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Health Psychology:

A Portfolio of Work and Practice

Including:

Addiction; Stigma and Quality of Life; and, Visual Impairment

Timothy J. Mahy

Portfolio submitted in fulfilment of the requirements for the degree of Doctor of Health Psychology

Department of Psychology, City University, London

January 2015

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p 396:	**Image for handout 3.1.**

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pp 207-223:	**The lived experience of guide dog ownership.** Case studies.
p 337:	**Appendix 11.** Poster for originally planned group.
p 349:	**Appendix 1.** Request for consultancy.
p 350:	**Appendix 2.** Minutes of planning meeting.
p 359:	**"Don't do groups" flyer.**
p 360:	**Appendix 5.** Minutes of meeting to evaluate consultancy.
pp 361-371:	**Area of competence.** Behaviour of an individual in order to achieve health outcomes.

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Glossary of Abbreviations

ACT	Acceptance and Commitment Therapy
AMD	Age-related Macular Degeneration
AUDIT	Alcohol Use Disorders Test for Hazardous Drinking Symptoms
BAC	Blood Alcohol Content
BPS	British Psychological Society
CBT	Cognitive Behavioural Therapy
DISC	Discrimination and Stigma Scale
GDO	Guide Dog Owner
GMI	Group Motivational Interviewing
GP	General Practitioner/Physician
[redacted]	[redacted]
HCPC	Health and Care Professions Council
IBS	Irritable Bowel Syndrome
ICD	International Classification of Diseases
IPA	Interpretative Phenomenological Analysis
KC	Keratoconus
MBCT	Mindfulness Based Cognitive Therapy
MET	Motivational Enhancement Therapy
MI	Motivational Interviewing
NHS	(United Kingdom) National Health Service
NHS SSS	NHS Stop Smoking Service
NICE	National Institute for Health and Care Excellence
NRT	Nicotine Replacement Therapy
QoL	Quality of Life
QUAD	Questionnaire on Anticipated Discrimination
RAPI	Rutgers Alcohol Problem Index
RP	Retinitis Pigmentosa
RYO	Roll Your Own Tobacco/Cigarettes
SI	Sight Impaired / Partially Sighted
SS	Stopping Self

SSI	Severely Sight Impaired / Blind
TMP	Treated More Positively by
TMU	Will Treat Me Unfairly
TTM	Transtheoretical Model/Stages of Change
UK	United Kingdom
US/USA	United States/United States of America
UT	Unfair Treatment
VI	Visual Impairment/Visually Impaired
VIF	Variance Inflation Factor
VIP	Visually Impaired Person
WHO	The World Health Organisation
WHOQOL	The World Health Organisation Quality of Life

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DECLARATION

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Integrating Health Psychology; Addiction; and, Long-Term Health

Preface

In order to achieve the competencies required of the Doctorate in Health Psychology a number of opportunities were negotiated with my workplace, plus work was done outside of the workplace, displaying a broad range of skills and expertise to demonstrate competence to achieve Health Psychologist status. This portfolio was compiled whilst working, voluntarily, as a Trainee Health Psychologist and Project Worker at [redacted] This role involved delivering group and one-to-one interventions, running client workshops and being involved in all aspects of the organisation. Outside of the workplace my interests are very much orientated toward understanding how people cope with, and view, long-term health conditions. Having worked in addiction it is apparent that, for some people, addiction is a long-term health condition.

The following sections will briefly introduce the competencies, and my journey along the path to becoming a Health Psychologist.

Section B: Research

The research study was developed due to an interest in visual impairment, and long-term health conditions. Having studied quality of life (QoL) in the past it was clear that stigma has an impact on quality of life of people with many conditions, yet I was unaware of studies into the impact of stigma on the QoL of the visually impaired. The aim of this study was to explore the possibility that this relationship exists. The intention was to do an exploratory study to build a foundation for future researchers to design more specific projects exploring the phenomenon. This exploratory study utilised revised measures for experienced and anticipated stigma, plus the WHOQOL-BREF to measure QoL. A mixed-methods approach was taken to assess the statistical relationship, in addition to gaining a qualitative context using thematic analysis. Participants were recruited through Facebook support groups, resulting in an international sample.

The results demonstrated there was a significant negative relationship between stigma and QoL in the visually impaired. Anticipated stigma had a greater relationship than experienced stigma, across all domains on the WHOQOL-BREF. The findings show that in the visually impaired, anticipated stigma or discrimination from healthcare professionals was a significant predictor of a lower QoL score across all four WHOQOL-BREF domains: Psychological, Physical, Social Relationships, and Environment. It was shown that some health care professionals could benefit from skills training for dealing with VI patients. One message that was clear within the research is the confusion that the term 'blind' causes in the general public, and the misconception that blindness means no sight. This can leave the visually impaired open to criticism, abuse, and the feeling of being a fraud.

A two additional research projects were undertaken, in accordance with the City University requirements.

The first study included is on the lived experience of guide dog ownership. A qualitative methodology was chosen, and transcripts were analysed using interpretative phenomenological analysis (IPA). The interviews were done face-to-face, one in London, the other in a Major North-Western City in England. To ensure that the study could explore the findings with sufficient depth a double case-study approach was used. As would be expected, the findings demonstrate how the guide dog enables someone with a visual impairment to continue living, rather than becoming socially isolated. A novel finding was that a guide dog has a positive impact on overall levels of confidence – to the point where confidence is still high even when the guide dog is not present.

