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Tobacco and alcohol use in people with mild/moderate intellectual disabilities: giving voice to their health promotion needs

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Published in:

Journal of Applied Research in Intellectual Disabilities

DOI:

[10.1111/jar.12255](https://doi.org/10.1111/jar.12255)

Publication date:

2017

Document Version

Peer reviewed version

[Link to publication in ResearchOnline](#)

Citation for published version (Harvard):

Kerr, S, Lawrence, M, Middleton, AR, Fitzsimmons, L & Darbyshire, C 2017, 'Tobacco and alcohol use in people with mild/moderate intellectual disabilities: giving voice to their health promotion needs', *Journal of Applied Research in Intellectual Disabilities*, vol. 30, no. 4, pp. 612-626. <https://doi.org/10.1111/jar.12255>

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Title

Tobacco and alcohol use in people with mild-moderate intellectual disabilities: giving voice to their health promotion needs

Running title

Tobacco and alcohol-related health promotion needs

Abstract

Background Concerns have been raised about the use/misuse of tobacco and alcohol by people with mild-moderate intellectual disabilities. Aiming to address an identified gap in the current evidence base, the current study sought to gain an understanding of the tobacco and alcohol-related health promotion needs of this client group.

Methods Informed by the principles of social cognitive theory, data were collected using focus group and telephone interviews. Participants were 16 people with intellectual disabilities, two family carers and 15 health and social care professionals. Data were analysed using the Framework approach.

Findings Four themes were described: Being like others; Social and emotional influences; Understandings, mis-understandings and learning from experience; and, Choices and challenges. Reasons for smoking and drinking alcohol echoed those of the general population; however, health promotion needs were more complex (e.g. linked to problems with consequential thinking; low levels of self-efficacy).

Conclusion This paper provides insight into the tobacco and alcohol-related health promotion needs of people with intellectual disabilities. There is a need for integrated service provision that addresses both personal and environmental influences on behaviour.

Keywords alcohol, tobacco, health promotion, intellectual disability, qualitative research, social cognitive theory

Introduction

Globally, estimates of the prevalence of intellectual disability vary, with differences due, in part, to methods of ascertainment and classification (World Health Organisation 2007). There is, however, general agreement that intellectual disability is common in both the developed and developing worlds (World Health Organisation 2007). In the UK, for example, it is estimated that 2.4% of the population has an intellectual disability, with mild-moderate intellectual disability being five times more common than severe/profound intellectual disability (NHS Health Scotland 2004; Emerson & Robertson 2011, ONS 2012). As a substantial number of people with borderline-mild intellectual disability are unknown to statutory services, the size of this population, often referred to as the 'invisible' or 'hidden' population, is likely to be higher than current estimates suggest (Emerson 2011).

People with intellectual disabilities have poorer health outcomes compared to their non-disabled counterparts (Emerson and Hatton 2014). The reasons for these inequalities are multiple and complex and include increased risk associated with specific genetic and biological causes of intellectual disabilities, deficiencies in healthcare provision, socio-economic factors such as unemployment and poor housing, communication/literacy problems and, increasingly, adoption of health risk behaviours (McGillicuddy 2006; Emerson *et al.* 2012; Emerson & Hatton 2014). With the closure of long-stay institutions, more people with intellectual disabilities are living in the community with support from family and/or health and social care professionals. As they lead more ordinary and less restricted lives, people with intellectual disabilities are more likely to be exposed to social and environmental pressures to adopt behaviours that will impact negatively on their health (Sutherland *et al.* 2002). While levels of smoking and drinking in people with intellectual disabilities, as a whole, are lower than in the general population, rates in people with mild-moderate intellectual disabilities are thought to be nearing that of the general population (e.g. Emerson & Turnbull 2005; McGillicuddy 2006; Taggart *et al.* 2008). Being male, young, having a borderline-mild intellectual disability, living independently and having a mental health problem have been identified as key risk factors for excessive alcohol consumption (Taggart *et al.* 2006; Taggart *et al.* 2008; Emerson 2011). Socio-economic deprivation,

adolescent mental health problems and having a borderline-mild intellectual disability appear to be associated with a great likelihood of smoking (Emerson & Turnbull 2005; Emerson 2011).

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). The health-related consequences of smoking are well-established. Similar to the general population, people with intellectual disabilities 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 amongst people with intellectual disabilities, such as diabetes and asthma (Gale *et al* 2009; Meyer *et al.* 2000; Royal College of Physicians 2000). Excessive alcohol consumption in people with intellectual disabilities presents a number of concerns, including risks to personal safety, interpersonal relationships and physical and mental health (Taggart *et al.* 2006; Taggart *et al.* 2008). More specifically, alcohol intoxication leads to impaired judgement and risk-taking, the consequences of which may include accidental injury, unintended unprotected sex, offending behaviour and acts of violence (e.g. McGillivray & Moore 2001; Davis & George 2006; Taggart *et al.* 2006; Taylor *et al.* 2010). Long-term health problems associated with persistent heavy drinking include, circulatory disorders, anaemia, cancer, gastric irritation, cardiac and cerebrovascular disease, neurological disorders, liver disease and mental health problems (World Health Organisation 2010; DoH 2016).

