Tobacco and alcohol-related interventions for people with mild-moderate intellectual disabilities: a systematic review of the literature.

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Tobacco and alcohol-related interventions for people with mild/moderate intellectual disabilities: a systematic review of the literature

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Abstract

Background The behavioural determinants of health among people with mild/moderate intellectual disabilities (ID) are of increasing concern. With the closure of long-stay institutions, more people with ID are living in the community. As they lead more ordinary and less restricted lives, people with ID may be exposed to social and environmental pressures that encourage them to adopt behaviours that impact negatively on their health. Levels of smoking and alcohol consumption in this client group are of particular concern.

Methods We undertook a mixed method review of the literature, aiming to assess the Feasibility, Appropriateness, Meaningfulness and Effectiveness (FAME) of interventions designed to address the use of tobacco and/or alcohol in people with mild/moderate ID. Key electronic databases were searched (e.g. Medline, Cochrane Register of Controlled Trials, PsycINFO) from 1996 to 2011. The search was developed using appropriate subject headings and key words (e.g. intellectual disability, tobacco use, alcohol drinking, health promotion). On completion of the database searches, inclusion/exclusion criteria, based on an adaptation of the PICO framework (Population, Intervention, Comparison, Outcomes), were applied. Methodological quality was assessed using a seven-point rating scale.

Results Database searches identified 501 unique records, of which nine satisfied the inclusion criteria. Four focused on tobacco, three on alcohol and two on both tobacco and alcohol. Located in the UK, the USA and Australia, the studies aimed to increase knowledge levels and/or change behaviour (e.g. to encourage smoking cessation). One was a randomised controlled trial, one a quasi-experiment and the others were before and after studies and/or case studies. Methodological quality was poor or moderate. The combined studies had a sample size of 341, with ages ranging from 14 to 54 years. The interventions were delivered by professionals (e.g. in health, social care, education) during sessions that spanned a period of three weeks to one academic year. The studies highlighted a number of important issues linked to the appropriateness of interventions for this client group (e.g. use of pictures, quizzes, role play, incentives); however, in the majority of
cases the interventions appeared to lack a theoretical framework (e.g. behaviour change theory). The appropriateness of the outcome measures for use with this client group was not tested. One study discussed feasibility (teachers delivering lessons on alcohol and tobacco) and only one was informative in terms of effectiveness i.e. increasing knowledge of the health and social dangers of smoking and excessive alcohol consumption.

Conclusions This review is the first to systematically collate evidence on tobacco and alcohol-related interventions for people with ID. While there is currently little evidence to guide practice, the review delivers clear insights for the development of interventions and presents a strong case for more robust research methods. In particular there is a need to test the effectiveness of interventions in large-scale, well-designed trials and to ensure that outcome measures are developed/tailored appropriately for this client group.

Keywords alcohol, health promotion, intellectual disability, mixed methods review, smoking

Introduction

Epidemiological studies demonstrate that intellectual disability (ID) is a common condition worldwide (World Health Organisation 2007a). Reported prevalence in the developed world ranges from 3 to 30 per 1000 members of the population. Variations in prevalence across countries are linked to different methods of case ascertainment, inclusion/exclusion criteria and classification (Fujiura & Taylor 2003; Leonard et al. 2003; NHS Health Scotland 2004; Emerson & Hatton 2008; Sendenaa et al. 2010). In Scotland, estimates suggest that 3–4 people in every 1000 have a severe/profound ID and that 20 people in every 1000 have a mild/moderate ID (NHS Health Scotland 2004).

While people with ID have an increased risk of early death, life expectancy is rising over time, and for people with a mild ID, it is approaching that of the general population (Patja et al. 2000; NHS Health Scotland 2004; Emer Lavin et al. 2006; Emerson & Hatton 2008). Improvements in the health of people with ID are linked to advances in medical science and an increase in proactive treatment; however, health problems in this client group, as a whole, continue to be more common and complex than in the general population and so much still needs to be accomplished to improve health and reduce inequalities (NHS Health Scotland 2004; Robertson et al. 2010).

In recent years there has been increasing concern regarding behavioural determinants of health among people with ID (Emerson & Hatton 2008). With the closure of long-stay institutions, more people with ID are living in the community with support from their family and/or health and social care professionals (Department of Health 2001). As they lead more ordinary and less restricted lives, people with ID may be exposed to social and environmental pressures that encourage them to adopt behaviours that impact negatively on their health (Emerson & Turnbull 2005; Taggart et al. 2008).

Smoking and excessive alcohol consumption have been identified as two of the most significant behavioural risks to health in the developed world (World Health Organisation 2002). In England and Wales the prevalence of smoking is currently 21% (Office for National Statistics 2011); in Scotland it is 24.2% (Scottish Government 2011). Rates of smoking among people with mild/moderate ID appear to be similar to the general population (Emerson & Turnbull 2005).

The health-related consequences of smoking are well established. Similar to the general population, people with ID who smoke have an increased risk of developing a range of health problems including cancer, heart disease, chronic obstructive pulmonary disease, circulatory problems, stroke and cognitive decline (Royal College of Physicians 2000). Smoking also exacerbates a number of conditions prevalent among people with ID, such as diabetes (Meyer et al. 2000; Royal College of Physicians 2000).