The second study was an update of a previous systematic review, looking into the efficacy of Cognitive Behavioural Therapy (CBT) based interventions for smoking cessation (Pires-Yfantouda & Sykes, 2010). As in the previous review, there was a paucity of good randomised controlled trials investigating the benefits of CBT for smoking cessation. Based on 3 studies, it was found that multimodal interventions featuring a blend of

CBT and Nicotine Replacement Therapy are most effective. Studies do not explore the efficacy of individual components of CBT and it is therefore not possible to assess which components of interventions contribute most change.

Section C: Professional Practice

Teaching and Training

The first case study is of the training delivered to a group of [redacted] staff and volunteers on brief solution focused therapy. The case study documents the process of surveying the staff and volunteers to gain an understanding of extant knowledge levels. The aim of the workshop was to furnish attendees with some basic skills in how solution focussed methods (O'Connell, 2012) could be used with substance misuse clients. Despite the very short timeframe available, a 1-hour staff development session, the session contained three practical components, building up practicable skills that the clinicians would be able to use immediately, and whet clinicians appetites to adding another skill to their skillset. On the whole the feedback from the workshop was very positive.

The second case study is of a series of workshops delivered to [redacted] service users. The aims of the workshops were to promote healthy living and give service users knowledge of how stress can impact health through negative physiological implications. This can be a challenge to explain to clients, therefore the metaphor of a zebra not getting an ulcer was used (Sapolsky, 2004). Positive psychology was also introduced to the service users in the second workshop, facilitating a discussion of how positive psychology can potentially boost health and mood. The feedback from the series of workshops was very positive with attendees reporting it was very useful and their understanding of how to boost their levels of happiness and well-being had increased having attended the workshop.

Consultancy

The consultancy case study involved looking into the efficacy of Group Motivational Interviewing (MI) for the Chief Executive of [redacted] (the

client). Using the “expert” model of consultancy (Schein, 1978) I was to deliver a summary of my findings. The aim was to perform a systematic review of Group MI for alcohol users, deliver these findings to the client, before designing and delivering a waiting list group based on the findings of the review. A contract was drawn up outlining the consultancy process. Not everything went to plan during the consultancy process: the review took longer than anticipated; I had to put a hold on the review due to [redacted] requiring my assistance in clearing the waiting list of clinical clients; and, due to an expanding waiting list a ‘recovery group’ was started before the review was completed. Once complete an executive summary was given to the client, summarising the findings that Group MI can be cost effective and effective for alcohol users. An applied element was included in the executive summary, whereby I had designed a flyer to attract people who are averse to attending groups.

Behaviour Change Intervention

Having been an experienced meditator for many years, and having attended many mindfulness workshops I was aware that mindfulness has many applications, and stress management is one of the main reported benefits (Kabat-Zinn, 2012). This case study was on the delivery of a mindfulness-based relapse prevention intervention. The client had significantly reduced alcohol use in the past but was stuck to binge drinking once a week. Having explored his life circumstances it was evident that there were many stressors affecting him. Together, we agreed to use a mindfulness approach. An intervention was initially adapted from a group mindfulness-based relapse prevention programme (Bowen, Chawla, & Marlatt, 2011). The intervention did not go to plan, yet the client utilised some of the techniques learned and reported abstinence from alcohol.

Section D: Systematic Review

Motivational interviewing (MI) was initially developed as a method for treating people who misuse alcohol (Miller, 1983). Despite MI’s heritage

being in the realm of alcohol misuse treatment, there have been no systematic reviews assessing the efficacy of Group MI interventions.

The review was developed to provide [redacted] with an evidence base for future group interventions. It was found that, as has been noted in reviews of individual MI, the methodological quality of many studies is weak (Britt, Blampied, & Hudson, 2003; Knight, McGowan, Dickens, & Bundy, 2006). There is evidence that Group MI can be a cost-effective treatment modality that is as good as individual interventions; however, it should be noted that the clinicians delivering the intervention should be skilled in rapport building and intervention delivery for the intervention to be successful.

Concluding Remarks

The work above demonstrates a small variety of topics that Health Psychology covers: interventions for addictions (alcohol, and smoking); stress management; wellbeing and quality of life; long-term health conditions; and interventions in long-term health conditions (e.g. guide dogs). This work demonstrates that I have achieved the competence required to become a qualified Health Psychologist.

This thesis defines the type of Scientist Practitioner that I strive to be. The intention was to develop accessible science that is enjoyable to read, provide an evidence-base for practice, and cover an intertwiningly broad array of topics.

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Does Stigma and Discrimination Affect the Quality of Life for the Visually Impaired?

A Mixed-Methods Study

Abstract

Introduction

It has been demonstrated that people with a visual impairment report a lower quality of life (QoL) than those who are normally sighted. Researchers have shown that in conditions such as cancer, HIV, and mental illness, experienced and anticipated stigma and discrimination can relate to lower QoL scores (e.g. Brown Johnson, Brodsky, & Cataldo, 2014; Liu, Xu, Lin. Shi. & Chen, 2013; Tang & Wu, 2012; Yen, Chen, Lee. Tang, Ko, et al., 2009). There is a paucity of literature, however, exploring this phenomenon within the field of visual impairment. The aim of this study was to explore whether a relationship exists between stigma and discrimination, and the QoL of visually impaired people.

Methods

This mixed-methods study was split into two sections. Both sections included the use of the DISC-VI, QUAD-VI, and WHOQOL-BREF scales to measure stigma and discrimination, and QoL, respectively. Fifty-three participants were recruited for the first part of this study, responding to the above scales plus two qualitative questions. A total of one hundred and seventy two participants were included in part two, where only the above scales were included. Qualitative data was analysed using inductive thematic analysis. Scales were assessed using psychometric analyses. Quantitative data was analysed using Pearson's correlations and multiple regressions.

