

Alcohol, other Drugs and Sight Loss: A Scoping Study

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Key findings

- People with sight loss are more likely than their sighted peers to abstain from drinking alcohol. Analysis of two UK datasets showed that they are also more likely to drink fewer units of alcohol per week.
- An international review of the literature found very little evidence for substance use leading directly to sight loss.
- There was evidence that substance use may be a risk for sight loss conditions such as 'tobacco-alcohol amblyopia' or 'toxic amblyopia' where heavy substance use is combined with other risk factors including smoking or poor nutrition.
- Among the people we spoke to who were living with sight loss and current or past substance use, some had been told by sight loss professionals that their alcohol or other drug use caused their sight loss.
- For some people their substance use was a way of coping with the negative experiences of sight loss.
- Among the professionals we spoke to, the number of people they worked with who had sight loss and substance problems was small but those who did posed considerable professional challenges.
- In general, professionals in sight loss and substance use services felt they were not adequately equipped with the knowledge, professional guidance or organisational policy frameworks, to help them to identify and respond confidently when working with someone with both sight loss and substance problems.

- Professionals identified partnership working as key to providing support and to stopping people falling through the gap in services. Joint training and resources for staff and individuals are recommended.

Research team

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Background

This was an exploratory study of the relationship between substance use – alcohol and other drugs - and sight loss. Its origins lay in practice-based concerns about the extent to which service provision met the needs of people with sight loss who were experiencing problematic substance use. A preliminary review of the international literature found limited evidence relating to medical or clinical associations¹ between sight loss and substance use but almost no literature that explored the experiences of those living, or working with, sight loss and substance use. Therefore, this study sought to answer three key research questions:

- What does current evidence reveal about the nature and extent of the relationship between substance use and sight loss?
- What is the role substance use plays in the lives of people with sight loss?
- What are the experiences of professionals working with people who have sight loss and substance problems?

Methodology

In order to answer the research questions, more detailed objectives were developed. These were:

- To explore what existing data can tell us about the extent of substance use among people with sight loss.
- To review any clinical and medical evidence of an association between substance use and sight loss.
- To explore the meaning and function of substance use in the lives of people with sight loss.

¹ 'Clinical' in this context refers to the treatment and support of people by a range of health professionals; 'medical' is a broader term but in this context refers to evidence that has focussed on medical connections between sight loss and substance use.

- To explore how professionals in a) substance use and b) sight loss services are currently working with the overlap between sight loss and substance use.

Three forms of data were collected and analysed. The first was a statistical exploration of existing large scale surveys which were analysed for prevalence data relating to both substance use and sight loss; the second was a comprehensive review of international research evidence to explore what is already known about the medical, clinical and social relationship between substance use and sight loss; the third sought the views of people living with sight loss and substance problems and the views of people working with, and supporting, these people.

This study focused on permanent and acute levels of visual impairment, rather than temporary or mild impairment. It focused primarily on problematic use of substances rather than any, or social, use. Finally, the focus of this study was initially on alcohol but given the dearth of research on other drugs and the fact that poly substance use is common in the UK, we also included problematic use of prescribed or illicit drugs.

Findings

Existing data set analysis

The following three datasets were identified from the UK Data Service database as meeting the search criteria most closely (see chapter 3 of the full report for details):

- The General Lifestyle Survey (GLS) 2009 and 2010
- The Health Survey for England 2000
- The Primary Care Trusts Patient Survey 2008

Analysis of the GLS found that people with sight loss were significantly more likely than sighted peers to abstain from alcohol and significantly less likely to exceed the weekly recommended limits. People with sight loss also consume fewer alcohol units per week on average compared to sighted peers. There was no statistically significant difference between those with sight loss compared to those without sight loss in relation to drinking every day of the week or binge drinking once adjustments were made for age and sex.

Analysis of the Health Survey for England dataset also found that people with sight loss were significantly more likely to abstain from alcohol and

consume fewer alcohol units per week on average than people without sight loss. There was no statistically significant difference among people with sight loss compared to those without sight loss once adjustments were made for age and sex on the following variables: exceeding the recommended alcohol limits, feeling a need to reduce their drinking, or having been drunk in last three months.

