The relationship between sight loss and substance use: users' perspectives.

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Abstract

This UK study emerged from the concerns of a sight loss charity which sought to meet the support needs of its service users with problematic alcohol use. This paper presents findings from one strand of the study focusing on service users' perspectives. Aims: The aim was to explore the meaning and function of substance use in the lives of people with sight loss. *Method*: Through purposive and snowball sampling, 17 semi-structured interviews were held with people face-to-face or via telephone. Data were analysed thematically through coding, recoding and categorising data with double coding providing quality control. *Results*: People were at different stages in their use of substances and their experiences of sight loss. They reported a number of relationships between sight loss and substance use with three main relationships emerging; substance use as i) a cause of their sight loss, ii) a contributor to their sight loss and iii) a coping mechanism for sight loss. *Conclusion*: The diverse experiences of people with sight loss and substance problems require an individual and tailored response from substance use professionals. This needs to include routine questioning and accurate information about the medical relationship between sight loss and substance use.

Key words

Sight loss, alcohol, drugs, visual impairment

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Introduction

The study reported in this paper emerged from the practice concerns of a sight loss charity in England. It sought to understand better the needs of its service users who experienced problematic substance use in addition to sight loss. In particular, the Charity wanted to know if it could do something more, or do something differently, in relation to its service provision for people experiencing sight loss and who drank heavily. These practice concerns were set within wider questions about the relationship between the two, such as the prevalence of their co-occurrence, the causal or correlational links, the experiences of staff who supported people with sight loss and problematic substance use, and the experiences of people with sight loss and problematic substance use. These four areas became the focus for this study. To our knowledge this is the first study of this kind. This paper draws primarily from the views and experiences of people living with sight loss and substance use.

Background

Evidence of a relationship between substance use and a range of health conditions including liver disease, different types of cancer, chronic obstructive pulmonary disease, blood borne viruses, and dementia, has been well documented internationally (Ridley et al., 2013; World Health Organization (WHO) 2014). However, there is considerably less evidence that explores the relationship between substance use and conditions leading to sensory disability, such as sight loss or visual impairment, and deafness or hearing loss (Templeton, 2014). Yet, these conditions are common worldwide particularly among older adults. In the

case of sight loss, there are an estimated 39 million people worldwide who are blind out of a total of 285 million with visual impairment (World Health Organization, 2014).

The association of substance use with sight loss appears to be a global phenomenon. Published case study material from around world identifies instances of substance-related sight loss among heavy alcohol and other drug users. Among these clinical case studies are examples of people from Europe (Anyfantakis et al. 2012, Bhatnagar and Sullivan 2008, Davies, C. et al. 2012, Shwe-Tin et al. 2007, Steel et al. 1993, Zoccolella et al. 2010), Asia (Kee and Hwang 2008, Shinya et al. 2003), and North America (Sivilotti et al. 2001, Syed and Lioutas 2013), whose use of substances had been judged to be a trigger for temporary or permanent sight loss. The substances identified range from alcohol and tobacco to poppers and lacquer thinner. Others identified the assessed cause of the sight loss to be the route of administration and related infection, rather than the drug itself (Shwe-Tin et al. 2007). Six of these studies found that the reduction or cessation of substance use had an impact on sight loss (Anyfantakis et al. 2012, Bhatnagar and Sullivan 2008, Davies, C. et al. 2012, Shinya et al. 2003, Sivilotti et al. 2001, Syed and Lioutas 2013), noting improvements in people's sight loss when they reduced or ceased their substance use, often in with supplementary vitamin administration. In cases where there was evidence of longer-term substance use, the damage was identified too late and the sight loss showed minimal improvement after reduction or cessation (Davies et al. 2012, Steel et al. 1993).

Clinical reports, however, can make no claims to representativeness. They will only ever offer an individual's experience or that of a small number of people. To determine representativeness much larger studies are required that explore both substance use and

sight loss over time. This type of research is missing from the research evidence although two population studies, from Australia and the USA, suggest some limited evidence of increased risk of sight loss from alcohol consumption combined with smoking. The Australian Blue Mountain Eye Study (Kanthan et al. 2010) looked at the association between alcohol consumption, tobacco smoking and cataracts, in two postcode areas west of Sydney (n=2564). The study found some protective considerations for moderate alcohol consumption (1-2 "standard" drinks per day) compared to abstainers or those drinking more than two standard drinks per day. It is worthy of note that the people defined as 'heavy' drinkers in the study were not consuming alcohol in the quantities that is often seen in the treatment seeking population suggesting the numbers of those at risk could be far greater. The American Beaver Dam study (Klein et al. 1999) also examined the links between tobacco smoking, alcohol and caffeine consumption and the incidence of age-related cataracts over a 5 year period. They found tobacco and alcohol consumption increased modestly the risks of nuclear cataracts over that time period although another paper from the same study exploring age-related maculopathy found no significant correlation except for beer drinking men and an association with retinal drusen (white or yellow deposits under the retina) (Moss et al. 1998).