Results

The hypothesis that there would be a significant negative relationship between stigma, discrimination and QoL was confirmed. The strongest relationships being between anticipated stigma and all domains of QoL. The scales were found to be psychometrically valid for this sample, although the DISC-VI's subscales were not used due to insufficient confidence about their validity in this sample. Qualitative findings show that the visually impaired face many challenges in life: avoidance, abuse, and challenges when accessing health care providers.

Conclusion

The impact of stigma and discrimination on the visually impaired person's QoL are an area that deserves further attention as it has been ignored for too long. Limitations of this study should be considered in interpreting the findings.

1. Introduction

"The stigmatized individual is asked to act so as to imply neither that his burden is heavy nor that bearing it has made him different from us; at the same time he must keep himself at that remove from us which assures our painlessly being able to confirm this belief about him. Put differently, he is advised to reciprocate naturally with an acceptance of himself and us, an acceptance of him that we have not quite extended to him in the first place. A phantom acceptance is thus allowed to provide the base for a phantom normalcy."

(Goffman, 1984, p147-148)

1.1 What is Visual Impairment?

1.1.1 The definition of Visual Impairment:

> *"A visual impairment is when a person has sight loss that cannot be fully corrected using glasses or contact lenses."*

(*NHS*, 2013)

In the 1990s there were an estimated 148 million visually impaired people (VIP) in the world, of which an estimated 38 million are classified as blind (Thylefors, Negrel, Pararajasegaram, & Dadzie, 1995). New estimates suggest that this figure is much higher than anticipated, with an estimated 285 million VIPs worldwide, of which 39 million are blind (WHO, 2014b).

1.1.2 Classifications of Visual Impairment

There are varying terms for visual impairments. Sight impairment is also known as partial-sightedness, low vision, or severe visual impairment (Royal National Institute Of Blind People, 2014d; WHO, 2003). The term 'blind', whilst still used in the ICD-10 (WHO, 2014a) has been replaced in the United Kingdom (UK)

with the term severely sight impaired (SSI) (Royal National Institute Of Blind People, 2014d).

The degree of impairment is usually measured based on visual acuity. Visual acuity is the ability of your central vision to distinguish shapes or objects (BootsWebMD, 2014). Visual acuity is usually measured with a Snellen test. The Snellen test is a chart consisting of rows of letters, starting large and getting smaller. The top line equates to 6/60 vision, meaning if you sit 6 meters away from the chart then you can read at 6 meters, what someone with normal vision could read at 60 meters. Similarly, with 3/60 vision, what you can read at 3 meters, someone with normal vision can read at 60 meters. Normal vision is 6/6 (Royal National Institute Of Blind People, 2014d). Prior to the use of the metric system in ophthalmology normal vision was known as 20/20 vision. With 20/20 vision the same principal applies as explained above, excepting the 20 relates to feet rather than meters (BootsWebMD, 2014).

As recommended by the ICD-10, the UK certifies VIPs as sight impaired when they meet the following criteria:

- Acuity of 3/60 – 6/60 with unrestricted visual fields
- Acuity of 6/24 with moderately restricted visual fields or some cloudiness or blurring of the central vision
- Acuity of 6/18 or better with significant loss of visual field

(*Royal National Institute Of Blind People*, 2014d)

The visual field loss component of the sight-impaired certification is not a component of the ICD-10 definition of severe visual impairment. The ICD-10's definition of severe visual impairment is 6/60 to 3/60 (WHO, 2003, 2014a).

The ICD-10 incorporates visual field loss when the visual field drops below 10° around a central fixation point in the better eye (for monocular vision this relates to the affected eye). When the visual field in the better eye falls below 10° the individual is then classified as being blind (WHO, 2003, 2014a), or SSI.

For someone to be certified SSI they must meet the following criteria (per Royal National Institute Of Blind People, 2014):

- Acuity of less than 3/60 with unrestricted visual fields
- Acuity of 3/60 – 6/60 with severely restricted visual fields
- Acuity better than 6/60 with very severely restricted visual fields, particularly in the lower area of the field

Whilst the UK's certification levels do not specify the exact degree of visual fields required for an SSI registration, they are featured as a consideration for the registering ophthalmologist. The US government, however, is more explicit, and more generous, with their required levels of visual field loss with a field of 20° or less being considered as the requirement for legal blindness (USA Social Security Administration, 2014).

1.1.3 The definition of blind:

"Unable to see because of injury, disease, or a congenital condition."

(Oxford University Press, 2014a)

This definition of 'blind' is quite misleading. As is shown in the ICD-10 blindness can mean severely restricted vision: it does not have to relate to no useful vision. The ICD-10, for this reason, has three levels of blindness: blind, light perception, and no light perception (WHO, 2014a). The latter two relating to VIPs who are unable to distinguish any shapes or objects.

