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Extended Research Article

Understanding the effectiveness and underlying mechanisms of lifestyle modification interventions in adults with learning disabilities: a mixed-methods systematic review

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Scientific summary

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Scientific summary

Background

Adults with learning disabilities are at an increased risk of unhealthy lifestyles consisting of multiple behaviours, including alcohol consumption, smoking, low physical activity, sedentary behaviour and poor diet. These health-risk behaviours often occur together and significantly impact their life expectancy. Lifestyle modification interventions that target health-risk behaviours can prevent or reduce such negative effects.

Aims and objectives

The goal of our project was to investigate the effectiveness and underlying mechanisms of lifestyle modification interventions in adults with learning disabilities.

Following are our objectives:

1. to determine the effectiveness of lifestyle modification interventions and their components in targeting health risk behaviours in adults with learning disabilities;
2. to establish how lifestyle modification interventions for adults with learning disabilities work, for whom they work, as well as why they may work in particular circumstances and not in others;
3. to integrate the findings of the quantitative and qualitative syntheses using a logic model;
4. to identify future research priorities to develop lifestyle modification interventions for the NHS and social care services to improve the health of adults with learning disabilities.

Methods

We conducted a mixed-methods evidence synthesis, which includes a systematic review, meta-analysis and realist evidence synthesis. Our patient and public representatives were consulted throughout the process.

Systematic review and meta-analysis

Our systematic review included randomised controlled trials (RCTs) and non-randomised controlled trials (controlled and uncontrolled pre–post studies and case-control studies) of lifestyle modification interventions for adults with learning disabilities.

Participants aged ≥ 18 years were considered as adults. Learning disability was defined as a limitation in intellectual functioning (intelligence quotient < 70) and adaptive behaviour with onset before age 18 years.

We included lifestyle behaviour change interventions targeting one or more of the following health-risk behaviours: alcohol consumption, smoking (cigarettes or tobacco), low physical activity only, sedentary behaviour and poor diet. We included studies that measured and reported any primary or secondary outcomes of lifestyle modification interventions.

We searched key databases, clinical trial registries, grey literature and additional sources such as citations of systematic reviews and included studies. Two review authors independently assessed studies for inclusion data. Three authors extracted the data and coded the extent of theory use and behaviour change techniques in interventions using Michie's 19-item theory coding scheme and 94-item behaviour change taxonomy. They also assessed the risk of bias in studies using the Cochrane Risk of Bias (ROB) Version 2 and Risk of Bias in Non-randomised Studies of Interventions (ROBINS-I).

We also conducted an intervention-level and component-level meta-analysis of weight management outcomes reported by randomised clinical trials whose interventions targeted low physical activity, sedentary behaviour and poor diet. The pairwise meta-analysis determined the effectiveness of all lifestyle modification interventions compared with treatment as usual (TAU). The network meta-analysis determined the effectiveness of all lifestyle modification interventions compared directly and indirectly with each other and TAU. A random-effects model was used. This analysis was extended to a component network meta-analysis to identify the most effective components of lifestyle modification interventions targeting weight management outcomes. An additive model, which assumes the effect of a multicomponent intervention is the sum of individual effects of each component, was used.

Realist synthesis

The realist synthesis was conducted to develop a programme theory to identify the contexts and mechanisms (e.g. how the intervention works: behavioural and emotional responses) that together contribute to intervention outcomes. First, a draft programme theory was based on non-systematic search of the literature and input from expert researchers and the patient and public involvement (PPI) group. Following this, formal searches were conducted and the systematic screening procedures were used to select a short list of eligible studies. This was conducted simultaneously with the systematic review. The formal searches conducted were used to shortlist a selection of studies. Following realist synthesis guidelines, these were then appraised for relevance to the programme theory and methodological rigour using pre-selected quality appraisal tools. Additional searches were conducted to address any gaps in the literature.

To synthesise the data, the richest sources were identified through rereading the studies. These were uploaded to NVivo, and a coding framework was developed. After this was finalised through iterative discussions between two researchers, the remaining studies were uploaded, and the coding framework was applied. Following this, the specific interacting contexts and underlying mechanisms were appraised, and the synthesis focused on developing context–mechanism–outcome configurations (CMOCs), which formed the basis of the emerging programme theory. This was finalised through discussions and feedback with the wider research team and the PPI group.