As a consequence of the public health concerns associated with smoking and excessive alcohol consumption, extensive efforts have been made, both nationally and internationally, to reduce the use of tobacco and alcohol through policy directives, targeted interventions and health education campaigns (Gruber & Koszegi 2008; Department of Health 2011). However, evidence suggests that inequalities exist and that people with intellectual disabilities have fewer health promotion opportunities than their non-disabled counterparts (Leeder & Dominello 2005; Baxter *et al.* 2006; Taggart *et al* 2008; Emerson *et al.* 2012). Reasons include professionals failing to address lifestyle issues with this client group and people with intellectual disabilities having difficulty in accessing

mainstream health services, including smoking cessation and alcohol services (Mendel & Hipkins 2002; Sutherland *et al.* 2002; McLaughlin *et al.* 2007; Taggart *et al.* 2008).

The situation has improved recently in the UK following the introduction of primary care-based annual health checks for people with intellectual disabilities (Robertson *et al.* 2010). However, while practice nurses and general practitioners are encouraged to ask about smoking and alcohol consumption (Royal College of General Practitioners 2010), there is currently little evidence on the effectiveness of health promoting interventions delivered in this setting (Robertson *et al.* 2010). Also, while generic evidence-based approaches exist to address tobacco and alcohol use in the wider population, studies that have informed contemporary guidelines have generally excluded people with communication and/or cognitive impairments (National Institute for Health & Clinical Excellence 2006). Therefore, it cannot be assumed that generic approaches are appropriate for people with intellectual disabilities. Indeed, key policy documents have stressed the need to tailor health promotion interventions for this client group i.e. for professionals to make reasonable adjustments, as required (Disability Rights Commission 2004; NHS Health Scotland 2004; Robertson *et al.* 2010; Turner & Robinson 2011).

A recent systematic review of the literature on the feasibility, acceptability/appropriateness and effectiveness of tobacco and/or alcohol-related interventions for people with intellectual disabilities highlighted a dearth of evidence to inform practice (Kerr *et al.* 2013). Nine studies were identified; however, while some important insights for the development of interventions were identified, the review highlighted the need for more robust research methods, interventions that are theoretically driven and the testing of the effectiveness of interventions in large-scale well-designed trials (Kerr *et al.* 2013).

In response to the above, and guided by the Medical Research Council's framework for the development and evaluation of complex interventions (Medical Research Council 2008), the authors of this paper are undertaking a programme of research that aims to develop/tailor and evaluate tobacco

and alcohol-related interventions for people with mild-moderate intellectual disabilities. The programme forms part of a small body of research in this area being led by researchers in the UK and internationally. In the developmental phase the purpose was to gather data to inform the design and content of the interventions, and to this end, the empirical and theoretical literature was reviewed and interviews conducted with key stakeholders.

The aim of the study reported here was to gain understanding of the tobacco and alcohol-related health promotion needs of people with mild-moderate intellectual disabilities. The objectives were to explore the participants' (people with intellectual disabilities, family carers, health and social care professionals) views and experience of:

- Smoking and the consumption of alcohol in people with intellectual disabilities
- Factors influencing smoking and alcohol consumption in people with intellectual disabilities (including barriers and facilitators to initiation and maintenance)
- Knowledge and understanding of the 'risks' associated with smoking and excessive alcohol consumption in people with intellectual disabilities
- Appropriate tobacco and alcohol-related health promotion approaches (including barriers and facilitators to behaviour change)

Methods

Design

A qualitative approach was adopted, guided by social cognitive theory (SCT) (Bandura 1986). SCT is commonly used in the public health field to underpin studies seeking to understand influences on behaviour/behaviour change (Baranowski *et al.* 2002). SCT proposes that a person's behaviour both influences and is influenced by environmental factors (including other people's behaviour), personal factors and attributes of the behaviour itself (Bandura 1986; 2004). Central tenets of SCT include self-efficacy and the value placed on the perceived outcomes or consequences of a change in behaviour (Bandura 2004).

Sample and Recruitment

Purposive sampling (Byrne 2001) was used to recruit people with intellectual disabilities, family carers and health and social care professionals (HSCPs). Participants were recruited from two large Health Board/Local Authority areas in Scotland. Inclusion criteria for people with intellectual disabilities were: 18 years or older; mild-moderate intellectual disability; experience of smoking and/or drinking (current or in the past). Family carers needed to be caring for an adult with a mild-moderate intellectual disability (and to have some experience of that person smoking and/or drinking) and professionals were required to be working in a post that brought them into regular contact with people with mild/moderate intellectual disabilities (and to have had some experience of working with people who smoked or consumed alcohol).

People with intellectual disabilities were recruited through four voluntary sector organisations. One of the authors, an experienced ID nurse, visited the organisations to meet potential participants, provide verbal information and distribute recruitment packs which contained a picture-based Information Sheet and Consent Form and a DVD which featured the same author providing information about the study. Guided by the study Advisory Group, which included people with intellectual disabilities, the research team's knowledge of the client group and existing literature on accessible writing (e.g. Mencap 2002), the recruitment materials were designed to be easily understood by people with a range of communication difficulties/impairments. Individuals who wished to take part were asked to return a completed Consent Form, assisted by key workers/family carers, as required. The aim was to recruit 20 people with intellectual disabilities. Family carers and HSCPs were recruited by another member of the research team, an intellectual disability Clinical Nurse Specialist. Family carers were recruited through two voluntary sector organisations; HSCPs were recruited from multi-disciplinary Community Learning Disability Teams and General Practice, with those wishing to participate being asked to return a completed Consent Form. The aim was to recruit 5-10 family carers and 15 HSCPs. The HSCPs and family carers were not recruited on the basis that they had a relationship with the who participated in the study.

