment: Participants were approached via the lead researchers' contacts within a social care setting and local partner organisations via convenience sampling.

The interview guide included use of pictures and vignettes to aid participation.

<p>3)-For what reasons might an adult with a (mild-moderate) learning disability want (or need?) to consider eating a healthier diet? (your service users/family member?)</p> <p>Outcome expectancies</p>	<p>Syrah has a moderate learning disability and lives in a shared home with other people who have learning disabilities. Her doctor says that she needs to do more exercise. What exercise can people do? (knowledge)</p> <p>Where would you go to find out more about different types of exercise? (knowledge, social support)</p>
<p>4)-What can help them to achieve this?</p> <p>Facilitators</p>	<p>Where can people do exercise? (knowledge)</p> <p>Who can Syrah go to if she wants help to do more exercise? (social support)</p>
<p>5)-How about the role of social support? (from carers? Peers? Others – anyone else?)</p> <p>Positive social support</p>	<p>What can Syrah do to make sure she does more exercise? (planning, goal-setting)</p>
<p>6)-What might hinder this? (get in the way/make it harder or more difficult?)</p> <p>Barriers</p>	<p>Scenario 2:</p> <p>Syrah has decided she would like to go for walks, but she is feeling a bit lazy today. What can she do or say to help herself get some exercise today? (self-efficacy)</p> <p>What can Syrah get out of doing some exercise? (outcome expectancy)</p> <p>What can make it more easy for her to do exercise? (facilitators)</p> <p>What can make it more hard? (barriers)</p>
<p>7)-What about the influence of others? In what ways can that make it harder?</p> <p>Negative social support</p>	
<p>8)-What might make, in your experience, a service-user/family member more confident they can move to/maintain a healthier diet? (particularly in the face of obstacles – e.g. low mood, when they're busy, at a social event?)</p>	
<p>9)-What can help you/other people who support a person/persons with learning disabilities feel more confident to help them have/maintain a healthy diet? (in the face of other obstacles such as competing demands, time constraints, challenging behaviour, considerations of choice?)</p>	

Interview process

Results

- An iterative approach was useful for gathering data, particularly facilitating participation of adults with ID and following up ideas explored in interviews with carers (e.g. use of pictures to aid monitoring and role modelling).
- Interviewing managers and experienced carers at the beginning helped gather rich data to build on for later interviews. Having well developed professional networks in social care settings helped to implement a targeted sampling strategy.
- For several participants with ID using closed questions or presenting simplified alternatives was needed as understanding and communication skills varied significantly.
- Adapting vignettes to reflect lived circumstances of participants with ID helped them to engage with these (e.g. if they were living in a supported living context, so did the characters in the vignettes used). Having more than one vignette available to tap into constructs was also helpful.
- The findings were used to guide development of a health promotion intervention.

Discussion

- Involving carers and adults with ID in future theory-based interview research on intervention development is **feasible**. This can help **develop interventions** with adults with ID and **guide staff training** on providing effective support.
- However, **cognitive ability** will significantly **moderate** this for adults with ID and it may not always be possible to ascertain this at the outset, even in discussion with those that know them well beforehand.
- Adults with ID may also continue to participate even if they are uncomfortable in order to **please the researcher**, so visiting them beforehand, establishing **rapport**, **understanding how they communicate discomfort or distress** and **monitoring** for signs of this during interviewing is important to ensure they participate freely and withdraw consent if they wish to do so.
- It would be highly recommended to encourage an adult with ID to **participate with a carer** present if they show **difficulties understanding and responding** to more complex questions, but this is difficult due to time and resource constraints. Carers also need to feel they are **not coerced into helping**. An adult with ID may only wish to participate with support so key persons in their life may be approached with their permission, but if unsuccessful they will need to be withdrawn from the study.
- It can be **difficult to precisely examine constructs intended** (e.g. outcome expectancies rather than motivation). Adults with ID may also misinterpret questions and need regular breaks. Thus it **may sometimes help to focus questions on particular topics of interest** in greater depth (as they arise, or if some areas are relatively understudied compared to others).

References

- [1] Dunkley, A. J., Tyrer, F., Gray, L. J., Bhaumik, S., Spong, R., Chudasama, Y. et al., (2017), Type 2 diabetes and glucose intolerance in a population with intellectual disabilities: the STOP diabetes cross-sectional screening study, *Journal of intellectual disability research*, 61 (7), 668-681
- [2] Melville, C. A., Oppewal, A., Elinder, L.S., Freiburger, E., Guerra-Balic, M., Hilgenkamp, T. I. M. et al. (2017), Definitions, measurement and prevalence of sedentary behaviour in adults with intellectual disabilities – A systematic review, *Preventive Medicine*, 97, 62-71
- [3] McDermott, S., Whitner, W., Thomas-Koger, M., Mann, J. R., Clarkson, J., Barnes, T. L. et al., (2012), An efficacy trial of 'Steps To Your Health', a health promotion programme for adults with intellectual disability, *Health Education Journal*, 71 (3), 278-290
- [4] Perez-Cruzado, D. & Cuesta-Vargas, A. I. (2016), Changes on quality of life, self-efficacy and social support for activities and physical fitness in people with intellectual disabilities through multimodal intervention, *European Journal of Special Needs Education*, 31 (4), 553-564
- [5] Conner, M. & Norman, P. (2015), *Predicting and changing health behaviour: research and practice with social cognition models*, Maidenhead, UK: Open University Press
- [6] Bandura, A. (1986), *Social foundations of thought and action: a social cognitive theory*, NJ: Prentice-Hall.
- [7] Bandura, A. (2000), Social cognitive theory: an agentic perspective, *Annual Review of Psychology*, 52 (1), 1-26.