In the Primary Care Trusts Patient Health Survey, people with sight loss were no more or less likely than people without sight loss to say that they had been asked about how much alcohol they drank by someone at their GP practice in the last 12 months. However, after adjustment for age and sex, people with sight problems were significantly more likely to say that they had been given advice or help about sensible alcohol intake by someone at their GP practice in the last year. Of those who didn't receive it, people with sight problems were more likely than those without sight problems to say that they would have appreciated it.

International literature review

There is a wide and varied range of evidence on this topic. Most of it suggests there is no causal relationship between the two, but it does suggest some relationship between substance use and sight loss. In other words, while no evidence was found for substances causing sight loss directly, there was evidence that substance use may have a part to play in sight loss as a risk factor in combination with other individual characteristics or lifestyle choices, for example, smoking or poor nutrition.

The clinical case study material suggested that early intervention is vital in maximising a person's chances of sight improvement and recovery when someone has substance-involved sight loss.

There is also a body of work that highlights some of the challenges that may expose people with sight loss to a higher risk of substance use, for example, living with chronic pain, stigma, social isolation and boredom that may accompany sight loss. This has to be balanced with the potential advantages of social integration through alcohol-related activities, such as going to the pub.

Finally, the call for training for all professionals involved in assessing, identifying and responding to both sight loss and substance use in a range of contexts was highlighted in much of the literature. So too is the need for services to provide information about sight loss and substance use in accessible formats.

Note: While this study focused on alcohol and other drug use, it is important to note that the literature consistently identifies **smoking** as posing a very significant risk in the development of a range of visual impairments. The list of ophthalmologic disorders associated with cigarette smoking continues to grow.

Individuals living with substance use and sight loss

Seventeen individuals with experiences of living with sight loss and substance use were recruited through contacts with a wide range of organisations, adverts in relevant publications, using social media, and by word of mouth or 'snowball' sampling. Of the 17 respondents, 13 were male, the average age was 53 years old and most were outside of paid employment. There was a broad range of experience of sight loss and substance misuse.

For some participants, alcohol or other drugs were a way of seeking comfort or temporary escape from the challenges their sight loss presented to them physically and emotionally. Substance use was clearly a way of coping with sight loss and associated losses, such as their inability to drive or continue paid employment. For others they lived with being told that their use of substances caused, or contributed significantly to, their sight loss. What was clear was that these were highly individual circumstances and experiences.

Some people had continued their substance use following their sight loss diagnosis, while others had long since changed their substance use behaviour. For those who chose to continue to use substances there was far more planning and deliberation about how to do it, including who else was involved and where to go. Daytime visits to pubs where the people and physical environment were known replaced night time visits due to noise, levels of drunkenness, and the darkness when going home. Others chose to socialise at home instead.

For the majority of people who had experienced problematic substance use in addition to their sight loss, there was a negative impact on their relationships with families and friends. Primarily as a result of the substance use, family and friends had walked away. This often compounded the sense of isolation they already felt as a result of their sight loss and the subsequent barriers they faced to participation in everyday activities.

Perhaps unsurprisingly the resources and information required by people with sight loss and substance use included information about the links between the two. People's need for information and communication about the risks and the potential prognosis was clear; so too was the need for specialist services - be they substance use or sight loss - to have accessible information about the 'other' issue available for staff and service users alike.

In sum, the people we spoke to had very different journeys and experiences relating to sight loss and substance use. The commonality was they all continue to seek ways to adapt to a society that provides little by way of knowledgeable support about the relationship between sight loss and substance use.

Professionals supporting people with sight loss and substance problems

Eighteen professionals were interviewed following recruitment through the same routes as individuals living with substance use and sight loss. Thirteen worked in the sight loss sector, three in substance use and two in other related professions. The professionals reported that only a small percentage of the people they worked with had sight loss and substance problems. However, these individuals took up a great deal of staff time and energy. The sight loss professionals reported no routine assessment of substance use and substance use professionals reported no routine assessment of sight loss. Many sight loss professionals did not, and would not, ask about the person's substance use unless it was obvious or disclosed and vice versa for the substance use professionals.

While alcohol remained the dominant substance of choice for the individuals supported by the professionals we spoke to, there were clearly concerns about other types of drugs including prescribed medications.