1.1.4 Prevalence and Causes of Visual Impairment

Globally the major causes of visual impairment (VI) are either reversible or preventable, with 43% linked to uncorrected refractive errors and 33% un-operated cataracts. These are predominantly issues within the developing world. As such, 80% of the world's VIs are preventable or curable (WHO, 2014b). There are varying estimates for the prevalence of blindness, and

differing causal factors, depending on the location. European estimates are varied, with one French study estimating the prevalence of blindness being 0.1% and low vision being 1.94% (Brezin, Lafuma, Fagnani, Mesbah, & Berdeaux, 2005), whilst an Italian study estimated blindness at 0.6% and low vision at 2.1% (Cedrone, Nucci, Scuderi, Ricci, Cerulli et al., 2006). The causal factors for Europe also are various. The major causal factors of blindness within working age adults are diabetic retinopathy, retinitis pigmentosa, and optical atrophy; whereas, in older adults age-related macular degeneration (AMD), cataracts, and glaucoma, plus uncorrected refractive errors, are the commonly reported causal factors of blindness or low vision (Brezin et al., 2005; Cedrone et al., 2006; Kocur & Resnikoff, 2002). North American countries also report a disparity between prevalence estimates, with the United States of America (USA) estimating that in the over 40s the prevalence for blindness is 0.78, and low vision is 1.98%, whilst Canada estimates an overall prevalence of visual impairment at approximately 1%, with 0.24% being blind, and 0.71% low vision. There are also disparities in North America with the causal factors of visual impairment.

In the USA they split the causal factors by ethnicity, so in whites the most common cause is age-related macular degeneration (AMD), blacks is cataracts and open-angle glaucoma, and Hispanic open-angle glaucoma. Whilst in Canada the most common causal factors are cataracts, AMD, visual pathway, and retinal disorders (Maberley, Hollands, Chuo, Tam, Konkal et al., 2006; The Eye Diseases Prevalence Research Group, 2004). It is estimated that the global prevalence of visual impairment is 2.62%, with 0.55% of the world being classified as blind (Resnikoff & Keys, 2012). The global prevalence figures appears higher than some of those above for westernised countries, figures which are likely skewed by developing countries, and tribal communities. For example, the estimated prevalence within an urban Indian community for blindness is 0.7%, and low vision is 16.8%. The majority of these figures are correctable through refraction (i.e. glasses). Excluding refractive errors the prevalence would be 0.4% blindness and 3.4% low vision. Cataracts are the main causal factor – again, a preventable and treatable condition, with diabetic retinopathy and AMD being the next most common causes (Zheng et al., 2011).

Similarly, in an indigenous Australian population, estimated prevalence of blindness was 2.8%, and low vision was 19.4%. As in the Indian example, the major causes were treatable with either refraction, or a cataract operation. The next main causal factors were diabetic retinopathy and trachomatous corneal opacification (Landers, Henderson, & Craig, 2010).

1.2 What is Stigma?

Originating from the Greeks, stigma referred to bodily signs exposing something unusual, or a reflection of bad moral status. Signs were burnt or cut into the body advertising the individual as a slave, criminal, or traitor. The sign indicated a blemished person, ritually polluted. Someone who must be avoided, especially in public places (Goffman, 1984). Goffman's work has been expanded upon, with a new conceptualisation of stigma as multi-component process incorporating labelling, stereotyping, separation, loss of status and discrimination. All of these, however, occur where there is a power imbalance between the stigmatised and the 'normals' (Link & Phelan, 2014, 2001). It has been suggested that currently the focus is on the stigmatized person or ailment, rather than on the discrimination experienced. Potentially due to researchers studying a topic that interests them, with no prior lived experience of the stigma they study (Link & Phelan, 2001). Stigma has the potential to significantly impact the life chances of the stigmatized individual, and should be considered within research and practice, as other sociodemographic variables such as socioeconomic status and ethnicity. As with sociodemographic differences, stigmatized individuals can experience less opportunities for good employment, with that impacting their access to healthcare and overall wellbeing (Link & Phelan, 2001; Phelan, Lucas, Ridgeway, & Taylor, 2014). Stigma can be either experienced (also known as enacted stigma), anticipated (also known as perceived or felt stigma), or internalized (self-stigma) (van Brakel & Galarza, 2014). Whilst experienced stigma is apparent from its title, anticipated stigma is not so obvious. Anticipated stigma is often due to the individual's awareness that they have a condition which is stigmatised or labelled by others, and the perception or expectation that they will experience stigma (Herek, 2014). The following study focuses on experienced and anticipated stigma. Various terms

are used for stigma, often referring to the same thing. Examples are: labelling, stereotyping, oppression, and discrimination (van Brakel & Galarza, 2014).

1.3 What is Discrimination?

1.3.1 The definition of discrimination:

> *"The unjust or prejudicial treatment of different categories of people on the grounds of race, age, or sex."*
>
> (Oxford University Press, 2014b)

It can be argued that there are two distinguishable forms of discrimination: Individual; and, Structural (Angermeyer, Matschinger, Link, & Schomerus, 2014; Link & Phelan, 2001). Individual discrimination is the person-to-person process whereby one individual overtly stigmatizes another based on stereotypes and labels. Structural discrimination is a more widespread, implicit, and institutional manner of stigmatizing a group through policy (i.e. government). These can be intentional, or unintentional.

1.4 What is Quality of Life?

1.4.1 The World Health Organisation definition of Quality of Life:

> *"Quality of Life is an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, and their relationship to salient features of their environment."*
>
> (The WHOQOL Group, 1993, p. 153)

There is a mix of perspectives into what QoL actually is, and within the health professions there is a lack of consensus over the definition of QoL (McKevitt, Redfern, La-Placa, & Wolfe, 2003). The WHOQOL definition, above, is a holistic approach to QoL, whereby QoL is a social construction – defined by a multitude of factors that lead to perceptions regarding one's own current life

situation (Skevington, 2001). Research has demonstrated that QoL can be affected by sociodemographic differences, such as educational attainment, with those who have a higher level of education reporting a better QoL (Skevington, 2010). The use of QoL measures also enables the exploration of facets of life affected by medical or psychological interventions. One study on the efficacy of antidepressants and quality of life show that increased happiness and contentment can predict depression – negative affect (Skevington & Wright, 2001).