In terms of alcohol consumption, approximately 26% of men and 18% of women in the general population in the UK regularly exceed the recommended weekly limits of 21 units for men and 14 units for women (Office for National Statistics 2011). Binge drinking is common, particularly in young men (Office for National Statistics 2011). Alcohol consumption/excessive consumption in people with ID, is, in the main, lower than in the general population (e.g. Emerson & Turnbull 2005; Taggart et al. 2006). However, levels of alcohol consumption in people with mild ID appear to be
similar to those in the general population (McGillivray & Moore 2001; George et al. 2009; Taylor et al. 2010). Long-term health problems associated with persistent heavy drinking include skin and hair damage, circulatory disorders, anaemia, cancer, gastric irritation, cardiac and cerebrovascular disease, neurological disorders and liver disease (World Health Organisation 2007b). Excessive alcohol consumption is also associated with mental health problems, including stress, anxiety and depression (World Health Organisation 2007b).

With the recent introduction in the UK of primary care-based annual health checks for people with ID, greater efforts are now being made to identify and address the physical and mental health needs of this population (Robertson et al. 2010; Royal College of General Practitioners 2010). While general practitioners and practice nurses are encouraged to ask about smoking and alcohol consumption (Royal College of General Practitioners 2010), there is little evidence regarding the accuracy of the information gathered. For example, issues relating to quantity, the strength of alcoholic beverages and units of alcohol are particularly difficult for people with ID to understand (Lawrence et al. 2009). Another important issue is that while health checks have been shown to detect unmet needs and to prompt delivery of targeted interventions, a recent systematic review of the effectiveness of health checks for people with ID highlighted that few studies have explored the short, medium and long-term impact of interventions on health status and/or health-related behaviour (Robertson et al. 2010).

Linked to the above, while generic evidence-based approaches exist to encourage and support smoking cessation attempts and the consumption of alcohol at non-hazardous/harmful levels, studies included in the systematic reviews that inform contemporary Guidelines for practice have generally excluded people with cognitive and/or communication impairments (e.g. National Institute for Health and Clinical Excellence 2006). Therefore, it cannot be assumed that these generic approaches are appropriate for people with ID. Indeed, key policy documents highlight the need to tailor interventions for this client group, taking into account specific communication and learning needs that may impact on health literacy (e.g. Disability Rights Commission 2004; NHS Health Scotland 2004; Robertson et al. 2010).

Our preliminary searches of the published literature highlighted that evidence-based tobacco and/or alcohol-related health promotion interventions for people with ID are rare (Lawrence et al. 2009). In response to this identified gap in the evidence-base, and guided by the Medical Research Council (MRC) framework for the development and evaluation of complex healthcare interventions (MRC 2008), we are undertaking a programme of research which aims to develop, implement and evaluate tobacco and alcohol-related health promotion interventions for people with mild/moderate ID. In the developmental phase (MRC 2008), we sought to explore the current evidence base and to undertake primary research with key stakeholders, including people with ID (Lawrence et al. 2009). This paper reports the results of our review of the evidence base.

Aim

We undertook a mixed methods review of the literature. Our aim was to assess the Feasibility, Appropriateness, Meaningfulness and Effectiveness (FAME) of interventions designed to address the use of tobacco and/or alcohol by people with mild/moderate ID. The FAME Model was developed by the Joanna Briggs Institute (JBI) for Evidence-Based Healthcare to complement their inclusive approach to the categorisation, synthesis and implementation of evidence (Pearson 2004; Pearson et al. 2005). In this context, the term feasibility refers to evidence that demonstrates whether it is possible to implement an activity or intervention within a given context (e.g. practice nurses delivering alcohol interventions to people with ID). Appropriateness refers to evidence that demonstrates whether an activity or intervention is ethically or culturally
appropriate. In this instance we assessed whether the interventions identified had been designed specifically for people with ID. *Meaningfulness* refers to evidence that takes the form of participants'/professionals' views and experiences of interventions, including their content and mode of delivery. *Effectiveness* is concerned with evaluating the effects of interventions on specified outcomes, e.g. alcohol consumption.

**Methods**

**Search strategy**

In August–September 2011, key electronic bibliographic databases were searched, including Medline, the Cochrane Register of Controlled Trials, DARE, PsycINFO, CINAHL, ERIC and AMED. To identify any additional papers, we also scanned the reference lists of papers included in the review.

The search was developed using subject headings (e.g. MeSH) and keywords, e.g. ‘intellectual disabilities’, ‘developmental disabilities’ ‘health promotion’, ‘behaviour change’, ‘tobacco use’, ‘smoking’, and ‘alcohol drinking’. Subject headings were exploded, where appropriate, and standard symbols used as wildcards, to truncate keywords and/or indicate proximity (e.g. intellectual disabilit*®, behavi*o*#r change, smoking N3 cessation). The Medline search is presented in Appendix 1. Other searches were broadly similar; however, some revisions were required linked to minor differences in subject headings across databases and differences in the standard search symbols across platforms (e.g. Ebsco and Ovid). The dates searched were 1996–2011, with the search being restricted to ‘English language’. Each database was searched individually. RefWorks was used to manage the bibliographic records.

