One-to-one volunteer befriending to reduce symptoms of depression in people with intellectual disability: a feasibility RCT

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Scientific summary

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Background

People with intellectual disability are more likely to experience chronic depression. They are more likely to be exposed to multiple social disadvantages, including smaller social networks, and have a higher prevalence of loneliness than the general population. These factors may increase their risk of depression.

Befriending is a relationship between two or more individuals that is initiated, supported and monitored by an external agency, and is characterised by a one-to-one friendship-like relationship. Befriending aims to increase social and emotional support, and enhance social networks and community participation. There is some evidence from other populations that befriending may reduce depressive symptoms, but no randomised controlled trials have been conducted in people with intellectual disability.

Objectives

The aim of the pilot study was to determine the feasibility and acceptability of a full-scale randomised controlled trial of one-to-one befriending by volunteers for people with intellectual disability, in addition to usual care, compared with an active control group.

The objectives were to:

- examine the recruitment and retention of individuals with intellectual disability and volunteers in the trial, and the number of successfully matched pairs
- record any adverse effects of befriending
- measure the adherence to the intervention by volunteers and the befriending schemes
- examine the acceptability of the intervention and study procedures
- examine changes in health and social outcomes by carrying out exploratory analyses of the impact of befriending on depressive symptoms (primary clinical outcome), measured by the Glasgow Depression Scale for people with a Learning Disability, and other outcomes (e.g. self-esteem, loneliness, quality of life and social participation) at 6 and 12 months post randomisation
- carry out exploratory analyses of the impact of befriending on volunteers' well-being, self-esteem, loneliness and attitudes towards people with intellectual disability at 6 and 12 months
- estimate the sample size required and determine the final trial design for a full-scale randomised controlled trial
- assess the feasibility of collecting data that would inform a future analysis of cost-effectiveness.

Methods

This was a parallel-group, two-armed randomised controlled trial with 1 : 1 individual participant randomisation to either the intervention group (befriending, resource booklet and usual care) or the control group (resource booklet and usual care). We aimed to approach 50 people with intellectual disability, with a view to recruiting 40 eligible participants. Participants with intellectual disability were recruited from intellectual disability services in North East London NHS Foundation Trust and from referrals to two community befriending services (based in Suffolk and Hackney). Volunteers were recruited by the befriending services through advertisements in local newspapers, on websites and social media, and via colleges. Outcome assessments were planned for baseline, and 6 and 12 months post randomisation. However, as a result of delays in the set-up of the study, only the 6-month follow-up was completed. The research assistant who completed the follow-up assessment was blind to group allocation.

A process evaluation was conducted to explore the acceptability of and adherence to the intervention. Interviews were conducted with participants with intellectual disability, volunteers, volunteer co-ordinators and carers to obtain feedback on their experiences of the intervention and study processes, whether or not there were any perceived benefits, and suggestions for improvements. Volunteer logbooks, and training and supervision logs completed by the volunteer co-ordinators were analysed.

The main progression criteria that were used to assess the success of the trial were:

- At least 70% (35) of participants are recruited from the 50 potentially eligible individuals who are approached.
- At least 70% of participants in the intervention group are successfully matched to a volunteer (befriender) and meet for a minimum of 10 meetings.
- The dropout rate of participants in both groups, post randomisation, is < 30% at 6 months' follow-up.
- The intervention and trial procedures are considered acceptable by volunteers and individuals with intellectual disability.

Ethics approval was received from the London – City and East – Research Ethics Committee (reference 18/LO/2188).

Inclusion and exclusion criteria

The inclusion criteria for participants with intellectual disability were as follows:

- aged ≥ 18 years
- mild or moderate intellectual disability (i.e. an intelligence quotient of 35–69) assessed using the Wechsler Abbreviated Scale of Intelligence™ (Second Edition)
- not attending college/education or a day service for ≥ 3 days per week
- a score of ≥ 5 on the Glasgow Depression Scale for people with a Learning Disability
- ability to speak English
- ability to provide informed consent.

Volunteers were:

- aged ≥ 18 years
- available once per week for at least 1 hour, over a period of 6 months.

Individuals with intellectual disability were excluded:

- if they had limited communication and comprehension skills that would prevent completion of the questionnaires.

Volunteers were excluded if they:

- had a criminal record (any documented offence, owing to the vulnerability of this population) recorded on their Disclosure and Barring Service check
- were unable to provide two references or had unsuitable references.

Randomisation

Randomisation was carried out by an unblinded member of the research team using a web-based randomisation system (sealed envelope™; Sealed Envelope Ltd, London, UK), which used randomly varying block sizes stratified by befriending service. This system randomly allocated participants to either the intervention group or the control group in a 1 : 1 ratio.

Intervention

The befriending intervention was managed by the befriending services that recruited, trained and supervised the volunteers. Participants in the intervention group were matched to a volunteer based on interest and availability. The pairs were provided with a resource booklet of local activities and were expected to meet once per week for a minimum of 1 hour, over the course of 6 months. A minimum of 10 meetings was considered adequate and at least half of the activities were expected to be in the community. Volunteers received monthly supervision by the volunteer co-ordinator and participants with intellectual disability were also contacted as part of the monitoring process. Volunteers recorded their activities in a structured logbook.