Data collection

People with intellectual disabilities who agreed to participate took part in semi-structured focus group discussions. The decision to use focus groups was based on the fact they have been used successfully with this client group previously, they are a useful method of exploring participants' views and experiences, they allow facial expressions and body language to be observed and, importantly, the group interaction can encourage people with intellectual disabilities to speak/share their views, something they may not be so keen to do on an individual basis (Fraser & Fraser 2001; Barbour, 2005). The focus groups were held in locations familiar to participants (e.g. voluntary organisation premises) and were facilitated by two members of the research team. A semi-structured topic guide and visual aids (pictures, empty beer bottles, cigarette packets with health warnings) helped stimulate discussion. The interviews lasted approximately one hour, with a short break in the middle, to take account of the fact that the attention span of some participants may have been limited (National Institute of Child Health & Human Development, 2014). Family carers and HSCPs took part in semi-structured one-to-one telephone interviews. Telephone interviews were chosen as they were considered a cost-effective method of collecting data when time and travel constraints were an issue for the participants (Sturges & Hanrahan 2004). The telephone interviews lasted between 30 and 45 minutes. The focus group and telephone interviews were audio-recorded. An outline of the areas explored in the discussions/interviews is presented in Table 1.

Table 1

Data analysis

Following verbatim transcription, the data were analysed with the assistance of NVivo v10. Drawing on the principles of Framework analysis (Pope *et al.* 2006), key issues and concepts were identified initially by drawing on *a priori* reasoning and linked, deductively, to questions in the interview guide. The data were then indexed thematically (and inductively) based on what was discussed by the study

participants. In the final stage, and with the aim of understanding the mechanisms involved, findings were viewed through the lens of social cognitive theory, with attention being paid to similarities and differences in the accounts of people with intellectual disabilities, family carers and the HSCPs. The coding and analysis of the data was undertaken, in the first instance, by the member of the research team who had conducted the interviews. The analysis process was then subject to peer-review by other members of the Team.

Ethical review

Ethical approval was obtained from the regional NHS Ethics Service, the appropriate Local Authorities and the University, prior to recruitment. The principles of the UK Data Protection Act (2003) were observed. All participants provided informed consent.

Findings

The results are presented below and in the Discussion are considered in relation to the study's theoretical framework (social cognitive theory) and the wider empirical literature.

Sixteen people with a mild-moderate ID (P_ID) participated in six focus group (FG) discussions. Eight participants were accompanied by support workers, who aided communication, if/as required. Seven participants were smokers and three were former smokers. Fifteen had experience of drinking alcohol; 12 were current drinkers. Further demographic information, including details of living arrangements, is presented in Table2.

Table 2

Fifteen HSCPs and two family carers (FCs) took part in the telephone interviews (Table 3). The HSCPs included nurses, physiotherapists, psychiatrists, psychologists, social workers and practice nurses. The family carers were both female; one was the foster carer for a young man (aged 22 years) who smoked

and drank alcohol, the other was a mother whose daughter (aged 19 years) consumed small amounts of alcohol but had never smoked.

Table 3

The key themes that arose following the analysis of the data are presented below. The themes include:

a) Being like others; b) Social and emotional influences c) Understandings, mis-understandings and learning from experience; and, d) Choices and challenges.

a) Being like others

A pattern of experimenting with tobacco and alcohol generally started in the teenage years with the most commonly reported influence being peer pressure and a desire to be 'like others' who did not have an intellectual disability.

P_ID03_M: I've been smoking [since I was] sixteen because my pal said "If you smoke I'll let you be in my team, in my gang," so I thought "Oh fine, I'll smoke." (FG 01)

P_ID13_M: I was just turned seventeen, and a couple [of friends] said to me "You're a coward if you don't take a drink." They gave a line of vodkas, wee halves, all straight and they said "I bet you couldn't drink all these." So I did ... and that's where it started. (FG05)

FC14: [His] friends were smoking in school ... there was a wee group [pupils with and without ID] who were smokers.

The influence of family was also discussed, but only in relation to smoking.

P_ID08_M: They were all smokers, ma grandparents, and that ... I was surrounded by people smoking so I thought ... "may as well start myself". (FG03)

b) Social and emotional influences

When considering the reasons people with intellectual disabilities continue to smoke, a number of explanations were put forward.

P_ID8_M: Stress relief ...coping with life, smoking helps. (FG03)

P_ID7_M: Smoking just gives you something to do when you're bored. (FG03)

HSCP7_Psychologist: [Clients] tell me how much they enjoy smoking, so there's the physical pleasure of smoking and most people who don't want to stop or control their intake say it is because they enjoy smoking.

There was no overt mention of addiction or habit, which is important when considering levels of knowledge and understanding.

When asked why they consumed alcohol, celebrations, the marking of significant life events and its use as a social lubricant were discussed.