**Inclusion/exclusion criteria**

Following completion of the database searches, the titles and abstracts of identified papers were screened for inclusion. At this stage, broad inclusion/exclusion criteria were applied, and papers were included if they had a focus on tobacco and/or alcohol use in people with ID. In the next stage, we applied narrow inclusion/exclusion criteria, which were produced using an adaptation of the PICO (Population, Interventions, Comparison, Outcomes) framework i.e. SPIO (Study design, Population, Interventions, Outcomes) (Table 1) (Joanna Briggs Institute 2008). Where insufficient detail was provided in the abstract, the full text was retrieved to enable an informed judgement regarding inclusion/exclusion. Two members of the review team (CD and SK) applied the SPIO inclusion/exclusion criteria independently. The researchers then met to discuss any discrepancies and reach consensus. A third reviewer (ML) was asked to provide an additional opinion, as required.

**Methodological appraisal**

To assess the quality of the studies, we used a revised version of a seven-point rating scale designed to enable synthesis of diverse sources of evidence (Popay 2006). Studies were assessed in relation to (1) design; (2) clarity of aims and objectives; (3) sampling; (4) description of the intervention (including theoretical underpinnings) and any comparator/control interventions; (5) data collection and analysis; (6) reliability/validity/rigour; (7) presentation/interpretation of the results/findings. Details of the ‘study design’ and ‘the description of the intervention’, as discussed above, replaced Popay’s assessment of the ‘supporting literature’ and the ‘context in which the studies were set’. One point was awarded for each of the seven areas if the issues had been addressed in a manner that was judged as satisfactory, no points were awarded if the procedures used were unclear, poorly addressed and/or open to bias (e.g. the sampling strategy). The possible range of scores was, therefore, 0–7. Studies scoring six or more were rated as good, scores of 4–5 were considered to be of moderate quality and studies scoring three or less were rated as poor. As is common in mixed method reviews, no papers were excluded on the grounds of quality (Garcia et al. 2002; Harden 2006).

**Data extraction and synthesis**

Following application of the narrow inclusion/exclusion criteria, data were extracted from the papers remaining in the review. A review-specific
data extraction tool was developed. Two reviewers (CD, SK) undertook data extraction for each paper independently. Initially there were a small number of discrepancies regarding extracted data; however, these were easily resolved following discussion. The data extracted are compiled in an evidence table (Table 2) and are synthesised and summarised below. Meta-analysis was not possible because of design issues (most were before and after studies with no control group), heterogeneity and limitations associated with reporting of the results. A lack of qualitative papers/findings also precluded meta-synthesis.

### Results

#### Searches and inclusion/exclusion of papers

Database searches identified 501 unique papers (once 149 duplicates had been removed) (Fig. 1). Following application of the broad inclusion/exclusion criteria, 421 papers were excluded. Commonly, papers were excluded because they focused on foetal alcohol syndrome. SPIO inclusion/exclusion criteria were then applied to the remaining 80 papers, with 72 being excluded. The main reason for exclusion at this stage was because the papers did not report on interventions (e.g. they discussed prevalence of smoking or alcohol consumption in people with ID). A scan of the reference lists of the papers at this point identified one additional paper, resulting in a total of nine papers that met the SPIO inclusion criteria. These papers were subject to quality appraisal and data extraction processes.

### Table 1 SPIO (Study design, Population, Interventions, Outcomes) framework

<table>
<thead>
<tr>
<th>Include</th>
<th>Exclude</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study design</td>
<td>Randomised controlled trials, quasi-experiments, before and after studies, cohort studies, feasibility studies, exploratory trials, qualitative studies</td>
</tr>
<tr>
<td>Population</td>
<td>People with a mild/moderate learning disability</td>
</tr>
<tr>
<td>Intervention</td>
<td>Information/advice, education, brief interventions, intensive interventions, group support, other psychological interventions, pharmacological interventions (e.g. nicotine replacement therapy) relating to tobacco and/or alcohol</td>
</tr>
<tr>
<td>Outcomes</td>
<td>Tobacco: carbon monoxide levels, cotinine levels, self-reported consumption, health-related quality of life, knowledge, attitudes</td>
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</table>

Alcohol: biological markers (e.g. gamma-glutamyl transferase), self-reported consumption, health-related quality of life, knowledge, attitudes

#### Summary of the papers reviewed

Four papers focused on tobacco-related interventions (Kelman et al. 1997; Tracy & Hosken 1997; Chester et al. 2011; Singh et al. 2011), three on alcohol-related interventions (Forbat 1999; Mendel...
## Table 2: Studies included in the review (n = 9)