1.5 How does Stigma affect Quality of Life?

Much of the extant literature looks at how stigma affects those with a mental illness. Research has shown that self-stigma, also known as internalised stigma, is significantly related to a lower QoL. (Mashiach-Eizenberg, Hasson-Ohayon, Yanos, Lysaker, & Roe, 2013; Mosanya, Adelufosi, Adebowale, Ogunwale, & Adebayo, 2013; Tang & Wu, 2012; Yen, Chen, Lee, Tang, Ko et al., 2009). High levels of self-stigma in those with schizophrenia in Nigeria are correlated with reliance on others for income, unemployment, severity of psychopathology, and a low education level. In this population self-stigma and poor QoL are strongly related to a poor treatment outcome, potentially exacerbated by increased use of maladaptive coping mechanisms such as social avoidance. The authors of this paper note that these effects may be due to a societal stigma toward mental illness (Mosanya et al., 2013).

Societal stigma has been shown to negatively impact the chances of recovery from mental illness (Chronister, Chou, & Liao, 2013). Similarly to the findings of Mosanya et al., (2013), self-stigma in mental illness has been significantly related to social withdrawal, but in addition to this, increased experience of stereotyping, discrimination, and alienation. Furthermore, there is a significant correlation between self-stigma, hope, and self-esteem, suggesting that behavioural interventions to improve self-esteem could have lead to a significant improvement in QoL. As briefly discussed above, societal stigma can negatively impact chances of recovery from mental illness, this is through the increased risk of adopting maladaptive coping strategies, such as secret coping and withdrawal. Both of which have been shown to increase the risk of

self-stigma. This can be improved through the use, or development, of positive social networks, where both emotional and tangible social support help reduce the likelihood of self-stigma and increase the chances of recovery from mental illness (Chronister, Chou, & Liao, 2013). A supportive social network can increase the individual's sense of empowerment, therefore increasing resilience to depression and improving QoL. Without a supportive social network an individual facing stigma is less likely to be empowered in their life, and is more likely to experience depression and poor self-esteem (Sibitz, Amering, Unger, Seyringer, Bachmann et al., 2011). This can result in a viscous cycle forming, with stigma and depression being related to a poor QoL, and with a poor QoL being a potential causal factor of depression (Yen et al., 2009). This could also be an explanatory reason for those who have an affective spectrum disorder reporting that perceived stigma affects their quality of life to a greater extent than those with a psychotic spectrum disorder (Randjelovic, Mihajlovic, Pantovic, & Ivkovic, 2012).

People with physical illnesses also report experiencing stigma. Individuals with lung cancer report a negative self-concept due to the perceptions that lung cancer is a disease that is avoidable. This stigma is present in both former/current smokers, and those with lung cancer who have never smoked. Lung cancer stigma is related to increased reports of anxiety and depression, and a significantly reduced quality of life (Brown Johnson, Brodsky, & Cataldo, 2014; Cataldo, Jahan, & Pongquan, 2012), whilst women with breast cancer experience unnecessary angst over their predicted level of stigma following breast cancer surgery – in particular mastectomy. In this instance the predictions were worse than reality with a significantly better than predicted level of stigma experienced postoperatively, and a significantly better quality of life too. The anticipation of stigma, however, may have an important impact on the health decisions made, regarding operations, breast reconstructions, and treatment options. This is likely to impact preoperative coping and adjustment to the condition (Waljee, Ubel, Atisha, Hu, & Alderman, 2011).

Historically epilepsy was perceived as demonic possession. Modern society now knows this to be false, although a stigma still exists. Within the developed

world there is little experienced stigma for those with epilepsy, but when they do experience stigma, it negatively impacts upon their QoL. Whilst it is acknowledged that there is an improving public attitude toward epilepsy, those who suffer from the condition are still likely to perceive stigma exists (Jacoby, 2002). Within Asian cultures research has suggested that women with epilepsy are more likely to experience stigma, potentially due to their role within society (Nehra, Singla, Bajpai, Malviya, Padma et al., 2014); a decreased likelihood of marriage and employment. Although, Asian societies with a high level of exposure to Western cultures, such as Hong Kong, have a more positive attitude toward those with epilepsy (Lim, Chan, & Ko, 2009).

As demonstrated above, social support can result in the ability to cope with illness better. Individuals with HIV have an increased life expectancy thanks to new and improved antiretroviral medications, yet HIV-stigma is still experienced and has a direct impact on reducing QoL. HIV-stigma, with all demographics controlled for, is a significant contributor to the explained variance in quality of life (Holzemer et al., 2009; Liu, Xu, Lin, Shi, & Chen, 2013; Slater, Moneyham, Vance, Raper, Mugavero et al., 2013). Those with HIV are, however, more likely to experience a poor quality of life should they have medical co-morbidities and adopt emotion-focussed coping. Social support, a positive coping strategy, and the wisdom of age, increases the chances of a better quality of life (Slater et al., 2013).