A number of studies incorporated questions about substance use into a study on a combination of other health conditions and eye health or visual impairment. For example, Mukamal (2007) reports on a study estimating the prevalence of problem drinking and other risk behaviours among adults with diabetes in the USA. A study from China explored eye injury and visual impairment identifying alcohol consumption as a significant risk factor (Wang et al. 2012). Another study from the USA explored male physicians' health including

an exploration of the relationship between alcohol and age-related macular degeneration (Ajani et al. 1999). The relevance of these studies is difficult to assess in relation to broader questions of alcohol consumption and sight loss given the limited population focus, e.g. male physicians aged over 40.

What the existing evidence does suggest is that substance use is a risk factor for sight loss or visual impairment, particularly when combined with other factors such as smoking and poor nutrition (McCarty 2002, Venza et al. 2011). Thus a person's lifestyle alongside their substance use appears to play a key role in determining the impact on their sight loss.

However, what is missing from the evidence is research exploring the perspectives of people living with both sight loss and current or previous substance use. Their understanding of the relationship between the two and their experiences of support are vital in determining appropriate policy and practice responses particularly given the relative dearth of evidence available.

Methodology

This gap in the evidence was addressed directly in one of the four strands of this multi-strand research project. The project's aims were to:

1. explore what existing data revealed about the extent of substance use among people with sight loss.
2. review any clinical and medical evidence of an association between substance use and sight loss.

3. explore the meaning and function of substance use in the lives of people with sight loss.
4. explore how professionals in a) substance use and b) sight loss services were working with these overlapping issues.

Four sources of evidence were identified to meet each of these aims. Respectively they were; i) secondary analysis of existing UK data sets, specifically the General Lifestyle Survey (GLS) 2009 and 2010, The Health Survey for England 2000 and The Primary Care Trusts Patient Survey 2008; ii) a comprehensive literature review of existing international research literature, using a systematic approach to searching and data extraction ii), iii) users' perspectives and, iv) professionals' perspectives, via semi-structured phone or face to face interviews.

Aim 3 sought to determine what role substance use played in the lives of people with sight loss living in the UK and is the focus of this paper.

Data collection and analysis

The new data collection with people experiencing sight loss and substance use comprised semi-structured, face-to-face, or telephone interviews. A semi-structured approach to interviewing allows for some focus and structure without conversation being restrained by an overly restrictive interview schedule or, conversely, by it being too unboundaried (Arksey and Knight 1999).

The interview schedule was designed anew due to the lack of previous research in this area. In addition to introductory questions and demographic data, there were six sections comprising questions relating to sight loss history, substance use history, relationship

between the two, relevant family history, support needs and services and community focussed questions, e.g. the extent to which they were aware of other people who experienced both substance use and sight loss. Some of the questions emerged from themes identified in the wider research evidence, e.g. questions around smoking and other substance use. The majority, however, were developed to directly explore participants' experiences of sight loss and substance use and to meet the aims of the study.

Data analysis of the interviews followed a thematic analysis approach in which the transcripts of the data were coded line by line, into key concepts. This type of coding has its origins in grounded theory approaches (Strauss and Corbin 1998) but has moved away from theory development as its goal, to a focus on identifying key thematic similarities and differences in the data. Its strength is that the text is the starting point for analysis rather than a researcher imposed framework, thus maximising the chances that the emergent themes are grounded in respondents' views. Once the coding has been completed for each transcript, patterns of data and connections between codes are identified. This process requires checking and rechecking of coding accuracy and fit. These patterns are then mapped into themes (O'Leary, 2010). Over 90 codes were identified from the 17 interviews, with initial clustering into 31 themes. It is the dominant recurring themes which are usually interpreted and presented as findings with dominant themes being indicated by those with highest number of references and/or source citations. For example, in this study three people (sources) made nine references to experiences of violence and abuse, whereas 17 people made 163 references to their experiences of loss relating to their sight loss. However, there is some bias as codes will often follow interview questions fairly closely. In this example, violence and abuse was not asked about directly in this study whereas the

positive and negative impact of sight loss was. Given the subjectivities of this process, quality control measures involving double coding of transcripts by two team members were applied at the start of the coding process. Computer aided software, NVivo version 10, was used to assist the coding and categorising process.

Recruitment strategy

The recruitment strategy for interview participants combined a number of traditional and creative methods. Purposive sampling was one strategy, where particular populations are chosen for their experience or knowledge of a topic (Davies and Hughes 2014). This sampling strategy targeted substance use (n=20) and sight loss (n=21) organisations within the UK and 11 other health and social care agencies who could disseminate information about the study on behalf of the research team. This purposive sample was supplemented with snowball sampling techniques (Browne 2005) via individual professionals, as well as professional contacts of the research team, the co-funders, and the project's wider project advisory group (PAG) that comprised sight loss, substance use and mental health specialists.