<table>
<thead>
<tr>
<th>Authors, aim, Quality Rating (QR)</th>
<th>Design + sample</th>
<th>Intervention</th>
<th>Methods</th>
<th>Results/findings</th>
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<tbody>
<tr>
<td><strong>Smoking prevention/cessation interventions</strong></td>
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<tr>
<td>Singh et al. (2011) USA</td>
<td>Case study Community-based group home n = 1</td>
<td>Training involved (1) intention; (2) mindful observation of thoughts; (3) meditation on the soles of the feet. Taught techniques 3 months ahead of quit attempt; ‘top-up’ sessions in first 12 months after quitting.</td>
<td>Logged number of cigarettes smoked. Participant kept log, staff also monitored cigarette consumption. Data collected daily during intervention period, follow-up at 12 months and 3 years.</td>
<td>Analysis: Basic descriptive statistics (frequencies) 12 cigarettes/day at baseline Reduced in a stepwise manner until 0/day. Duration 82 days. Did not smoke during the 12-month maintenance period or in 3-year follow-up period</td>
</tr>
<tr>
<td>Chester et al. (2011) England, UK</td>
<td>Audit Forensic inpatient unit (low secure, medium secure and rehabilitation) n = 79</td>
<td>1-to-1 health information from named nurse. Group sessions did not rely heavily on literacy or abstract thinking included discussions, quizzes, videos, pictures. 7 weekly sessions. Patients also encouraged to obtain relevant leaflets from a GP and could make appointments with a cessation nurse; nicotine replacement therapy (NRT) provided if suitable. Smoking timetable number of cigarettes smoked restricted to 1 per hour during waking hours.</td>
<td>Data gathered by 4 nurses from case notes, patients and charge nurses over a 1-week period. Data collected retrospectively, period between admission and the point of data collection assessed.</td>
<td>Analysis: Basic descriptive statistics + chi-squared analysis for categorical variables and t-tests for continuous variables 29/48 baseline smokers attempted to stop; 15 were successful Proportion of patients smoking following exposure to the cessation programme dropped significantly Male smokers more likely to have quit (P &lt; 0.05) Patients in low secure wards more likely to have quit than patients in medium secure wards (P &lt; 0.05)</td>
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<tr>
<td>Kelman et al. (1997) Scotland, UK</td>
<td>Before and after study Recruited from adult training centre n = 5</td>
<td>Focus on harmful physical, social and financial consequences of smoking and benefits of being a non-smoker. Role play videos, quizzes. 7 weekly group sessions. Delivered by training centre staff.</td>
<td>Questionnaire: to assess knowledge of smoking. Data collected: baseline, 1 week (Time 2) and 3 months (Time 3) after the health education programme. Potential scoring range: 0–40 Analysis: Basic descriptive statistics.</td>
<td>Baseline scores: ranged from 15 to 33 Time 3 scores: ranged from 28 to 37 Baseline to Time 2: Knowledge levels in all 5 participants increased Time 2–Time 3: Scores dipped but knowledge increase was maintained compared with Baseline n = 3 stopped, 3 cut down 5 people expressed a desire to quit at the start of the course, 9 expressed a desire to quit at the end (including those who had quit) Knowledge levels: increased (no scores provided)</td>
</tr>
<tr>
<td>Tracy &amp; Hosken (1997) Australia</td>
<td>Before and after study Recruited from tertiary education facility n = 11</td>
<td>Modified version of an established generic smoking cessation programme. Group discussions, videos, role play board games, incentives (pens, badges, certificates). 7 weekly group sessions. Unclear who delivered the intervention.</td>
<td>Questionnaire: to assess smoking habits, knowledge and interest in stopping. Data collected: baseline and end of course. Potential range of scores not reported Analysis: Basic descriptive statistics.</td>
<td>Baseline scores: ranged from 15 to 33 Time 3 scores: ranged from 28 to 37 Baseline to Time 2: Knowledge levels in all 5 participants increased Time 2–Time 3: Scores dipped but knowledge increase was maintained compared with Baseline n = 3 stopped, 3 cut down 5 people expressed a desire to quit at the start of the course, 9 expressed a desire to quit at the end (including those who had quit) Knowledge levels: increased (no scores provided)</td>
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Alcohol-related interventions

Steel & Ritchie (2004)
Scotland, UK
Aim to explore potential of a psycho-educational approach to increase knowledge and motivation to change behaviour

QR: 3

Case study
Recruited from secure accommodation
n = 1
No control group
Harmful drinker
Age: 23 years
Male, normally lives at home with parents

Information on: the effects of alcohol; alcohol and the law; sensible drinking; what influences alcohol use; physical + psychological dependence; substance use and mental health; health issues

Motivational interviewing techniques, homework, modified handouts
12 weekly sessions of 40 min (this included sessions on drug use); unclear who delivered

Knowledge questionnaire, 20 alcohol-related questions, with true/false responses
Data collected: baseline and post-intervention; potential range of scores 0–20
Analysis: Basic descriptive statistics

Alcohol-related knowledge level rose from 8 at baseline to 14 at the end of the 12-week course

Participant willing to engage but easily distracted, undertook homework

Mendel & Hipkins (2002)
England, UK
Aim to use motivational interviewing to assist clients in moving through the Stages of Change process

QR: 4

Before and after study
Recruited from medium secure accommodation
n = 7
No control group
All had alcohol problems
Age: 18–54 years
All men

Alcohol Awareness Course aimed to:
provide information on alcohol; encourage the development of learning skills; help the participants make informed choices regarding alcohol consumption
Motivational interviewing, interactive sessions, group exercises, visual aids, case vignettes, references to celebrities
3 ¥ 1 h sessions over a 2-week period; delivered by 2 trainee clinical psychologists + 2 support workers

CAGE: 4-item measure; assesses quantity + frequency of alcohol consumption; no details of scoring
Alcohol Related Problems Questionnaire: checklist to assess relationship between drinking + problems caused; no details of scoring
Readiness to Change Questionnaire: 12-item measure; no details of scoring
Analysis: Basic descriptive statistics