P_ID11_M: Say like the fibaw [football] team wins, you want to go out and celebrate, dancing, eh, parties, if you want tae drink, I know it's no' a nice thing to say but, some people drink at a funeral after somebody in their family gets buried or cremated they go for the [wake], and [you] have a drink at a wedding. (FG05)

P_ID06_M: You wouldn't chat up a woman if you didn't have a drink first! I did that at my mate's party. (FG03)

FC17: [My daughter] will tell you, "I'm allowed one glass of wine," if it's maybe the weekend, or if it's a special occasion, or a family meal.

For some, smoking/drinking was associated with a mental health problem and appeared to be used as a form of self-medication.

P_ID8_M: [Yes], if you're depressed ... smoking helps. (FG03)

P_ID07_M: I think because I've got em, em mental health problems, I like to block it [out] some of the time [with alcohol].

Others linked excessive drinking to difficult events in their lives, including bereavement.

P_ID05_F: Basically ... what I was going through was a very difficult time, because I lost my granddad, and then my mum and dad they were moving [abroad], and then at the same time I was getting [victimised] ... and basically before that it was my marriage breakdown, right, and that was messy ... (FG03)

P_ID08_M: I used to drink heavy a lot, but you know, when I lose someone I care about, that I love close, and it just feels like I'm building up anger and ready to explode, I find that, if I go for a drink ... it's kind of like to stop the pain and anger (FG03)

c) Understandings, mis-understandings and learning from experience

Health risks of smoking

Most focus group participants demonstrated a basic level of understanding of the association between smoking and (ill) health. One participant who had recently stopped smoking picked up the empty cigarette packet with a picture of someone with throat cancer (a visual aid) and observed:

P_ID03_M: See when you smoke, it will tell you on the packet, right, see that there [shows picture] ... that's what you can get. (FG01).

However, when asked what 'that' was, his response was that he did not know, which suggests that he had grasped the message that it was not good to smoke, but did not fully understand the specific health implications. Similarly, although other participants raised the issue of the link between cancer and smoking, their understanding appeared to be superficial.

*P_ID8_M: It can spread throughout all parts of your body and sometimes you can't cure it.
It could spread through your back and then all around your body, which kind of sucks.
(FG03)*

The relationship between smoking and heart and lung function was also raised in the focus groups although, again, a basic level of understanding was apparent. However even this level of understanding is important, as it demonstrates that health promotion messages are being taken on board by people with intellectual disabilities.

P_ID8_M: What's the thing about your lungs? What's that important stuff? Breathing! You need to breathe [or] your lungs go black, and that's you. (FG03)

P_ID14_M: It can go in to your chest ... and give you a heart attack. (FG06)

Perhaps the most straightforward of health promotion messages in relation to smoking and ill health is illustrated by the quote below. The message is simple but the point is certainly not lost.

P_ID13_M: All I know [is] you would die from it eventually. (FG05)

Environmental tobacco smoke

In addition to the above, understanding of the health risks associated with second hand/environmental tobacco smoke (i.e. passive smoking) was explored. Non-smokers voiced concerns about the effects of passive smoking on their health.

P_ID6_M: Well I used tae hang about wae [about with] guys and they were smoking and we would just be in the same atmosphere. Big worry for me. (FG 03)

P_ID13_M: That's a known fact ... passive smoking is worse for the person that's breathing it in [from] the person that's dain [doing] the smoking. (FG 05)

As can be seen in the above quote, while there was an awareness of the danger of environmental tobacco smoke, knowledge was not always accurate. In a similar vein, television advertising campaigns

focusing on the effects of passive smoking appeared to have been successful with regard to getting the message across to people with intellectual disabilities, as the following example indicates.

P_ID3_F: Aye that's a good [advert] and then [you] see all the smoke going in like to the baby and everything, do you know what I mean, and all the smoke and everything, and then it's going everywhere, do you know what I mean? (FG 03)

However, while this quote demonstrates that the dramatic nature of the advert appears to be conveying the message that smoking is harmful, it does not show whether the participant had understood the underlying, more complex, health promotion message.

Units of alcohol

When discussing alcohol, the participants' (with intellectual disabilities) knowledge and understanding of 'units' was explored. The concept of 'units of alcohol' is complex, as alcohol is sold in different volumes, of varying strength. For many people with intellectual disabilities, this degree of complexity makes the concept difficult to understand and apply to their actual drinking behaviour. Participants were generally aware that the recommended 'sensible' drinking levels, at the time, were lower for women than for men, and, when asked about the number of units of alcohol that is considered 'low risk' [worded accordingly], the responses varied.

P_ID06_M: Fourteen units for a woman, and I think it's twenty something for a man ...

P_ID08 M: Is it thirteen units, or is it twenty? (FG03)

P_ID15_M: On the label of the back of a bottle it tells you how many ... how many drinks a woman and man can have ... it's three or four units for a woman and for a man it's five or six. (FG 06)

As highlighted in the quotes above, an additional factor that complicates understanding of alcohol units is that they are often discussed as 'daily' rather than 'weekly' limits (Scottish Government 2009).

At the time the data were collected, daily limits were 2-3 for women, 3-4 for men, with a recommendation of two alcohol free days per week (Department of Health, 2013).