Flyers with information about the project were distributed widely to the organisations and individuals identified, followed by more individual approaches to these organisations to verify the dissemination of the flyer, to determine whether further information was needed and to establish their timeframes for dissemination. In addition, social media was used to provide information about the project and to seek participants. This consisted of Linked In, Twitter and Facebook.

A slow response rate for individuals with sight loss and substance use was anticipated given the sensitive nature of the research, therefore a second phase of recruitment was planned. This second phase proved important in ensuring our request for support was not forgotten or that it was picked up by colleagues, for example where an initial contact had left the organisation or was on leave.

Ethical approval

The research governance processes of University of Bedfordshire and Lancaster University were adhered to. One process comprised a two tier process, resulting in approval at Institute and University level. The other comprised a one tier process at University level. Individual consent was given in writing or verbally depending on the interview method and preference of the participant. People read, or had read to them, the information sheet about the research, in particular, confidentiality and data protection issues. They were provided with an opportunity to ask questions. Some people were able to provide a written signature while others interviewed by phone were not able to provide a signature and verbal consent was digitally recorded. Gratuity payments in the form of high street gift vouchers were provided at the end of the interviews in person or via mail. No participants were aware of this at the start of the interview. A second information sheet in various formats was offered post interview detailing local and national support services for people to contact as needed.

Results: sample profile

Of the 26 people who initially responded to our invitation to participate, our final sample comprised 17 people. Four could not be contacted on follow-up and five did not have

experience of both sight loss and problematic substance use. Of the 17 who participated, the majority of them did so for altruistic reasons (n=14); they wanted to help others to support the agencies that had supported them. The remaining three participated for reasons including their own recovery process, an interest in research, and because they felt it was relevant to their experience. The average length of the interviews was 78 minutes and interviews were conducted either in people's homes or in a venue of their choice in their local neighbourhood (n=13). Four people chose to be interviewed by telephone.

The profile of the group is set out in table 1 (below):

[Insert table 1 here]

As the table shows, this was a largely male, white sample with alcohol or polydrug use as their substance/s of choice. Most participants were from the south of England and were current or previous smokers. Smoking status is relevant due to the evidence linking smoking, drinking and sight loss. There was a range of employment status although none of the sample were in full time employment and while just under half had no religious affiliation, of those who did, most identified as Christian. Religious affiliation can be an important aspect of shame and stigma relating to substance use but can also be a motivating factor in help seeking and changing problematic substance use (Bradby and Williams 2006, Hurcombe et al. 2010)). The length of time people experienced sight loss varied considerably with seven people experiencing sight loss for more than 20 years and 10 people 20 years or less.

Results: thematic analysis

To recap, the aim of this strand of the study was to hear from people with sight loss about the meaning and function of substance use in their lives. There were no pre set hypotheses or explanations and the responses we received demonstrated how substance use, and problematic substance use, served a variety of functions and purposes in people's lives. There were eight key themes which emerged from the data analysis process as follows:

1. The impact of sight loss on their lives
2. Substance use as a cause or contributor to sight loss
3. Using substances to cope
4. The challenges of negotiating substance use with sight loss
5. The impact on others
6. Knowledge of other people with sight loss and substance problems
7. Services attended
8. Service access and improvements.

To allow for a fuller presentation of the findings, this paper will present, and subsequently discuss, the first three themes. These three themes, in particular, provide an overview of service users' understandings of the relationship between their sight loss and substance use. Further information can be found on all the themes from the final project report (Galvani et al. 2014). All participants' names have been anonymised as have other potentially identifying factors.

The impact of sight loss

Understanding the impact of sight loss on people's lives, and the challenges society presents to people with sight loss, provides vital knowledge and contextual information for substance use professionals. Without considering the relationship between sight loss and substance use, health and social care professionals, be they substance specialists or not, are unlikely to be able to respond appropriately.

Participants in this study reported feeling a tremendous sense of shock among their initial responses to their sight loss. As time progressed, depression and a sense of uselessness also emerged, with the realisation, and expectation, of a loss of autonomy and independence in the way they are traditionally conceived and understood.