CAGE (used at baseline only) range 12–288 units/week; mean = 101 (prior to admission to secure unit – relied on retrospective memory)
Alcohol Related Problems (used at baseline only) 6 of the 7 participants identified problems with their drinking prior to admission e.g. aggression, trouble with police
Readiness to Change: T1 (baseline) pre-contemplators n = 2; contemplators n = 5; action n = 0; T2 (end of course) pre-contemplators n = 0; contemplators n = 5; action n = 1

Forbat (1999)
England, UK
Aim to pilot an alcohol awareness course for people with ID

QR: 1

Before and after study
Recruited from a medium secure unit
n = 5
No control group
No demographic information provided.
Participants appeared to have limited experience of alcohol

Content focused on: where/why/what people drink; the law and alcohol; strength of different drinks/units; physical, emotional and behavioural effects; attitudes; problem drinking; individual drinking plans
Quizzes, group discussion, diagrams, videos, vignettes; 3 facilitators
8 weekly group sessions (2 h), including a trip to the pub

Knowledge alone assessed. Not clear how information was gathered. Possible range of scores 0–30
Data collected: baseline, at the end of the intervention and 6 months post-intervention
Analysis: Basic descriptive statistics

Knowledge of all 5 participants rose at the end of the intervention; it continued to rise in 2 of the participants 6 months post-intervention and fell in 3 of the participants
Mean score at baseline 21.5 (range 16–24)
Mean score post-intervention 23.3 (range 22.5–27.5)
Mean score at 6 months 25.4 (range 23–27.5)
<table>
<thead>
<tr>
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<tbody>
<tr>
<td><strong>Tobacco and alcohol interventions</strong>&lt;br&gt;<strong>Lindsay et al. (1998)</strong>&lt;br&gt;Scotland, UK</td>
<td>RCT&lt;br&gt;Recruited from a resource centre and a hospital for people with ID&lt;br&gt;Smoking: n = 48, 3 groups of 16; intervention group, no treatment control, control group that received a leaflet&lt;br&gt;Alcohol: n = 46, 2 groups of 23; intervention group, no treatment control</td>
<td>Smoking: what is smoking, why people smoke, short and long-term effects, passive smoking, cost; ways of refusing&lt;br&gt;Alcohol: why people drink, when is drinking appropriate, drunkenness, effects of alcohol, designer rinks, strength of alcohol, sensible drinking, effects on health, social hazards of drinking&lt;br&gt;Fact sheets, illustrations/cartoons, team games, role play, quizzes, discussion, demonstrations</td>
<td>Questionnaire: 42 item administered by Research Assistant. Range of scores 0–42&lt;br&gt;Data collected baseline, on completion of the 8-week intervention + 3-month post-intervention&lt;br&gt;Analysis: descriptive statistics + two way analysis of variance (ANOVA). When appropriate, selected pairs compared using Tukey's pairwise comparison</td>
<td>Groups similar at baseline&lt;br&gt;Smoking: differences post-intervention, treatment group differed significantly from control groups (P &lt; 0.01). Mean score in the treatment group 30.9 at 3 months, 19.9 in no-treatment control, 19.6 in leaflet control&lt;br&gt;Alcohol: Significant differences in the 2 groups post-intervention (P &lt; 0.00). At 3 months mean score in the treatment group 22.7, 10.3 in the no treatment control</td>
</tr>
<tr>
<td><strong>Demers et al. (2000)</strong>&lt;br&gt;USA</td>
<td>Quasi-experiment (preliminary evaluation)&lt;br&gt;Recruited from 6 schools&lt;br&gt;n = 13 teachers; n = 138 students&lt;br&gt;Intervention group: 3 schools, 6 teachers, 65 students&lt;br&gt;Control group: 3 schools, 7 teachers, 73 children</td>
<td>Teachers taught to adapt existing health promotion messages for children with special educational needs. 1-day training + booster sessions over 1 year&lt;br&gt;Programme focused on dangers of alcohol and tobacco, resisting peer pressure; avoiding particular “risky” situations, dealing with stress&lt;br&gt;5 lessons delivered during class time; teachers also encouraged to take advantage of “teachable” moments; no other details provided</td>
<td>Teachers completed questionnaire on usefulness of training + how often provided prevention messages. Data collected at baseline, post-training and end of academic year&lt;br&gt;Questionnaire used to determine if students ever used alcohol and tobacco (A&amp;T); use of A&amp;T in last 30 days; intent to use A&amp;T in future; perception of harm from A&amp;T; peer pressure relating to A&amp;T; self-image; portrayal of best friends’ use of A&amp;T (7 criteria). Potential range of scores not provided&lt;br&gt;Data collected: baseline (T1), winter break (T2), end of school year (T3)&lt;br&gt;Descriptive and inferential statistics: chi-square + Mann–Whitney U-test&lt;br&gt;Teachers unanimously expressed support for the programme, stating that they were discussing A&amp;T on a regular basis (weekly) following training and throughout the academic year&lt;br&gt;No information provided on teachers from the “control” schools&lt;br&gt;Results demonstrate levels of smoking and alcohol consumption in the PALS schools were similar to control schools at baseline&lt;br&gt;On all 7 criteria the performance of the students in the intervention schools, at the end of the school year, was higher or more positive than students in the control schools. Results were not statistically significant</td>
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GP, general practitioner; ID, intellectual disability; RCT, randomised controlled trial.
& Hipkins 2002; Steel & Ritchie 2004), and two on interventions designed to address both tobacco and alcohol (Lindsay et al. 1998; Demers et al. 2000).