For those who suffer from Irritable Bowel Syndrome (IBS), perceived stigma affects QoL, although the level of illness intrusiveness mediates this. Men are particularly affected by mediation of illness intrusiveness, whereas women have a stronger link between QoL and symptom severity (Dancey, Hutton-Young, Moye, & Devins, 2002). It is interesting to note that those who use complimentary and alternative methods of treating their IBS are more likely to experience healthcare discrimination, stereotype endorsement, alienation and social withdrawal, contributing to a greater level of internalised stigma. As has been previously discussed, both internalised stigma and perceived stigma have positive correlations with anxiety and depression, and negatively with QoL. Whilst this study demonstrated that those with IBS perceive more stigma from

personal relationships than from healthcare workers, when they do experience stigma from healthcare workers this is related to a significant increase in their experience of IBS symptoms (Taft, Riehl, Dowjotas, & Keefer, 2014).

The above studies into stigma and its impact on quality of life have demonstrated some commonalities. There is a negative relationship between stigma - self, experienced, or anticipated - and quality of life. The existence of a supportive social network can act as a protective factor, helping mitigate the risk of depression and anxiety, improving coping with illness and disability, and aiding to improve overall QoL. The notion of a stigma being a 'mark' of disability does not always get corroborated by research as the perception of stigma is a more significant predictor of poor quality of life than deformity and lepra reaction in individuals with leprosy (Tsutsumi, Izutsu, Islam, Maksuda, Kato et al., 2007). It has been argued that a biopsychosocial approach to interventions development could be beneficial in mitigating stigma (Nehra et al., 2014), with behavioural interventions having a positive impact on reducing the amount of stigma perceived by individuals (Taft, Riehl, Dowjotas, & Keefer, 2014). Population level interventions may also prove beneficial, with some cultural factors being apparent within the literature: in particular within non-westernised countries (Lim, Chan, & Ko, 2009; Mosanya et al., 2013; Nehra et al., 2014); and, an Hispanic cultures, where individuals are more likely to experience stigmatisation (Holzemer, Human, Arudo, Rosa, Hamilton et al., 2009; Taft et al., 2014).

1.6 How Does Stigma and Discrimination Affect the Quality of Life of the Visually Impaired?

There is a paucity of research into the stigma of visual impairment. This is evident through a search of research titles containing the terms "stigma" and "blindness", which revealed a solitary paper on Google Scholar. This paper suggested that within the blind stigma affects both self-acceptance as well as social acceptance (Allen & Birse, 1991). Further exploration of titles using Google scholar proved fruitless, with searches of article titles containing the terms "stigma" combined with "visual impairment"; and, "sight impairment"

resulting in zero hits. This suggests that the exploration of the impact of stigma on visual impairment is either not required, or is required.

In a study on barriers in attending low vision rehabilitation it was apparent that the fear of stigma and discrimination could cause a visually impaired person (VIP) to refrain from help-seeking activities for fear of being deemed a fraud, with some disbelieving their level of impairment. VIPs do not want to be devalued within society: they value their independence. This high value placed on independence is increasing their sense of normalcy, mitigating the risk of experiencing negative societal views of disability, discrimination, pity and stereotyping (Lam & Leat, 2013). Reinforcing these findings, a recent meta-synthesis on AMD found that one of the main concerns of VIPs is the loss of independence. In particular, the impact that the loss of a driving license has on increased isolation and dependence on others. Struggles with coping can lead to an active avoidance of social situations, potentially due to the fear of attracting the label of 'fraud'. The VIPs in this study also feared adopting the white cane as this forced the adoption of a blind identity – enforcing the labels and stereotypes of the blind. The authors note that women within the study also have a fear of being deemed snobby due to ignoring friends when out and about (Bennion, Shaw, & Gibson, 2012).

There could be cultural differences within the perceived or experienced stigma in visual impairments. With refractive errors being a major contributor to global blindness, a simple treatment of spectacles could significantly improve an individual's vision. Yet in a study on Indian school children some respondents related low vision to witchcraft. The stigma surrounding wearing spectacles resulted in many respondents rejecting them for fear of judgement and bullying, fear of rejection by the opposite sex, and being deemed weak (Dhoble, Agarwal, Patel, Anand, Sharma et al., 2013). Research suggests that there is a more positive attitude toward injury related disabilities than illness related, with women who have an illness related disability more likely to experience social distancing. There is a shift in acceptance, however, when the disability becomes more visible – for instance, when a white cane is used – as this exacerbates social distancing, in both those with illness and injury related

disabilities (Shiloh, Heruti, & Berkovitz, 2011). This could be an explanation for the reason why people who are legally blind are less likely than non-disabled, and people with other disabilities, to be employed (Benoit, Jansson, Jansenberger, & Phillips, 2013). Although, as we discussed earlier, legal blindness does not always mean 'blind' per the dictionary definition, and therefore is not always visible. A recent anthropological study of women in Israel has shown that women can use appearance to redefine their sense of self, pushing the appearance of them as women to the fore as their main defining feature rather than their disability. The disability is relegated to a feature of the individual, rather than their defining characteristic (Hammer, 2012). Whilst the author of the study on women's use of appearance did not explore the impact of appearance strategies on QoL, the explanations imply a sense of empowerment over their disability – not allowing it to define them. As shown above in the discussion on stigma and mental health, empowerment can elicit resilience toward societal stigma, reducing the risk of depression and therefore increasing the chances of an improved QoL. During the development of a self-acceptance scale for visual impairment it was found that a belief in oneself has an impact on the level of perceived stigma (Morgado, Campana, & Tavares, 2014), providing further support to the notion that belief, empowerment, and positive attitude can improve QoL, and coping.