> I was a bit shocked, you know a bit taken back thinking... I think my first question was, "can it be cured?" I think once I found that out, that it wasn't going to happen, I was a bit, sinking into quite a big depression. (Charlie, 30-35 years old)

> When I lost my sight, ... I felt useless, I felt that my life had ended, I couldn't read, I couldn't drive, I couldn't work. (Martin, 40-45 years old)

Both Charlie and Martin had sudden sight loss over short periods of time, however one woman who had lost her sight gradually reported the same sense of shock:

> …until you come to the very last point, the very last bit where you stop seeing anything and you see nothing, that I think is as much of a shock as it

> probably is to somebody losing all their sight at once. (Wilma, 76-80 years old)

Other participants talked of a sense of fear and vulnerability engendered by their sight loss:

> Since they told me about my loss of peripheral vision, I've actually become really quite scared, it's in the dark, I can't see ... you only have to decrease the light a bit and I tend to start panicking. (Penny, 66-70 years old)

> I went into shock and that stayed for quite a long time and a massive amount of denial. …I felt very vulnerable, I think, [that] would be the overall feeling of that time and a sense of not knowing what was going to happen, what would go on. (Karen, 36-40 years old)

There was also a range of examples provided about the isolation or lack of social participation people experienced. The lack of independence to drive, work, do DIY or continue hobbies had a significant impact on people's lives. Connor (aged 66-70) felt that sight was the worst sense to lose compared to losing your hearing or the ability to speak, "if you can see, you can participate, you can see what's going on in the world". Others spoke about their inability to do what they had previously done socially, whether it was playing football with the kids or socialising with work colleagues. Anger and frustration were also frequently expressed, when people found themselves unable to perform "normal" tasks.

Substance use as a cause or key contributor to sight loss

There were a number of relationships reported by participants between their substance use and sight loss histories. For some, they felt their substance use was a cause of their sight loss, while for others it was one of a number of contributing factors.

Despite the existing evidence suggesting that substance use alone is unlikely to cause sight loss without other factors being present, there were several participants who had been told by clinicians, or who felt clear themselves, that their substance use had led directly to their sight loss. For James, he was informed by a clinician that the alcohol was to blame.

> ...it was caused by [alcohol], they say, toxic amblyopia[i]. I was told that ... I shouldn't drink or smoke because I'm an alcoholic so they said 'cut down as much as you can'. I thought, because I was hitting the booze very heavily,... if anything, it might get my liver… . (James, 51- 55 years old)

Charlie was given a diagnosis of malnutrition amblyopia but feels that it was his drinking that caused it:

> The way they say amblyopia, I don't think it was malnutrition amblyopia, I think it was toxicity amblyopia, through the drink. Because obviously the drink was the one that poisoned me to that point. (Charlie, 31-35 years old).

For Charlie, however, his drinking had continued and it remained a worry to him:

> Every time I take a drink, the one thing I worry about the most is the fact that I'm going to affect my eyesight even more from it. If I happen to be going on a very dangerous binge myself again, I could very well end up losing more vision. That sort of stuff should scare the shit out of me, pardon my French, it should really scare the crap out of me.

For three participants prescription medication played a causal role in their sight loss. Only one of them had taken excessive amounts of medication, the other two had taken it as prescribed. Jenny relates the nerve damage to her eyes caused by an attempted overdose:

> I was taking tablets when I was suicidal, I'd have drink first and then I wouldn't know what I was doing and then take the tablets,...I've damaged my nerves at the back of my eyes with these [prescribed] tablets. (Jenny, 41-45 years old)

In two cases the participants took prescribed drugs as directed, one for a heart condition and one for epilepsy. Both were clear their prescribed drugs were responsible for their sight loss. Connor (66-70 years old) said he had "a heart arrhythmia ... they decided that what [I] needed to do was go on [amiodarone]". Current clinical guidance on amiodarone advises immediate medical advice for anyone experiencing the "very common" side effect of "blurred vision or any visual disturbances as some eye problems may very rarely lead to blindness" (National Health Service, n.d.). Connor states "they never once told me". For Norm (21-25 years old), he felt his epilepsy caused his sight loss but that the medication he took for his epilepsy made it worse.

For other participants, they felt their substance use had been a contributor to their sight loss, often combined with poor diet and lifestyle choices.

> I think it was the steroids [that] kicked off cell deterioration which is the retinal degeneration, so basically over the years, the cells were dying off but obviously that was exacerbated by my drinking, drug and smoking habits. Since I've become a good boy, the cell deterioration has slowed down but it's lots of things, could be diet as well, lifestyle, everything...well anything basically that you're putting into your body, any substance, if your body's not well and your blood's not well, it's going to affect your eye-sight. (Chas, 61-65 years old).