Methodological quality

The methodological quality of the studies was assessed using the adaptation of Popay’s (2006) rating scale; all papers were judged as being of poor or moderate quality (Table 2). The quality of the four tobacco-related papers was poor (Kelman et al. 1997; Tracy & Hosken 1997; Chester et al. 2011; Singh et al. 2011). Lindsay et al.’s (1998) tobacco and alcohol-related study scored highest (i.e. 5/7).

Geographical spread

Two of the tobacco-related studies were undertaken in the UK (Kelman et al. 1997; Chester et al. 2011), one in the USA (Singh et al. 2011) and one in Australia (Tracy & Hosken 1997). The three alcohol-related studies were undertaken in the UK (Forbat 1999; Mendel & Hipkins 2002; Steel & Ritchie 2004). One of the studies that focused on both tobacco and alcohol was conducted in the USA (Demers et al. 2000), the other in Scotland (Lindsay et al. 1998).

Aims

One of the tobacco-related studies aimed to increase knowledge levels linked to physical, social and financial consequences of smoking (Kelman et al. 1997). The others sought to encourage cessation attempts (Tracy & Hosken 1997; Chester et al. 2011; Singh et al. 2011). The alcohol-related studies aimed to increase knowledge and motivation to change behaviour (Forbat 1999; Steel & Ritchie 2004) and to increase clients’ readiness to change (Mendel & Hipkins 2002). Demers et al. (2000) aimed to evaluate a school-based health education programme designed to address/prevent the use of tobacco and alcohol in 14–17-year-olds. Lindsay et al.’s (1998) study sought to increase knowledge levels linked to the health and social dangers of smoking and excessive alcohol consumption.
Design of the studies

The studies that focused on both tobacco and alcohol were strongest in terms of research design i.e. Lindsay et al. (1998) conducted a randomised controlled trial and Demers et al. (2000) a quasi-experiment. Otherwise, three of the studies used a case-study approach [Singh et al. 2011 (tobacco); Kelman et al. 1997 (tobacco); Steel & Ritchie 2004 (alcohol)], three were before and after studies [Mendel & Hipkins 2002 (alcohol); Forbat 1999 (tobacco); Tracy & Hosken 1997 (tobacco)] and one was an audit [Chester et al. 2011 (tobacco)]. Four studies were also described as pilot studies/preliminary evaluations (Tracy & Hosken 1997; Forbat 1999; Demers et al. 2000; Mendel & Hipkins 2002). No qualitative studies were identified.

Recruitment/sampling

The total number of participants with mild/moderate ID across the nine studies was 341. Little detail was provided regarding recruitment/sampling. Only two of the nine studies reported control/comparator groups (Lindsay et al. 1998; Demers et al. 2000) and only Lindsay et al. (1998) randomly allocated participants to groups. The ages of the participants ranged from 14 to 54 years (Table 2).

The interventions

Three of the four tobacco-related interventions sought to increase knowledge levels. They delivered the interventions in a group format over 7 weeks (Kelman et al. 1997; Tracy & Hosken 1997; Chester et al. 2011). A number of standard educational approaches were adopted in the three studies, including group discussions, quizzes, videos, board games, and visual prompts. Participants were encouraged to be actively involved, and role play was used to reinforce new ideas and to work through problem-solving scenarios. Positive reinforcement was used (e.g. badges) following particular tasks. No educational or behaviour change theories were discussed. The tobacco-related intervention discussed in Singh et al. (2011) aimed to support a cessation attempt. It was delivered on a one-to-one basis over a period of 82 days and used a ‘mindfulness’ approach (described as a form of meditation).

Two of the alcohol-related interventions aimed to increase levels of motivation to change behaviour (Mendel & Hipkins 2002; Steel & Ritchie 2004), with Steel & Ritchie (2004) also seeking to increase knowledge levels. The one-to-one intervention developed by Steel & Ritchie (2004) was delivered weekly for 12 weeks. Six sessions focused on alcohol consumption; the remainder focused on illicit drugs. Motivational interviewing techniques, as described by Miller & Rollnick (1991), were used in this study. Mendel & Hipkins (2002) ran group sessions over a period of 2 weeks (three sessions), with motivational interviewing also being used, in addition to visual aids and vignettes. Forbat (1999) aimed to increase knowledge levels. Group sessions ran over a period of 8 weeks, with quizzes, group discussions, videos and vignettes being used.

Lindsay et al.’s (1998) intervention sought to increase tobacco and alcohol-related knowledge. Small group sessions ran over a period of 8 weeks that incorporated discussions, fact sheets, cartoons, team games and quizzes. The school-based programme developed by Demers et al. (2000) aimed to equip the children with attitudes/skills that would help them resist peer pressure. It ran throughout one academic year and was delivered by teachers. The programme included five planned lessons; in addition, teachers were encouraged to take advantage of ‘teachable’ moments if a child raised an issue about smoking and/or alcohol during another lesson.