Importantly, any knowledge that the participants with intellectual disabilities had of weekly/daily limits did not generally extend to having a good understanding of what actually constituted a single unit of alcohol. One female participant knew, for example, that the recommended daily amount for women was no more than three units a day; however, when asked to define 'three units', she replied,

P_ID2 F: Three glasses of wine, am I right? ... small glasses, right? (FG 01)

While this participant's knowledge levels were generally good, it should be noted that a small glass of wine (125mls) is more likely to contain 1.5 units of alcohol rather than 1 unit (12.5% abv). What the participant considered to be three units was therefore more likely to be at least 4.5 units (i.e. above the recommended daily limit).

Levels of alcohol consumption and impact on behaviour

As might be expected, accounts of drinking habits varied considerably. For example, one individual summed up his feelings about why he only drank a limited amount of alcohol.

P_ID04_M: I don't, don't, don't, don't feel right wae [with] two pints ... fu Rabbie Burns [feels drunk]. (FG02)

As this participant had communication difficulties, his support worker expanded on what had been said, and described the level of choice and control he had in his life, and the decisions he made in relation to his drinking,

P_ID04_M [Support Worker]: Em, the only thing I can say is [PwLD4] enjoys a drink, he's not a heavy drinker but [he] will have a pint of shandy, and it's his choice when to have it or not, if you're out for a night at a party, or at the summer ball, or wherever, [he'll] maybe

have two or three pints, but that's his choice, but he knows when to stop ... because he knows what he wants, or doesn't want. His pal [friend] will bring ... a bottle of lemonade and they will share a can of beer, but it's always in his house, and it's his choice if he wants it. (FG02)

Other participants with an intellectual disability described similar, moderate drinking habits,

P_ID16_F: I just have a drink at the weekend ... I drink ... martini ... I put lemonade in it, and I take eh, Budweiser. (FG06)

However, some were drinking excessively, including 'binge drinking' as the following examples indicate

P_ID8_M: Quite a lot, I'd go through a few bottles of vodka and then go on Jack Daniels and then probably cider and then beer ... and then After Shock. (FG03)

P_ID07_M: On Monday, Tuesday, Wednesday, Thursday, Friday, Saturday, Sunday ... every day, aye ... Em, twelve bottles of beer ... em, a couple of glasses of wine, blue WKDs, a bottle of blue WKD em, em, red cola that's like vodka ... I usually start drinkin about ... six o'clock at night and that would be me to em, one o'clock, two o'clock. (FG03)

In addition to an understanding of 'hangovers,' participants' experience of the negative sides to drinking, in people with intellectual disabilities, extended to the more serious consequences of excessive consumption, such as 'withdrawal' symptoms (when alcohol dependant), dis-inhibition and anti-social behaviour.

P_ID02_F: Aye, it wis really hard because I had the DTs [delirium tremens] ... I wis in hospital because I wis hallucinatin, I wis freekin out and aw that ... I can only remember bits about it. (FG01)

P_ID8_M: Indecent exposure, goin about the street butt naked and doing something stupid ... in front of a police station. (FG03)

HSCP04_Nurse: They'll say "I know the drink makes me more aggressive," but the next night they're out at the pub again.

People with intellectual disabilities and family carers also raised concerns about the increased vulnerability associated with drinking.

P_ID02_F: Everybody called me a Lambrini [a brand of light perry] girl ... I used to wake up ... [and] say to myself, "Am I in my own bed, or am I in somewhere else?" ... half the time I was somewhere else. (FG01)

FC14: If he's had too much to drink he's got a tendency to stare at people ... you're going to get some thug that's going to say, "What the hell are you staring at?" ... So I feel he's vulnerable.

FC17: People with ID have got hormones like everybody else. Obviously, if anybody has had too much to drink their defences are down and that is another worry for any parent of a special needs child.

Health consequences associated with drinking excessively

While they freely discussed the social side of drinking and the short-term consequences of drinking excessively, little was said or apparently understood, by people with intellectual disabilities, about the medium and long-term health-related consequences of drinking too much. For example:

HSCP16_Psychiatrist: Because the liver isn't something you can see, I don't think they can immediately relate drinking alcohol to liver damage.

An added complication is that, for many people with ID, alcohol is contra-indicated because of long-term health problems (e.g. diabetes and epilepsy) and/or medications taken on a regular basis. While most appeared to have a reasonable understanding of this issue and limited their alcohol intake accordingly, some found other solutions, as noted by the social worker below.

P_ID16_F: We [people with ID] are often not allowed, to take much drink because with our problems ... I'm on tablets, I can only have one drink. (FG06)

HSCP01_Social Worker: The main difficulty, for some clients, is alcohol and ... other medications they're on [e.g. anti-epileptics] ... some of them can work out, "well, if I don't take the medication, I can drink," which brings on other problems.

d) Choices and challenges

Health promotion needs

When considering the health promotion needs of people with intellectual disabilities, most HSCPs believed they had a health promoting role. However, only a limited number had received any formal education/training relating to tobacco and alcohol (see Table 3), and knowledge was often gained from the media and personal experience rather than from specific evidence-based guidance.

HSCP10_Social Worker: The only thing I've maybe seen is anything you'd see in your own doctor's ... I have some knowledge from my own personal experience ... but on a professional level, no.

Different health promotion approaches were described/advocated by the HSCPs, ranging from a person-centred approach, in which individuals were supported in making their own choices, to a paternalistic approach (less common).