Using substances to cope or self-medicate

Participants spoke of using substances to cope with their sight loss and social isolation. Karen's use of substances helped her to be part of a wider group of people who were "numbing" themselves through drug use. She had lost her sight in a car accident aged 14 years:

> I think people use drink and drugs to numb pain and that's what I was doing in a huge way. ... I felt kind of a bit broken, you feel broken because you've got this disability or whatever it is there and you're with other people who are all the same, there's no judgement between you, you're all

> numbing yourself in the same way for different things, so you feel part of a group...we were all the misfits together. (Karen, 36-40 years old)

Tommy (66-70 years old) also felt there was a relationship between his sight loss and his heavy drinking and also other life events that he could not cope as well with as a result of his sight loss:

> I think the more my sight's gone away, the more I've been drinking. So there's definitely a relationship,... It dulls the frustration, if you know what I mean? That, and also my wife has been very sick.... and I think that adds to the frustration of the sight loss, the fact that I can't do everything that I feel I should be doing for her.

Some participants reported using the substances prior to their sight loss, and the sight loss exacerbating their previous use. Barnaby (61-65 years old) recounts his experience of heavy spirit drinking when he "[was] trying to work it all out...Why me? What am I going to do with myself? Am I going to go blind?".

Stefan (56-60 years old) had switched his substance-related coping mechanism from valium when he was at work to alcohol when he left work. Stefan also spoke of being shocked at his loss of confidence and as his sight failed he increasingly took valium to boost his confidence and reduce stress in work situations such as meetings and presentations. Subsequently his drinking had increased and he remained concerned about the future:

> So I think, actually, I do sit down and worry about my sight, then I have a beer, and I don't. There's still a bit of that [worry] there, but whether it's just the alcohol that I'm more hooked on [rather] than the fact that it helps me with, I could say my sight loss, the worry because of my sight loss. I don't think I'll go completely blind, but it is it impacting, and if I wasn't married I would be in serious trouble. I wouldn't be able to manage very well on my own I don't think.

Brandon (41-45 years old) lost his sight as a teenager. He had chosen to use a number of substances in later years of his life, following the end of a relationship. However, his substance use appeared to include a response to his disability as well:

> I'd never been crazy so I thought you're [*age*] now and you've never been crazy, it's time for you to... and I've been married,... [and] now the relationship is over, now it's time for you to look after you and be crazy. And just you know, you're disabled as well and fuck that as well, I just thought, you know, live a little.

Discussion

This was an exploratory study triggered by the practice concerns of a national UK sight loss charity. It set out to hear the perspectives of people with sight loss on the meaning and function of substance use in their lives, particularly those whose substance use had become problematic. It is limited in a number of ways, primarily due to its small sample size and the lack of ethnic or cultural diversity within this sample. In the UK there are currently 360,000

people registered blind or partially sighted (RNIB 2015a) and this figure rises to nearly 2 million when serious visual impairment is taken into account (RNIB 2013). Mixed methods research with a larger sample accessed through a wide range of specialist substance use and sight loss organisations, educational establishments and health service clinics, is likely to provide a far clearer picture about the experiences, and support needs, of this group of people. Further, a larger study would be more likely to access a large enough sample to explore any significant issues of diversity by experience by age, gender, class, housing status, ethnicity and religion, to name a few.

However, it is the first study of its kind internationally. What these findings show is that relationships between sight loss and substance use exist, and that a combination of sight loss and substance use presents individuals with a number of emotional and practical challenges. It demonstrates the dynamic relationship between the two but also the diversity in people's experiences. The people we spoke to were at very different stages of their sight loss journey and substance use played different roles in that process. For some it was a parallel experience that occurred alongside their sight loss and may, or may not, have contributed to it; for others their substance use was, or had been a coping mechanism. Previous literature has theorised the relationship between visual impairment and substance use and this study grounds such theorising in evidence. A North American paper by Koch et al. (2002) proposed three types of interactions between sight loss and substance use:

i) an individual's substance use limits their ability to adjust to a new experience of sight loss,

ii) their substance use post sight loss, has a detrimental effect on their ability to continue adjusting to their sight loss

iii) substance use is a coping mechanism but risks the person developing problematic substance use.

In this study, while evidence of these three types of interactions occurred, people also reported substance use as a perceived causal factor or correlate of their substance use. Further, their experiences were not solely about substance use affecting their *adjustment* to sight loss at different stages. Their experiences included the relative role of the substance in explaining or exacerbating their sight loss and then living with that understanding.

Of course, the use of substances as a coping mechanism is not confined to sight loss. There is a body of evidence demonstrating that substances are used to cope with a range of traumatic events including loss, experiences of child abuse, and domestic abuse (Galvani, 2006; Kishore et al., 2008; Ullman et al., 2013). In such cases, the substance acts as a temporary chemical nullifier of emotional and psychological pain.

However, people with sight loss face additional, and often difficult, practical challenges; for example, trying to move around the house, or walking between the pub[ii] and home, as identified by participants in this study. These everyday tasks can become even more difficult when the sight loss and intoxication are combined. For people with more recent sight loss or deterioration of sight, intoxication can also present challenges to professionals offering practical support in the early stages of sight loss. Examples include a visual rehabilitation officer who is offering mobility or cane training to someone who may be drinking at home

and intoxicated much of the time (Livingston et al, *in preparation*), or moral dilemmas for support staff such as helping someone with problematic alcohol use to get to and from the local pub. These types of concerns have been raised by practitioners within the sight loss field with conflicting responses from individual professionals (RNIB 2015b).