Much of the research into the QoL with VIPs is targeted at an older adult population, or developing countries. Within the developing world there are similarities in the research findings, indicating strong correlations between poor visual functioning, visual acuity, and quality of life (Adigun, Oluleye, Ladipo, & Olowookere, 2014; Taylor, Shah, Gilbert, Jadoon, Bourne et al., 2008; Tran, Mahdi, Sivasubramaniam, Gudlavalleti, Gilbert et al., 2011). Within developing countries there is a link between reduced QoL and older adults, women, manual working, couching, not living as married (Tran et al., 2011), residing in a rural location, education (illiteracy) and poor visual functioning and QoL (Taylor et al., 2008; Tran et al., 2011). Adigun and colleagues note that in Ibadan a similar phenomenon is reported, whereby those who are unemployed experience a reduced QoL. Whilst these experiences are relating to developing countries, there could be similarities between the experiences of VIPs in these studies,

and individuals living within developed nations. It has been shown that as the severity of the visual impairment increases, QoL decreases accordingly (Chia, 2004; McKean-Cowdin, Varma, Wu, Hays, & Azen, 2007; Varma, Wu, Chong, Azen, & Hays, 2006). In particular, psychological QoL is affected by the impact of reduced visual functioning relating to driving and ease of task completion, resulting in reduced independence and potential isolation (McKean-Cowdin et al., 2007; Varma et al., 2006). These aforementioned limitations reduce the sense of empowerment and can reduce the sense of life satisfaction, increasing the risk of depressive symptoms (Brown & Barrett, 2011). Research has shown that non-visual factors may have more of a causal relationship with a reduced quality of life than actual visual issues, suggesting the physical functioning and mental health/psychological issues are the main contributing factor in the quality of life in VIPs (Hernandez Trillo & Dickinson, 2012). This finding suggests that by implementing psychosocial interventions VIPs can experience a better QoL, without an improvement in vision. This notion is supported with evidence that attitude; self-acceptance; self-esteem; anxiety and depression; self-efficacy; and, self-control, all have a significant impact on social functioning, visual functioning, psychological health and overall QoL (Zhang, Wang, & Yin, 2014). Self-efficacy has been shown to have a strong mediating effect on depression and life satisfaction, which can therefore impact the sense of empowerment in life, improve social functioning and increase overall QoL (Brown & Barrett, 2011).

1.7 Summary & Purpose of the Study

This introduction has given a brief overview of the extant field of research in stigma, QoL, and visual impairment. What was evident is that blindness, even if only affecting a small percentage of the population, affects a large number of people across the world. Researchers have specifically explored the experience of stigma within the field of mental health, as well as cancer and physical and gastroenterological health conditions, yet a Google scholar search highlighted one solitary paper looking specifically at stigma and blindness. The stigma research within other fields have extended their reach to consider the impact of stigma on QoL of those afflicted with various conditions. There is a wide range of studies investigating the QoL of individuals with a visual

impairment, although these are mostly vision or health specific: health-related QoL; and, vision related QoL. In addition to the health focus, a considerable proportion of studies investigate the QoL in older adults.

With the findings presented above, suggesting links between QoL, coping, self-acceptance, depression, and stigma, it is clear that researchers have overlooked the impact of stigma on VIPs.

The purpose of this study is to start a conversation. To explore initially whether there is a link between stigma and QoL in the visually impaired, and to understand some of the stigmatising and discriminating aspects in the lives of VIPs. Hopefully providing a foundation for future researchers to build upon.

1.8 Aims and Objectives

The aims of this study are:

1 – Assess whether a relationship exists between Stigma and QoL in the visually impaired. It is hypothesised that, based on the literature review above, there will be a significant negative correlation between stigma and QoL.

2 – Gain an understanding, through the exploration of participants' views on their experiences of stigma and discrimination across various aspects of their life.

2. Method

2.1 Ethics

City University London's Department of Psychology Ethics Committee granted ethical approval for this study. The information form held on the Surveymonkey.co.uk website and was the first page that potential participants viewed. Having read the information sheet participants consented through a digital form (Appendix B1-1). To ensure participant anonymity IP addresses were not collected and no personal identifying information was collected. Participants were able to withdraw at any point by closing the webpage. Once the data had been submitted participants were no longer able to withdraw: this was specified in the information form.

2.2 Design

A cross-sectional, mixed-methods survey, design was used. This permitted the quantitative exploration of the research question, whilst allowing the researcher to ascribe meaning to the results through the exploration of qualitative responses (Terrell, 2011) without making inferences.

2.3 Data Collection Modality

Online surveys were used as the data collection method. The benefits of the internet in survey research are the ability to reach a wide audience at a lower cost than printed surveys (Dillman, Smyth, & Christian, 2009). The use of online surveys in this study allowed for an international sample with a broad range of causes of visual impairment.

2.4 Participants & Recruitment

Participants were recruited through online support groups. These were predominantly support groups for Retinitis Pigmentosa; Stargardt's Disease; Lebers Hereditary Optic Neuropathy; Macular Degeneration and general groups for the Visually Impaired. Further to the Facebook groups, the study was

posted to a retinitis pigmentosa LISTSERV. Permissions were sought and granted from all group moderators and administrators prior to posting the recruitment advertisements.

In one instance a participant identified himself or herself in a response – this was overwritten with a pseudonym to prevent identification within the results.

2.4.1 Opening Study: Visual Impairment as a Differentiator

For this component of this study there were 70 participants that consented to participate, with 53 responding to questions other than the demographic information. The sample was made up of 38 females (mean age = 45.9) and 15 males (mean age = 41.3). The participants were living in 7 different countries: The United Kingdom, 29; The United States of America, 16; Canada, 2; Australia, 3; Spain, 1; Norway, 1; and, The Channel Islands, 1. The majority of the participants are diagnosed with Retinitis Pigmentosa (35), followed by Ushers Syndrome, 7; Macular Degeneration, 6; Stargardt's Disease, 4; and, Retinitis Pigmentosa plus Macular Degeneration, 2. Twenty-six participants were classified as Severely Sight Impaired/Blind, with the remainder being: sight impaired/partially sighted, 14; not yet registered, 12 and, in the process of registering, 1.