Outcomes

The following outcomes were assessed:

- recruitment and retention rates, and the number of participants with intellectual disability who had been matched with a volunteer
- adherence to the intervention, based on the number of meetings completed by volunteers and by training and supervision logs
- the acceptability of the intervention, based on feedback from interviews carried out as part of the process evaluation
- symptoms of depression in participants with intellectual disability, measured using the Glasgow Depression Scale for people with a Learning Disability (primary clinical outcome)
- other social outcomes, namely self-esteem (measured using the adapted Rosenberg self-esteem scale), quality of life (measured using the Maslow Assessment of Needs Scale – Learning Disability and the adapted World Health Organization Quality of Life measure), loneliness and social satisfaction (measured using the Modified Worker Loneliness Questionnaire), social support (measured using the Social Support Self Report for intellectually disabled adults) and social participation (measured using the Guernsey Community Participation and Leisure Assessment)
- outcomes in volunteers, namely self-esteem (measured using the Rosenberg self-esteem scale), psychological well-being (measured using the Warwick–Edinburgh Mental Wellbeing Scale), loneliness (measured using the University of California, Los Angeles, Loneliness Scale) and attitudes towards people with intellectual disability (measured using the Attitudes Towards Intellectual Disability Questionnaire).

To assess the feasibility of conducting a future economic evaluation, data on intervention costs, health services resource use (measured using the adapted Client Services Receipt Inventory) and health-related quality of life (measured using the EuroQol-5 Dimensions – Youth) were also collected.

Data management and analysis

Quantitative data were collected using the study case report forms and entered into a secure web-based database. Data on recruitment and retention are presented in a Consolidated Standards of Reporting Trials flow diagram showing the flow of participants through the study. As a result of the limited data that we were able to collect, data analysis was restricted to descriptive statistics. However, regression analysis to explore the effects of befriending on depressive symptoms was performed, as this was the main clinical outcome of interest.

Results

Recruitment and retention

Over a 6-month period, 24 referrals were received, of which 21 were assessed and 16 participants with intellectual disability were eligible and agreed to be randomised. Twelve volunteers expressed an interest and 10 completed the necessary checks and training. Owing to delays in setting up the study and the slow rate of referrals, an extension to the recruitment period was not granted and, therefore, we were not able to implement significant changes to the recruitment strategy. Of the eight participants who were randomised to the intervention group, six were matched to a befriender (75%) with whom they met on at least one occasion. There was no dropout of participants with intellectual disability, but two volunteers dropped out (20% dropout). One participant had to be rematched after their volunteer left.

Adverse events and unintended consequences

There were no adverse events reported in participants with intellectual disability. However, the 12-month assessment could not be completed and, therefore, it was not possible to monitor adverse effects beyond 6 months. There was a positive outcome for one participant who was encouraged by their volunteer to report that they were being mistreated by a paid carer at their accommodation. One volunteer experienced conflict with paid carers at the befriendee's supported living placement, which led to the volunteer becoming distressed and dropping out of the study.

Adherence

The mean number of meetings completed by matched pairs was 11.8, which was above the minimum threshold of 10 meetings (although only four pairs completed more than 10 sessions). The average duration was 118 minutes (above the minimum stipulated duration of 60 minutes). The majority of activities were outside the home (63.3%) and included visits to cafes and restaurants and going for walks. Five volunteers participated in supervision, and the mean number of sessions completed was 4.2.

Acceptability

The low recruitment rate suggests that the intervention may not be acceptable to some individuals with depressive symptoms. However, the dropout rate of both participants with intellectual disability and volunteers was low, which suggests that the intervention may have been acceptable to those who participated in the study. Data from the limited number of interviews that were conducted suggest that volunteers were satisfied with the trial processes, although some participants with intellectual disability reported not understanding relevant information about the study, including randomisation. Participants, volunteers and carers reported positive experiences of the intervention, and there were benefits for all three groups. However, the intervention was perceived to be too rigid and prescriptive in terms of frequency of visits (once per week was too frequent) and the nature of contacts (other types of contacts should be encouraged, e.g. via social media). Suggestions were made to improve the recruitment process for volunteers (e.g. through the hosting of events) and to make the training more practical.

Exploratory analysis of the primary outcome

After adjustment for depressive symptoms at baseline, the Glasgow Depression Scale for people with a Learning Disability score was lower in the intervention group than in the control group (adjusted mean difference −4.0, 95% confidence interval −11.2 to 3.2). It is not possible to draw any conclusions because of the very small sample size and differences between the two groups at baseline.

Exploratory heath economic evaluation

It was possible to collect data on health resource use from carers in the majority of cases. However, there were discrepancies observed between participants' ratings on the EuroQol-5 Dimensions – Youth and the EuroQol visual analogue scale, indicating that it may be more appropriate to use both of these measures alongside a proxy measure of health-related quality of life in a future study.

Conclusions

We recruited only 40% of the numbers required and, therefore, we did not meet our progression criterion in relation to recruitment. This suggests that recruitment would not be feasible in a larger trial using the same methods. We overestimated the number of people who would be recruited through the befriending services, and when these issues became apparent there was insufficient time to implement changes. During the study, one of the befriending services experienced funding cuts, which had implications for staffing and is likely to have had an impact on the recruitment of both volunteers and participants with intellectual disability.

The other feasibility outcomes relating to matching, retention of participants and adherence to the intervention were met, and the positive reports from volunteers and participants suggest that the intervention may be acceptable to those who took part, although some modifications were suggested. Based on our limited data, we found that, at 6 months, the score for depressive symptoms on the Glasgow Depression Scale for people with a Learning Disability was 4 points lower in the intervention group than in the control group, which is a meaningful difference, but there were baseline differences in comorbidities between the two groups and, therefore, this finding should be interpreted with caution. It is therefore important that the impact of befriending in people with intellectual disability continues to be evaluated, although a randomised trial is unlikely to be feasible. Other study designs, such as observational studies, should be considered.

Trial registration

This trial is registered as ISRCTN63779614.

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