The mix of information that people had been given about the relationship between sight loss and substance use, demonstrates the need for an accurate picture of the relationship between the two. Having accurate information is important for the education and training of professionals working in both sight loss and substance use services as well as wider welfare organisations that offer support to people with one or both issues, for example, veterans' associations and social care professionals. Furthermore, this accurate information needs to be disseminated to all those in clinical, support or family/carer roles as well as the individuals themselves.

On their own, education and training will probably not change attitudes to substance use or sight loss but it is a necessary first step set within a wider movement to counter disabilist attitudes by practitioners or others, whereby substance use, for example, is seen as a reasonable response to the 'tragedy' of sight loss (French and Swain, 2012). Similarly, it will begin to highlight the wider context of a society that is often disabling in its construction of an able-bodied norm and disabled lives as somehow lacking (Oliver, 2004).

Further, such education and training is timely given the aging population in many countries. While this study was not focusing on older people, they are an age group where sight loss, and other long term conditions, are likely to occur more frequently (RNIB 2015a). Given

that research evidence is already demonstrating the increased levels of older people experiencing alcohol-and drug-related harm (Wadd, 2014; Wadd et al. 2011), this is a combination of factors that needs attention.

The recommendations emerging from this study suggest that i) much clearer information on the nature of relationship between substance use and sight loss is needed for both individuals and professionals alike; ii) this information needs disseminating to both sight loss and substance use support services in order for it to inform practitioner and service responses; iii) such policy and practice development will place professionals in a stronger position to fully support people to the best of their ability, iv) far more research is required to address the gaps in the evidence base, in particular to ensure the prevalence and incidence of these issues are accurately recorded as well as to ensure that people with diverse backgrounds and experience are adequately represented.

Conclusions

The literature on disability, disabled people and their relationship with substance use is limited worldwide (Csiernik and Brideau 2013). This is true of sight loss too but there is a particular dearth of research reflecting people's personal experience. This exploratory study was the first to ask people with both sight loss and problematic substance use to recount their experiences and perspectives on the links between the two. One of the research questions underpinning this study asked 'What is the role substance use plays in the lives of people with sight loss?'. For many participants, their substance use (problematic or non-problematic) remained an important part of their engagement with friends and social activity. For others, their sight loss, and the role of substances within that, had led to

abstinence from substance use, or reduction of substance use to non-problematic levels. What is clear is that the range of responses from our participants will require a range of responses from professionals from substance use and sight loss services. For substance use services this includes asking questions about sight loss routinely and considering the complex mix of physical, emotional, psychological and social meanings that substance use offers to people with sight loss as well as the practical challenges they may face in accessing the service

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References

Ajani, U. A. Christen, W. G. Manson, J. E. Glynn, R. J. Schaumberg, D. Buring, J. E. and Hennekens, C. H. (1999) 'A prospective study of alcohol consumption and the risk of age-related macular degeneration', *Annals of Epidemiology* , 9 (3), 172-177.

Anyfantakis, D., Symvoulakis, E. K., Cristodoulakis, E. V. and Frantzeskakis, G. (2012) 'Ruling in the diagnosis of methanol intoxication in a young heavy drinker: a case report', *Journal of Medicine and Life*, 5 (3), 332-334.

Arksey, H. and Knight, P. (1999) *Interviewing for Social Scientists.* London: Sage

Bhatnagar, A. and Sullivan, C. (2008) 'Tobacco–alcohol amblyopia: can OCT predict the visual prognosis?' *Eye,* 23, 1616-1618.

Bradby, H. and Williams, R. (2006). 'Is religion or culture the key feature in changes in substance use after leaving school? Young Punjabis and a comparison group in Glasgow.' *Ethnicity and Health*, 11(3), 307-324

Browne, K. (2005) 'Snowball sampling: using social networks to research non-heterosexual women.' *International Journal of Social Research Methodology,* 8 (1), 47-60

Csiernik, R. and Brideau, M. (2013) 'Examining the Intersection of Addiction and Issues of Ability in Canada', *Journal of Social Work Practice in the Addictions*, 13 (2), 163-178.

Davies, M. and Hughes, N. (2014) *Doing a Successful Research Project: Using Qualitative or Quantitative Methods* (2nd edition) London: Sage.

Davies, A. J., Kelly, S. P., Naylor, S. G., Bhatt, P. R., Mathews, J. P., Sahni, J., Haslett, R. and McKibbin, M. (2012) 'Adverse ophthalmic reaction in poppers users: case series of 'poppers maculopathy'', *Eye* 26 (11), 1479-1486.