Data collection and analysis

Two of the tobacco-related studies used questionnaires to collect data (Kelman et al. 1997; Tracy & Hosken 1997). Singh et al. (2011) used a log book and Chester et al. (2011) used an audit tool. The reliability and validity of the data collection tools were not discussed and there was no attempt to determine smoking status objectively (e.g. by measuring levels of expired carbon monoxide or salivary cotinine). Singh et al. (2011) followed their one participant up for a period of 3 years. All four studies used descriptive statistics to report results, Chester et al. (2011) using chi-squared analysis and t-tests to make comparisons across groups.

The three alcohol-related studies used questionnaires to collect data. Steel & Ritchie (2004) and
Forbat (1999) developed a questionnaire, based on the content of their educational programmes. Mendel & Hipkins (2002) used instruments which had not been validated for use with people with ID i.e. CAGE (Mayfield & McLeod 1974) and the Readiness to Change Questionnaire (Rollnick et al. 1992). Basic descriptive statistics appear to have been undertaken; however, little detail is provided.

The two studies that focused on tobacco and alcohol (Lindsay et al. 1998; Demers et al. 2000) developed their own data collection instruments (questionnaires) which were not assessed for reliability and/or validity. Lindsay et al. (1998) highlighted that data collection was not always ‘blind’ as participants sometimes inadvertently disclosed their group allocation. Descriptive and inferential statistics were used to analyse the data. Further details, including the data collection time points for all studies are presented in Table 2.

Effectiveness of the interventions

While the four tobacco-related studies provide interesting information on knowledge levels and quit rates (Table 2), the study designs are weak (no control groups, data collection instruments used with no demonstrable reliability and validity, no biochemical verification of smoking status); therefore, little can be deduced regarding the effectiveness of the interventions.

Again, when considering the alcohol-related interventions, methodological issues, e.g. small numbers, lack of control groups and use of data collection instruments not tested for reliability and validity with people who have ID, indicate that the results should be treated with caution. Steel & Ritchie (2004) and Forbat (1999) reported that participants’ knowledge levels rose (a combined total of six participants). Mendel & Hipkins (2002) reported an increase in readiness to change alcohol-related behaviour following delivery of their intervention. However, as the participants ($n = 7$) had no access to alcohol (they were currently in secure accommodation and no details of their release dates were provided), the relevance of moving participants into the ‘action’ phase is difficult to judge.

The studies that focused on both tobacco and alcohol were of higher quality therefore more may be deduced from the results. The study undertaken by Lindsay et al. (1998) reported a significant increase in knowledge levels (compared with the control group) that was maintained over time (3 months). Demers et al. (2000) found that, measured against all seven criteria (Table 2), students in the intervention group achieved higher/more positive results than students in the control group; however, differences between the groups were not statistically significant.

Feasibility, appropriateness and meaningfulness of the interventions

No qualitative papers/papers with a substantial qualitative element were identified and we were therefore able to extract little information on the meaningfulness of the interventions (i.e. participants’ views on/experience of the interventions). Chester et al. (2011) summarised comments made by the participants exposed to their tobacco-related intervention. Participants who did not try to stop smoking reported that they enjoyed smoking and did not want to give up. Those who had stopped smoking or cut down reported that, following the intervention, they understood more about the effects of smoking on their health, and that of others, and this had encouraged them to try to stop smoking. Nicotine replacement therapy and the smoking timetable were also thought to have been useful.

When considering feasibility, Demers et al. (2000) found that teachers who had received training could easily incorporate tobacco and alcohol-related messages into their lessons. No other findings relating to feasibility were identified.

All studies addressed the issue of appropriateness, with efforts being made to tailor the interventions in a manner suitable for people with ID. Kelman et al. (1997) and Tracy & Hosken (1997) in their tobacco-related interventions reported that the participants readily engaged with group work, which included role play, quizzes and board games. However, Mendel & Hipkins (2002) (alcohol-related intervention) felt that some people with mild ID do not have sufficient verbal and interpersonal skills to enable them to interact effectively in a group situation. Steel & Ritchie (2004), who reported on a one-to-one intervention relating to alcohol use, found that holding the participant’s attention was problematic.
The provision of concrete examples of the effects of smoking was found to be an appropriate educational tool (Kelman et al. 1997). However, abstract concepts, such as long-term health effects, were difficult for people with ID to grasp (Kelman et al. 1997). In particular the concept of units of alcohol was raised as something that was difficult for people with ID to understand (Mendel & Hipkins 2002). As discussed, in order to address cognitive and literacy needs of people with ID, information was provided in a variety of formats including pictures/cartoons, videos and team games (Table 2). Interestingly, Steel & Ritchie (2004) found that homework, which required reference to information materials provided during the course, was an appropriate learning aid.

When reflecting upon the appropriateness of the data collection instruments, Mendel & Hipkins (2002) stated that while the instruments used (i.e. CAGE, Stages of Change Questionnaire) had been validated with the general population, they believed they were too complex for use with people who have ID. Little comment was made by other authors about the appropriateness of their data collection instruments; none appeared to have been assessed for reliability and validity with people who have ID.

Discussion

In recent years there has been increasing concern regarding the mortality, morbidity and behavioural determinants of health in people with ID (Emerson & Hatton 2008). When considering health-related behaviours, levels of smoking and alcohol consumption in people with mild/moderate ID present a cause for concern (Emerson & Turnbull 2005; McGillicuddy 2006; Taggart et al. 2006, 2008).