HSCP11_Practice Nurse: While I respect completely ... that they are adults and they are trying to lead an independent life, I do sometimes think we are being a bit stupid about it, in giving them choices ... and making [things] possible ... that they haven't maybe got the insight to understand the consequences of ... [I think we should be] overriding people's rights in certain situations, I think smoking is like that ... I think that you've got to have a bit of common sense about it.

The HSCPs reported that control exerted by support workers may be linked to feelings of accountability.

HSCP05_Psychologist: I think there's also fears within paid care groups that they'll not be able to control that person ... if the person was to get drunk ... I think, they would prefer if the person didn't drink, in case something went wrong and that then reflected badly on how they were looking after the person.

Other areas discussed included motivation and levels of self-efficacy, with self-efficacy referring to an individual's belief that they can achieve a task, for example, stopping smoking, if they wished to do so. Interestingly, issues of motivation and self-efficacy were discussed by the HSCPs but not by the participants with ID.

HSCP08_Nurse: I think people who live on their own struggle ... they find it much harder to stop because they're there's not really any motivation to stop smoking when you sittin' yourself in your house, and people often say that, 'Well, I've nothin' else to do, so I sit and smoke.'

HSCP16_Psychiatrist: [Thinking of alcohol] I wouldn't say that the motivation to cut down generally comes from them [people with intellectual disabilities]

HSCP03_social worker: [My clients] are saying that they can't stop it [smoking], they find it very, very difficult.

Engaging with health services

For those who were potentially interested in stopping smoking or cutting down alcohol consumption, a number of factors were reported as limiting effective engagement with General Practice and specialist smoking cessation/alcohol services. It appeared that 'reasonable adjustments' based on the specific needs of people with intellectual disabilities were not always made.

HSCP02_Psychologist: Some GP practices aren't very ID friendly, they're not aware of our clients' needs I would be thinking about the dynamics of that for our clients you know, is that a situation they are going to struggle with, are they going to get the most out of it is it going to be too much for them to deal with?

HSCP05_Psychologist: The standard GP appointment time [7-8 minutes] doesn't really lend itself well to working with a person with a learning disability.

HSCP12_Practice Nurse: Obviously there's the social thing if people [with ID] go to a group [smoking cessation service] they feel they are maybe not able to speak as well as other people, or say what they think, and that's an issue for them.

Issues relating to accessibility and health literacy were discussed at length and participants were asked to share their views on what would facilitate access to tobacco and alcohol-related health promoting messages, services and resources. There was general agreement that mainstream smoking services and alcohol services could be utilised by people with intellectual disabilities, but that information and support should be tailored and staff in specialist ID services should work jointly with staff in specialist smoking cessation/alcohol services when seeking to provide support for people with intellectual disabilities. A small number of examples where this type of approach had worked successfully were provided.

HSCP07_Psychologist: We work with [alcohol services] to ensure they are tackling things at the right level, so the person they're talking with is understanding what they're saying.

HSCP03_Social Worker: They [local GP surgery] run their own smoking group and they have facilitated groups for people who need that wee bit extra help, people with mental health problems or learning disabilities ... the nurses are trained up and ... I thought they pitched it very well, because a lot of our [clients], the barrier is communication. It was at a level they understood, really basic terms, but not patronising.

The key role of support workers in facilitating attendance at specialist tobacco and alcohol services and in providing regular day to day support and guidance was highlighted.

HSCP05_Psychologist: Support Workers need to know where to get information that is accessible for that person, how to support the client, should the client wish to use ... nicotine replacement or something like that ... Support Workers would probably be the most powerful people to use, because if the person decided to stop smoking, it would be the day-to-day carer that would have the most contact with the person.

HSCPs discussed the fact that difficulties with memory, concentration, consequential thinking and planning, experienced by people with intellectual disabilities, impact on their ability to understand and apply abstract knowledge; this is important when developing/delivering interventions. Simple, concrete examples of how to change behaviour were advocated, with a need for health promotion materials to be available in a range of accessible formats.

HSCP11_Practice Nurse: I [might say] "Why don't we try cutting [alcohol] out two nights a week?" ... And that's an easy thing to ask ... even if it meant saying, "On a Tuesday and a Thursday," you know, being a bit more specific.

FC14: I mean he's a clever laddie [young man] in his own way, but giving him a [standard] leaflet to read, it would go over his head.

Finally, peer support was suggested as a way of encouraging behaviour change.

FC17: I think rather than one [saying], "I'm stopping smoking" ... maybe they wouldn't be brave enough to be seen to be different. Getting a peer group together would be better ... a lot of people [with ID] go to day centres ... and college, and I think where they go is probably the best place to target.

Discussion

The findings are discussed below, linked to the central tenets of social cognitive theory (SCT) and the wider literature. As noted previously, SCT proposes that behaviour and behaviour change are affected by personal factors, environmental influences and attributes of the behaviour itself; each may affect or be affected by either of the other two (Bandura 1986).