Results

Systematic review and meta-analysis

We found 80 studies (35 RCTs, 11 controlled pre–post studies, 28 uncontrolled pre–post studies and 6 case-control studies), with 4805 participants reporting the effects of interventions targeting alcohol consumption, smoking, low physical activity only, sedentary behaviour and poor diet. We identified and defined a range of core components present in lifestlyle modification interventions based on the descriptions of included studies and any follow-up studies. Core components are single or multiple interacting contents of an intervention which influence its outcomes. We identified six core components of the interventions and comparators: (1) aerobic exercise; (2) resistance exercise; (3) energy-deficit diet; (4) diet advice; (5) mindfulness; and (6) behaviour change techniques. Interventions and comparators could comprise of any combinations of these core components. These components could be present in interventions targeting single or multiple health risk behaviors, either individually or in various combinations. It must be noted that the behaviour change technique component was only identified if explicitly stated by the study. Whereas, Michie's 94-item behaviour change taxonomy is a tool used separately to identify the extent which these techniques were used.

We have reported our findings according to the target health behaviour of the studies.

- Six studies with 228 participants targeted alcohol consumption and smoking behaviour. This included two RCTs, one controlled pre–post and three uncontrolled pre–post studies. Core components of interventions and comparators consisted of behaviour change techniques, mindfulness and a combination of both. These interventions targeted behavioural, cognitive, knowledge-related, psychosocial and quality-of-life outcomes of participants. The RCT-based intervention for alcohol consumption had mixed effectiveness results, improving behavioural outcomes but worsening quality of life outcomes. The RCT-based smoking intervention also improved behavioural outcomes. Among the non-RCTs, the strengths of improvement in outcomes varied, a strong improvement was observed on knowledge-related outcomes. However, these results were based on limited evidence and had a varying level of statistical significance.

- Thirty-three studies with 1413 participants targeted low physical activity only behaviour. This included 16 RCTs, 2 controlled pre–post, 13 uncontrolled pre–post and 2 case-control studies. Core components of interventions and comparators primarily consisted of aerobic exercise only or a combination of aerobic exercise, resistance exercise, behaviour change technique and mindfulness. These interventions targeted anthropometric, cardiorespiratory, functional and general health outcomes. In RCTs, intervention effectiveness was mixed, leading to improvements in outcomes as well as instances of no change or worsened outcomes. Non-RCTs also exhibited a similar range of effects on outcomes across different studies. No change or worsened outcomes could be attributed to the presence of a single core-component or a combination of similar core-components. However, the interventions had a varying level of statistical significance.
- Forty-one studies with 3164 participants targeted multiple behaviours, that is, low physical activity, sedentary behaviour, and poor diet together. This included 17 RCTs, 8 controlled pre–post, 12 uncontrolled pre–post and 4 case-control studies. Core components of interventions and comparators primarily consisted of a combination of energy-deficit diet (EDD), aerobic exercise and behaviour change technique. Other component combinations included diet advice and resistance excercise. These interventions targeted anthropometric, behavioural, cardiorespiratory, functional, cognitive, food and nutrition, physical activity and sedentary behaviour-related, psychosocial, quality of life and general health outcomes. Similar to the low physical activity-only interventions, multiple behaviour interventions reported results of mixed effectiveness. RCT-based interventions resulted in improvements across a range of outcomes, although the strength of these effects varied or, in some instances, led to no change or adverse outcomes which could be attributed to the presence of a single core-component or a combination of similar core-components. Similar results were observed in non-RCTs. Compared to interventions targeting low physical activity only, fewer studies with interventions targeting multiple behaviours reported no change or worsened outcomes. However, the interventions had a varying level of statistical significance.

Our meta-analysis was conducted on weight management outcomes: change in weight, change in body mass index (BMI), change in waist circumference and change in body fat. The pair-wise meta-analysis was conducted on two weight management outcomes: change in weight and change in BMI. The network meta-analysis was conducted on all weight management outcomes listed above.

- Change in weight (kg): Pair-wise meta-analysis (9 RCTs, 542 participants) found that the change in weight by the lifestyle-modifying interventions was not significant when compared to the TAU (mean difference = −0.46; 95% CI −1.25 to 0.33). Network meta-analysis (13 RCTs, 690 participants, 8 interventions) showed that the change in weight ranged from a decrease of 3.7 kg to an increase of 700 g when compared to TAU. None of the interventions could show a statistically significant change in weight.
- Change in BMI (kg/m^2): Pair-wise meta-analysis (11 RCTs, 721 participants) found that the change in BMI by the lifestyle-modifying interventions was not significant when compared to TAU (mean difference = −0.45, 95% CI −1.05, 0.15). Network meta-analysis (13 RCTs, 798 participants, 9 interventions) showed that the change in BMI ranged from a decrease of 1 kg/m^2 to an increase of 0.6 kg/m^2 when compared to TAU. None of the interventions could show a statistically significant change in BMI.
- Change in waist circumference (cm): we found a disconnected network (8 RCTs, 378 participants, 6 interventions). Our network meta-analysis showed that none of the interventions could show a significant change in waist circumference when compared with TAU (a decrease of 2.8 cm to an increase of 1.8 cm). None of the interventions could show a statistically significant change in waist circumference (cm).
- Change in body fat: we found a disconnected network (4 RCTs with 139 adults evaluating 4 interventions). In a connected network, the TAU was not the comparator. Instead, the comparator was dietary advice and aerobic exercise. None of the interventions could show a statistically significant change in body fat.