The professionals clearly understood how substance use could be a coping mechanism for people with sight loss. This was particularly apparent when substance use had been part of the person's socialisation, often linked to their work culture, for example, veterans of the armed forces. Similarly, professionals acknowledged that substance use could be a coping response to a combination of losses and stresses in people's lives. In general, the professionals were unsure about whether or not there was a causal link between substance use and sight loss.

Almost without fail the professionals we interviewed were committed to doing their best in their role for people with sight loss and substance use

even though they found this challenging at times. Some professionals went outside their employer's usual procedures to offer what they felt was appropriate support and were often creative in their support and care. In substance use services the professionals faced particular challenges as many aspects of their practice models involved written tasks.

Partnership working was identified as key to providing the necessary support to people with sight loss and substance use and to stop people falling through the gaps in services. This was particularly so when practitioners doubted the 'truthfulness' of the people they supported but lacked adequate knowledge of sight loss or substance use to challenge or respond appropriately.

Finally, the professionals made a number of suggestions for resources to support them in their learning and also as information for service users directly. Some commented on the demise of sensory specialist staff and services. Within the current climate of public health and local authority cuts, this is unlikely to improve and may heighten the demand for partnership practice and free training exchanges.

Conclusion

This is the first study of its kind to combine the evidence about sight loss and substance use from three forms of data:

1. existing datasets
2. the international research literature
3. the views of people living with sight loss and problematic substance use, now or in the past, and the views of people working with, and supporting, them.

The findings present a number of clear messages. First, conclusions from the existing dataset analysis are that people with sight loss are more likely to abstain from alcohol and consume fewer units of alcohol per week. Second, the existing literature found no consistent evidence for substance use causing sight loss, but there was evidence that substance use may have a role to play as a coping mechanism for individuals with sight loss and also as a contributing risk factor through conditions such as 'tobacco-alcohol amblyopia' or 'toxic amblyopia'. Third, there is a relationship between sight loss and substance use for some people living with sight loss and substance use. Some people had been told by professionals that this was a causal relationship, while for others their substance use was a way of coping with their sight loss. Fourth, for

professionals, the number of people they worked with who had sight loss and substance use was small but those who did posed considerable professional challenges.

This study has begun the important conversation about what needs to improve in research, policy and practice. Future research needs to reflect the perspectives of people with sight loss and substance use, their partners, families, carers; these voices are largely absent from the literature. More comprehensive UK-wide prevalence data is much needed. A survey of people via sight loss and substance use services would be a start although ideally longitudinal research is needed to assess the impact of substance use on sight loss over time and vice versa, taking into account other lifestyle choices and environments. There is a research gap in relation to the impact of prescription medication on sight loss; this was a feature for several of our participants. Finally, the needs of people under 50 years old is a gap in the evidence base; the majority of the evidence focussed on older age groups. Research with a younger group will establish the potentially different impact of sight loss and substance use and could provide a cohort to follow, longitudinally, into later life.

Implications for practice

1. Education and training on sight loss and substance use is needed. Professionals need to be equipped with the knowledge to support people appropriately. This will need tailoring to different roles and different areas of practice.
2. Resources and materials that focus on early intervention with harm reduction, and provide guidance for interventions/ models for practice, are needed to support staff in substance use and sight loss services.
3. Routine monitoring and screening within sight loss and substance use services is needed so that substance use services screen for sight loss and vice versa.
4. Resources and material about the relationship between substance use and sight loss are needed for people who use sight loss or substance use services. Services are likely to need guidance on how to meet this need appropriately.

The need for the development of a range of resources and materials for both individuals and professionals provides an ideal opportunity for joint training and resource development through locally formed partnerships.

Further Information

The full report and supplementary appendices are available from www.alcoholresearchuk.org. Alternately contact Sarah Galvani at S.Galvani@mmu.ac.uk or telephone 07775 680418.

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Alcohol Research UK works to reduce levels of alcohol-related harm by ensuring that policy and practice can always be developed on the basis of research-based evidence.

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Thomas Pocklington Trust is a charity committed to increasing awareness and understanding of the needs of people with sight loss.

Research is central to Pocklington's work. We fund, and in other ways support, social and health research aimed at identifying practical ways to improve the lives of people with sight loss, and seek to influence the policies and services that affect them.

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