Personal factors and attributes of smoking and drinking

When considering personal factors that influenced behaviour, the findings demonstrate that many people with intellectual disabilities have a superficial understanding of the health-related consequences of smoking and drinking excessively and they may be unaware that their health will improve if they stop smoking or reduce alcohol consumption. The perceived attributes of smoking and drinking, were very similar to those discussed by members of the general population (e.g. Kerr *et al.* 2006; Fidler & West 2009; Sharp 2014).; both were considered to be enjoyable, to function as a social lubricant and to have therapeutic qualities such as helping reduce stress and anxiety, alleviate boredom and to elevate mood. Again, similar to the general population (Viner & Taylor 2007) and in line with previous research (McGillicuddy 2006), younger people with intellectual disabilities appeared to be more susceptible to peer-pressure and more likely to indulge in binge drinking than their older counterparts. Outcome expectations were generally more negative than positive and when considering the consequences of changing behaviour, also, the HSCPs reported that levels of motivation and self-efficacy were often low. Bandura (1986) posits that a person must believe in their ability to change a particular behaviour and must perceive an associated incentive, that is, the person's positive expectations of changing the behaviour must outweigh negative expectations. Additionally, a person must value the outcomes or consequences that s/he believes will occur as a result. The expected outcomes are filtered through a person's perceptions of being able to perform the behaviour and self-efficacy is therefore believed to be a key characteristic that determines a person's ability to change their behaviour (Bandura 1986; 2004).

In relation to the perceived positive attributes of smoking, while stress-relief and enjoyment are commonly reported reasons for continuing to smoke, in all smokers, research-based evidence suggests that habit and nicotine dependence are, in fact, more influential than most people realise (Aveyard & West 2007). Nicotine acts on the mid-brain, creating impulses to smoke caused by stimuli associated with smoking. Also, when nicotine levels drop, smokers experience symptoms such as anxiety, irritability and low mood which are then relieved by smoking a cigarette (Hughes 2007). Smoking is therefore thought to cause, rather than alleviate, stress, anxiety, and low mood (Aveyard & West 2007). When considering alcohol consumption, as highlighted, alcohol may be contraindicated for some people with intellectual disabilities, linked to medications and/or pre-disposing conditions (Turner *et al.* 2001). For others, while drinking within the recommended daily/weekly limits poses little concern, and may be an enjoyable and social experience, excessive alcohol consumption presents risks to personal safety and to physical and mental health (Taggart *et al.* 2008). The findings also demonstrate that some people with intellectual disabilities may stop taking important medications (e.g. anti-epileptics) so that they can consume alcohol and this presents an additional health risk.

Bandura's (1986) concept of *behavioural capacity* is important when reflecting on the content and delivery of tobacco and alcohol-related health promotion interventions for people with intellectual disabilities. Behavioural capacity refers to the knowledge and skills required to perform/change a particular behaviour. Findings from the study reported here, and the wider literature, suggest that stopping smoking or reducing excessive alcohol consumption will present particular challenges for people with ID, who often struggle with cognitions, perception, memory and language (e.g. Willner *et al.* 2010). Individually and collectively these factors will impact on the ability of people with intellectual disabilities to make informed decisions about smoking and/or drinking and to understand what needs to be done to change their behaviour, if they wish to do so (Willner *et al.* 2010; Rowe *et al.* 2006). For example, the term 'units of alcohol' is something that many members of the public and health professionals do not properly understand (Webster-Harrison *et al.* 2001) and therefore, it is unsurprising that people with intellectual disabilities struggle with this concept.

Environmental Influences

The importance of the social and physical environment in encouraging or discouraging a particular behaviour is also discussed by Bandura (1986). In the current study, similar to the wider population (e.g. Simons-Morton *et al.* 2001), the role of social influence/norms (friends and family) was evident in the initiation and maintenance of smoking and drinking. There appeared to be a strong desire in some people with intellectual disabilities to mimic the behaviours of their non-disabled counterparts and in some cases this meant adopting behaviours such as binge drinking. Also, when considering stopping smoking/reducing alcohol consumption, few *role models* appeared to exist, which limited opportunities for observational learning (Bandura 1986). *Observational learning* occurs by watching the actions and outcomes of the behaviour of 'similar others' (Bandura 2004) and observing successful attempts to change behaviour in other people with intellectual disabilities is considered to be particularly important.

The potential for HSCPs, support workers and family members to encourage and support behaviour change was evident. It is therefore essential that they are aware of the influence of their own behaviours, beliefs and attitudes on the behaviour of people with intellectual disabilities. For example, the prevalence of smoking is known to be high in nurses and support workers (McKenna 2001; Beletsioti-Stika & Scriven 2006) and this can impact negatively on their health promoting role, as the people with intellectual disabilities who they work with often know that they smoke and they feel hypocritical if they raise the issue of smoking cessation (Beletsioti-Stika & Scriven 2006; Kerr *et al.* 2007).

The concept of behavioural capacity, discussed previously in relation to people with intellectual disabilities, is also relevant for HSCPs, support workers and family carers. HSCPs must have the appropriate knowledge and skills to raise the issue of smoking cessation/reduction in alcohol consumption effectively and to give evidence-based advice. In the current study, knowledge levels

were often low and few had received training to equip them with appropriate knowledge and skills. Lack of tobacco and alcohol training in HSCPs has been highlighted in previous studies (McLaughlin *et al.* 2007; Johnson *et al.* 2011; Kerr *et al.* 2011). Also, of note was the fact that HSCP participants raised the issue that professionals who had expertise in the delivery of smoking and alcohol-related interventions for the general population often lacked knowledge of how to tailor messages appropriately when working with people with intellectual disabilities. Family carers also have important health promoting training needs and this has been highlighted previously (Melville *et al.* 2009).