For the component network meta-analysis (CNMA), we included core components, as mentioned above, and identified further components that were deemed as important by our PPI group members. This included mode of delivery of interventions, availability of support mechanisms, and residence status. We also combined aerobic exercise and resistance exercise core components as exercise. Exercise was the most common intervention component. CNMA was conducted only for BMI outcomes due to the availability of extensive data. Our analysis showed that none of the individual components could produce a statistically significant change in BMI when compared to TAU.

Overall, our review found that adults with learning disabilities who are of ethnicities other than Caucasian, who are older than 65 years, who have long-term medical conditions and who have severe to profound levels of learning disabilities are underrepresented in the studies. The evidence base in this field is imbalanced in terms of the health behaviours targeted by the interventions.. It also lacks methodological and reporting rigour. There is a lack of high-quality, appropriately powered studies in this field. Sample size is often unjustified. The intervention, its intensity and follow-up period varied across studies. Most studies had short follow-ups (maximum of 12–18 months). Primary and secondary outcomes were not always clearly defined in studies. Variety of outcomes also contributed to studies neglecting the correlation between multiple outcomes, and the same outcome measures at multiple time points. There was a lack of standardised measures used to assess similar outcomes. Other important information about participant and intervention characteristics, including extent of theories and behaviour change techniques used in intervention development, was limited.

Realist evidence synthesis

A total of 79 studies were included in the realist evidence synthesis. These included intervention studies along with relevant qualitative and mixed-methods studies. The programme theory developed consisted of 33 CMOCs and involved 6 partial programme theories. These partial programme theories are related to negotiating the balance between autonomy and behaviour change, importance of support involvement, accessibility and suitability of intervention strategies, delivery of the intervention, social connectedness and fun and the broader pathways to behaviour change. The programme theory emphasised the complexity of lifestyle modification for adults with learning disabilities and the importance of including people with lived experiences when developing interventions.

Synthesis of findings

We integrated the findings from the systematic review, meta-analysis and realist evidence synthesis by developing a logic model. We started by examining the studies that were included in both the systematic review and realist evidence synthesis to explore why some interventions were (in)effective. Our logic model shows the intervention mechanisms and provides guidance on designing an appropriate lifestyle modification intervention for a maximum and long-lasting impact on lives of adults with learning disabilities.

Conclusion

This study was the first comprehensive mixed-methods evidence synthesis to explore lifestyle modification interventions targeting multiple unhealthy lifestyle behaviours in adults with learning disabilities. The study was coproduced with people with learning disabilities and ensured the findings reflected their needs and experiences. Our quantitative and qualitative findings complement each other.

Key research recommendations:

1. Codevelop new research studies with people living with learning disabilities. There needs to be greater reflection on how to make methods more accessible to improve the inclusion of adults with severe and profound learning disabilities in research.
2. Undertake research to codevelop population-specific materials, including new frameworks for assessing extent of theory and behaviour change taxonomies used in development of interventions.
3. Undertake research to address variability in methodologies used in assessing effectiveness of interventions in research studies. This includes designing high-quality studies with appropriate outcomes.
4. Undertake more qualitative and mixed-method research to improve understanding of what works, for whom and why.

Key recommendations for policy and practice:

1. New lifestyle interventions need to be co-designed with people living with intellectual disability and their caregivers.
2. There is unlikely to be a one-size-fits-all approach, instead a more holistic person-centred approach is required that addresses root causes, is tailored to individual context and codeveloped with the individual and their carers.

3. Communications should be clear, simple, precise and codeveloped with the target audience.
4. Future interventions should include peer support, fun, group-based activities and opportunities for social interaction. All of which can offer important far-reaching benefits such as improved well-being and quality of life which should be considered as part of a person-centred compassionate approach to long-term care and measured accordingly.

Trial registration

This trial is registered as PROSPERO CRD 42020223290.

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