Davies, C., English, I., Lodwick, A., McVeigh, J. And Bellis, M. A. (eds.) (2012) *United Kingdom Drug Situation: Annual Report to the European Monitoring Centre for Drugs and Drug Addiction* (EMCDDA) London, Department of Health.

French, S. and Swain J. (2012) *Working with Disabled People in Policy and Practice: A social model* Basingstoke: Palgrave Macmillan

Galvani, S. (2006) 'Alcohol and Domestic Violence: Women's views'. *Violence against Women*, 12 (7), 641-662

Galvani, S., Livingston, W., Morgan, H. and Wadd, S. (2014) *Alcohol, other Drugs and Sight Loss: A Scoping Study*. Final report. Available online at: http://alcoholresearchuk.org/alcohol-insights/alcohol-other-drugs-and-sight-loss-a-scoping-study/

Hurcombe, R., Bayley, M. and Goodman, A. (2010) *Ethnicity and alcohol: a review of the UK literature*. *Summary report*. York: Joseph Rowntree Foundation. Available at www.jrf.org.uk

Kanthan G. L., Mitchell, P., Burlutsky, G. and Wang, J.J. (2010)'Alcohol Consumption and the Long-Term Incidence of Cataract and Cataract Surgery: The Blue Mountains Eye Study.' *American Journal of Ophthalmology,* 150 (3), 434-440.

Kee, C. and Hwang, J-M. (2008) 'Optical coherence tomography in a patient with tobacco-alcohol amblyopia.' *Eye,* 22, 469-470.

Kishore, V., Theall, K.P., Robinson, W., Pichon, J., Scribne, R., Roberson, E. and Johnson, S. (2008) 'Resource loss, coping, alcohol use, and posttraumatic stress symptoms among survivors of Hurricane Katrina: a cross-sectional study.' *American Journal of Disaster Medicine,* 3 (6): 345-57

Klein, B.E. K. Klein, R.E. and Lee, K.E. (1999) 'Incident cataract after a five-year interval and lifestyle factors: The Beaver Dam Eye Study.' *Ophthalmic Epidemiology,* 6 (4), 247-255.

Koch, D. S., Nelipovich, M. and Sneed, Z. (2002) 'Alcohol and other drug abuse as coexisting disabilities: Considerations for counselors serving individuals who are blind or visually impaired', *Review: Rehabilitation and Education for Blindness and Visual Impairment*, 33 (4), 151-159.

Livingston, W., Galvani, S., Morgan, H. and Wadd, S. (*in preparation)* 'Seeing the alcohol and drug use in visual impairment treatment.'

McCarty, C. A. (2002) 'Cataract in the 21st Century: lessons from previous epidemiological research.' *Clinical and Experimental Optometry: Journal Of The Australian Optometrical Association*, 85 (2), pp. 91-96

Moss, S.E., Klein, R., Klein, B.E., Jensen, S.C. and Meuer, S.M. (1998) 'Alcohol consumption and the 5-year incidence of age-related maculopathy: the Beaver Dam eye study.' *Ophthalmology*, 105 (5) pp. 789-94.

Mukamal, K. J. (2007) 'Hazardous drinking among adults with diabetes and related eye disease or visual problems: a population-based cross-sectional survey'. *Ophthalmic Epidemiology* , 14 (1), 45-49.

National Health Service (n.d.) 'Amiodarone.' Available at: http://www.nhs.uk/medicine-guides/pages/MedicineSideEffects.aspx?condition=Heart%20rhythm%20disorders&medicine=Amiodarone&preparation= [accessed 27 August 2015]

O'Leary, Z. (2010) *The Essential Guide to Doing Your Research Project.* London: Sage

Oliver, M. (2004) 'The Social Model In Action: If I had a hammer?' In C. Barnes and G. Mercer (Eds.) *Implementing the Social Model of Disability* Leeds: The Disability Press, pp. 18-31.

Ridley, N.J.,Draper, B. and Withall, A. (2013) 'Alcohol-related dementia: an update of the evidence.' Alzheimer's Research and Therapy, 5 (3), 108.

Royal National Institute of Blind People (RNIB) (2013) *Sight loss UK 2013: The latest evidence*. London: RNIB.

RNIB (2015a) 'Key information and statistics.' Available online at: http://www.rnib.org.uk/knowledge-and-research-hub/key-information-and-statistics [accessed 9 November 2015]

RNIB (2015b) 'Solve my dilemma.' Available online at: https://www.rnib.org.uk/services-we-offer-advice-professionals-nb-magazine-health-professionals-nb-features/solve-my-dilemma [accessed 9 November 2015]

Shinya, H., Hoshino, K., Kiritohshi, M., Kiuchi, S., Yamagami, K. andNakatani, T. (2003) '[2 Cases of Acute Retrobulbar Neuritis by Thinner Inhalation; Detected Methanol of High Concentration in Gas Phase Assay]', *ChudokuKenkyu: ChudokuKenkyukai Jun Kikanshi = The Japanese Journal of Toxicology*, 16(3), pp. 329-333.