Strengths and limitations

A key strength of the study is that people with people with intellectual disabilities (in addition to family carers and HSCPs) have been given a voice in helping to inform the development of tobacco and alcohol-related health promotion interventions. As might be expected, the 'richness' of the data was affected by the fact that we were interviewing people with cognitive and language difficulties. That said, we believe the data generated are of value, and that the results shine an important light on the health promotion needs of people with ID and issues that should be addressed when developing/tailoring future interventions.

Issues that may limit the potential transferability of the findings include the fact that we failed to recruit participants with intellectual disabilities from black and minority ethnic groups and we did not recruit the desired number of family carers, despite strenuous efforts to do so. Also, while the presence of support workers during some of the focus group discussions assisted with issues relating to communication, it is acknowledged that their presence may have influenced the information shared by the person they were supporting.

Conclusion

In conclusion, an important finding is that the reasons people with intellectual disabilities smoking and drink (including drinking excessively) appear, in many ways, to be very similar to the wider population. However, when considering the health promotion needs of this client group, important issues have been raised that need to be addressed if current health inequalities are to be reduced.

The increased understanding provided by our study findings, and the accompanying literature, highlights that interventions for people with intellectual disabilities should focus on the following *personal factors*: knowledge of the health-related consequences of smoking and drinking (and stopping taking prescribed medication); motivation; self-efficacy; ways of coping with boredom, low mood and anxiety that bypass the urge to smoke and/or drink alcohol; and, the knowledge and skills required to make a quit attempt/cut down alcohol consumption. When considering the wider *environment*, the role of family and the multi-disciplinary team who have regular contact with this client group is central; health and social care professionals and family/paid carers should receive smoking cessation and alcohol education/training that addresses knowledge, attitudes and skills. Also, staff working in specialist health promotion services should receive training that raises awareness of the needs of people with intellectual disabilities. The most appropriate intervention model would appear to be joint/integrated service provision, and this has been raised previously (e.g. McLaughlin et al. 2007). Finally, it is essential that health promotion interventions are theoretically driven and tailored to address the varying cognitive, perceptive, memory and language needs of this client group.

[Word Count 7,001]

Source of funding

Queen's Nursing Institute (Scotland)

Conflicts of interest

None.

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Table 1 – Interview Guides (Outline of areas discussed)

People with Intellectual Disabilities (P_ID)	Family Carers	HSCPs
<p>Smoking When and why started (if smokes or smoked previously)? Good things and bad things about smoking? Can smoking do anything to other people who don't smoke? Who/what can help people to stop smoking if they want to?</p> <p>Alcohol When and why started (if drinks or drunk previously)? Why do people drink alcohol? Good things and bad things about smoking? How much alcohol is it okay to drink in a day? What happens if you/someone drinks too much? Why do people drink too much? Where can people get help they drink too much? What things might help people to learn about drinking safely?</p>	<p>Smoking Factors influencing initiation and continuation? Understanding of health-related consequences of smoking (P_ID)? Smoking cessation Health promotion needs of P_ID Health promotion approaches appropriate for P_ID</p> <p>Alcohol Factors influencing initiation and continuation? Understanding the health-related consequences of drinking too much (P_ID)? Health promotion needs of P_ID Health promotion approaches appropriate for P_ID</p>	<p>Smoking Experience smoking in P_ID Views on factors that influence smoking in P_ID Views and experience of tobacco-related health promotion needs of P_ID Views on their own health promoting role Views on appropriate tobacco-related health promotion approaches for P_ID</p> <p>Alcohol Experience of alcohol consumption in P_ID Views on factors that influence alcohol consumption in P_ID Views and experience of alcohol-related health promotion needs of P_ID Views on their own health promoting role Views on appropriate alcohol-related health promotion approaches for P_ID</p>

Table 2 - People with intellectual disabilities: demographic data

n=16	Frequency	percent
Sex		
male	12	75
female	4	25
Age		
<25	3	19
25-34 years	3	19
35-44 years	5	31
45-54 years	4	25
55-64 years	1	6
Range 18-64 years; Median 38 years		
Living arrangements		
Own tenancy, no support	1	6
Own tenancy, support worker visits	9	56
Core and cluster arrangement (self-contained flats with support on site)	6	38
Employment/further education		
employed	4	25
attending college	2	12
unemployed	10	63
Scottish Index of Multiple Deprivation scores*		
1-2	15	94
3	0	0
4-5	1	6
*Scottish Index of Multiple Deprivation (Scottish Government 2010) – participants' postcodes used to calculate scores. Data zones grouped into quintiles. Areas scoring 1 most deprived, areas scoring 5 least deprived.		
Note: All percentages have been rounded up/down and so may not add up to 100%		

Table 3 - Health & Social Care Professionals: demographic details

n=15	Frequency	percent
Professional group		
ID/mental health nurse	4	27
practice nurse	3	20
psychologist	3	20
psychiatrist	1	7
physiotherapist	1	7
social worker	3	20
Sex		
male	2	13
female	13	87
Age		
25-34 years	1	7
35-44years	7	47
45-54 years	6	40
55-64 years	1	67
Range 27-58 years; Median 44 years		
Undertaken any formal training relating to smoking/smoking cessation		
yes	3	20
no	12	80
Undertaken any formal training relating to alcohol use and misuse		
yes	5	33
no	10	67
Note: All percentages have been rounded up/down and so may not add up to 100%		