This review has demonstrated that worldwide the body of evidence on the feasibility, appropriateness, meaningfulness and effectiveness of tobacco and alcohol-related interventions for people with ID is small. The evidence that does exist is of poor/moderate methodological quality, drawn from studies which often used small convenience samples, and with two exceptions, did not use a control/comparator group. None of the studies included in the review was hypothesis-driven, which would be expected in quantitative studies purporting to assess effectiveness. In many of the papers, reporting of data collection and analysis processes lacked detail.

Although the studies included in the review have significant methodological limitations, and therefore make a limited contribution to our understanding of the impact of the tobacco and alcohol-related interventions they described, they did highlight some important issues linked to the appropriateness of health promotion interventions for this client group. The papers tended to focus on the content of the interventions and their mode of delivery, thus demonstrating an awareness of the need to tailor interventions to meet the specific needs of people with ID. One of the studies sought to help participants develop skills that would assist them in resisting the urge to smoke or consume alcohol in an attempt to conform or 'fit in' (Demers et al. 2000). This is an important issue, as research suggests that people with ID may be encouraged to smoke and/or drink alcohol in order to be, in their view, more like their peers who do not have ID (Lawrence et al. 2009). While some authors commented on the participants’ high level of engagement with the intervention(s), little qualitative data were collected. Consequently, little is known about the participants’ views of the interventions (meaningfulness).

Another important issue is that only two of the nine studies appeared to have appropriate theoretical underpinnings i.e. the two alcohol-related studies used motivational enhancement techniques (Miller & Rollnick 1991), with one also incorporating the concept of Readiness to Change, which links to the Transtheoretical Model of Behaviour Change (Prochaska & DiClemente 1992). This is surprising, as there is strong evidence that health promotion interventions designed to alter behaviour should be based on a solid understanding of the personal and environmental factors that can influence both behaviour and behaviour change (National Institutes of Health 2005). Issues such as empowerment, health literacy and the ability to make informed decisions are particularly important in this client group (NHS Health Scotland 2004; Lawrence et al. 2009; Robinson et al. 2010). The apparent tendency to develop and deliver health promotion interventions without identifying an appropriate theoretical approach with which to
inform these processes has been noted in other specialties, such as stroke (Lawrence et al. 2011).

When considering feasibility, only one study commented on this (Demers et al. 2000). As discussed previously, the issue raised related to the teachers’ ability to incorporate the health education programme into their regular work.

The only study that is informative in terms of effectiveness is the study undertaken by Lindsay et al. (1998). This randomised controlled trial appeared to be effective in terms of raising the knowledge levels of people with ID in relation to tobacco and alcohol. However, there were methodological limitations that may impact on the validity of the results.

Conclusions

This review is the first to systematically collate evidence on tobacco and alcohol-related interventions for people with ID. The dearth of evidence in this area has important implications for practice, as there is little to guide the approaches that health and social care professionals should take when working with this client group. There is, therefore, an urgent need to develop theoretically driven tobacco and alcohol-related health promotion interventions and to ensure that the effectiveness of these interventions is tested in large-scale well-designed trials. In addition to addressing issues relating to the research design, there is a need to ensure that interventions and outcome measures are developed/tailored appropriately for this client group.

Informed by the systematic review and qualitative interviews with people with ID and professionals who have regular contact with this client group (Lawrence et al. 2009; Fitzsimmons 2011), we now plan to develop and test a series of tobacco and alcohol-related interventions for people with mild/moderate ID. Our aim is to improve the health of this population and to help reduce health inequalities.

References


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## Appendix I Search (Medline)

<table>
<thead>
<tr>
<th>Topic</th>
<th>MeSH headings and keywords</th>
</tr>
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</table>
| Intellectual disability | 1. learning disorders/ OR developmental disabilities/ OR mental retardation/ OR mentally disabled persons/  
2. intellectual disability  
3. intellectual N3 disability  
4. developmental disability  
5. developmental N3 disability  
6. learning disability  
7. learning N3 disability  
8. learning disabled  
9. mental retardation  
10. mental N3 retardation  
11. mental handicap  
12. mental N3 handicap  
13. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12                                                                                                                                                                                                                     |
| Tobacco and alcohol     | 14. ethanol/ OR drinking behavior/ OR alcoholism/ OR alcohol intoxication/ OR alcohol drinking/  
15. alcohol  
16. problem N3 drink  
17. hazardous N3 drink  
18. harmful N3 drink  
19. dependent N3 drink  
20. binge N3 drink  
21. alcohol N3 use  
22. alcohol N3 misuse  
23. smoking/ OR tobacco use  
24. tobacco N3 smoking  
25. smoking  
26. 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25                                                                                                                                                                                                                              |
| Interventions           | 27. health promotion/ OR health education/ OR preventive medicine/ OR primary prevention/ OR secondary prevention/ OR smoking cessation/ OR tobacco use cessation/  
28. health N3 promotion  
29. health N3 education  
30. prevention  
31. relapse N3 prevention  
32. smoking N3 cessation  
33. behavior N3 change  
34. behavior  
35. psycho N3 education  
36. psychosocial N3 intervention  
37. counseling  
38. nicotine replacement therapy  
39. 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38  
40. 13 and 26 and 39  
41. limit to 1996–2011, English language, humans                                                                                                                                                                                                                                                                 |

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