Shwe-Tin, A., Ung, T., Madhavan, C. and Yasen, T. (2007) 'A case of endogenous Clostridium perfringensendophthalmitis in an intravenous drug abuser.' *Eye,* 21, 1427-1428

Sivilotti, M. L., Burns, M. J., Aaron, C. K., McMartin, K. E. and Brent, J. (2001) 'Reversal of severe methanol-induced visual impairment: no evidence of retinal toxicity due to fomepizole', *Journal of Toxicology. Clinical Toxicology* , 39 (6), pp. 627-631.

Steel, J.R., Cockcroft, J.R. and Ritter, J.M. (1993) 'Blind drunk: alcoholic pancreatitis and loss of vision. '*Postgraduate Medical Journal*, 69(808), pp. 151-152.

Strauss, A. and Corbin, J. (1998) *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. (2nd edition.) London: Sage

Syed, S. and Lioutas, V. (2013) 'Tobacco-alcohol amblyopia: a diagnostic dilemma'. *Journal of the Neurological Sciences*, 327(1-2), pp. 41-45.

Templeton, L. (2014) *Deaf Alcohol Project*. Final Report to Funder. Alcohol Research UK.

Ullman, S.E., Relyea, M., Peter-Hagene, L. and Vasquez, A.L. (2013) 'Trauma Histories, Substance Use Coping, PTSD, and Problem Substance Use Among Sexual Assault Victims.' *Addictive Behaviour*, 38 (6): 2219–2223. doi:10.1016/j.addbeh.2013.01.027.

Venza, I., Visalli, M., Oteri, R., Teti, D. and Venza, M. (2011) 'Combined effects of cigarette smoking and alcohol consumption on antioxidant/oxidant balance in age-related macular degeneration', *Aging Clinical and Experimental Research*, 24 (5), 530-536.

Wadd, S. (2014) *The Forgotten People: Drug Problems in Later Life*. Luton: University of Bedfordshire.

Wadd, S., Lapworth, K., Sullivan, M., Forrester, D. and Galvani, S. (2011) *Working with older drinkers.* Luton: University of Bedfordshire.

Wang, J. D., Xu, L., Wang, Y. X., You, Q. S., Zhang, J. S. and Jonas, J. B. (2012) 'Prevalence and incidence of ocular trauma in North China: the Beijing Eye Study.' *Acta Ophthalmologica*, 90 (1), e61-e67.

World Health Organization (2014) *Global status report on alcohol and health 2014.* Available online at: http://apps.who.int/iris/bitstream/10665/112736/1/9789240692763_eng.pdf?ua=1 [accessed 10 Feb 2016]

World Health Organization (2014) 'Visual impairment and blindness.' Fact Sheet no. 282. Available online at: http://www.who.int/mediacentre/factsheets/fs282/en/ [Accessed 190 February 2016]

Zoccolella, S., Petruzzella, V., Prascina, F., Artuso, L., Pacillo, F., Dell'Aglio, R., Avolio, C., DelleNoci, N., Attimonelli, M. and Specchio, L.M. (2010) 'Late-onset Leber hereditary optic neuropathy mimicking Susac's syndrome.' *Journal of Neurology*, 257 (12), 1999-2003.

Tables and Figures

Table 1: Sample characteristics

Gender	Male = 13; Female = 4
Average age	53 years (range 20s to 80s)
Ethnicity (self-defined)	White English/British = 16; Asian = 1.
Religious identity	Christian = 7; Quaker = 1; Pagan = 1; None = 8
Employment	Full time paid = 0; Part-time paid = 4; Unpaid employment/ voluntary role = 2; Students = 2; Retired = 3; "Full-time mum" = 1; Unemployed = 5.
Smoking status	Current = 5; Previous = 6; Never smoked = 6
Sight loss (start of sight	1-5 years ago = 4;

loss)	5-10 years ago = 3; 10-20 years ago = 3; 20-30 years ago = 1; more than 30 years = 5; since birth = 1
Substance/s of choice **(current or previous)**	Alcohol - 7; Illicit drugs = 1; Prescribed medication = 3; Poly drug use = 6
Region of the UK	South-East England = 4 South-West England = 6 Wales = 2 East Midlands (England) = 3 Scotland = 1 North West England = 1

[i] Amblyopia is a loss of vision in one eye when the brain and the eye are not functioning together as they should be.

[ii] A pub is short for public house, common in England as a place to go and drink alcohol with other people from the local community. It is often a house style building rather than a bar or cafe.