On average, participants have been aware of their condition for a reasonable length of time, with the mean time since diagnosis being 15.42 years.

The majority of participants to not use any mobility aids (22); although, 18 occasionally use a cane, 2 of which are guide dog owners; 11 regularly use a cane; and, 4 use a guide dog.

2.4.2 Remainder (Psychometric; Quantitative; and, Qualitative)

For the remainder of the study there were 349 consenting participants, of which 172 completed every single question asked. The final sample was 182. The sample was made up of 62 males (mean age = 44.95) and 120 females (mean age = 41.37). The participants were predominantly UK based (43.5%) with a diagnosis of Retinitis Pigmentosa (59.9%) and registered Severely Sight

Impaired/Blind (50%). The majority was married or living as married (55.5%) and in employment (41.2%). Some participants had recently been diagnosed; others were diagnosed 62 years ago (mean years diagnosed = 19.41 years). A minority of the participants required assistance to complete the surveys (6%).

2.4.2.1 Demographics of the study

Table 1 – Demographic Information

		Male (62 – 34.1%)		Female (120 – 65.9%)		Total (182)	
Relationship Status							
	Single	26	41.9%	31	25.8%	57	31.3%
	Married/ Living as Married	32	51.6%	69	57.5%	101	55.5%
	No Longer Married	4	6.5%	20	16.7%	24	13.2%
Employment							
	Employed	21	33.9%	54	45.0%	75	41.2%
	Student	10	16.1%	14	11.7%	24	13.2%
	Retired	9	14.5%	4	3.3%	13	7.1%
	Disability Benefits	13	21.0%	23	19.2%	36	19.8%
	Unemployed/Carer	9	14.5%	25	20.8%	34	18.7%
Education Level							
	Professional Qualification	15	24.2%	12	10.0%	27	14.8%
	Postgraduate	13	21.0%	26	21.7%	39	21.4%
	Undergraduate	22	35.5%	40	33.3%	62	34.1%
	Non-Tertiary	12	19.4%	42	35.0%	54	29.7%
Residential Locality							
	UK & CI	27	43.5%	57	47.5%	84	46.2%
	North America	21	33.9%	48	40.0%	69	37.9%
	Australasia	7	11.3%	8	6.7%	15	8.2%
	Europe and Rest of World	7	11.3%	7	5.8%	14	7.7%
Diagnosis							
	Retinitis Pigmentosa or Related	39	62.9%	70	58.3%	109	59.9%
	Keratoconus	8	12.9%	13	10.8%	21	11.5%
	Other Retinal Dystrophies	6	9.7%	13	10.8%	19	10.4%
	Other Causes	9	14.5%	24	20.0%	33	18.1%
Current Status							
	Severely Sight Impaired/Blind	32	51.6%	59	49.2%	91	50%
	Sight Impaired/Partially Sighted	14	22.6%	30	25.0%	44	24.2%
	Chosen not to register	4	6.5%	9	7.5%	13	7.1%
	Not yet registered/Awaiting registration	12	19.4%	22	18.3%	34	18.7%

2.5 Procedure

The survey went live on Surveymonkey.co.uk on 14 November 2013. A link to the survey was then posted on relevant Facebook support groups (as discussed above). Potential participants were then able to review the information sheet and consent form. Should the participants consent to participate they would continue on to the survey questions, consisting of sociodemographic questions plus the questions from three surveys. The surveys included are discussed in greater detail below (see appendix B1-1 for the full version). Due to the high level of anonymity afforded to participants,

once survey responses had been submitted they were unable to withdraw from the study.

Due to a low initial response rate two questions (see below) were removed from the survey (leading to a small separate section included within this study). The page structure was then reorganized to ensure that all survey and sociodemographic questions were spread across one page following the consent form. A strategic opportunistic marketing approach was then adopted, whereby links to the survey were posted to numerous groups over bank holidays weekends (most significantly Easter weekend 2014), as potential participants were most likely to have free time. This proved successful and the number of participants increased significantly.

Survey responses were available from Surveymonkey in an MS EXCEL format, which was downloaded for analysis.

2.5.1 Questions Removed from Study

Participants answered two open-ended questions, and were requested to give as much detail as possible. The two questions posed were:

1 – Please explain how you feel that your eye condition differentiates you from others around you
2 – Please describe your feelings of using/not using a cane

2.6 Questionnaires

2.6.1 Discrimination and Stigma Scale (DISC)

The DISC was developed to bridge the gap between extant stigma measures and create a psychometrically validated measure facilitating a greater understanding of the scope and content of stigma experiences. The measure was designed to investigate stigma in individuals with a mental illness using an interview format. The DISC includes 32 questions whereby respondents score their experience using a Likert scale response, plus give a narrative account of

when they experienced this specific type of stigma. The DISC has been shown to have good psychometric properties (Brohan, et al., 2013).

2.6.2 Questionnaire on Anticipated Discrimination (QUAD)

The developers of the QUAD noted Goffman's notion of the 'discredited' individual and the negative consequences that can be attributed to having a stigmatizing condition. As there were no measures to research the phenomenon of anticipated discrimination, despite reports that people with a mental health problem were experiencing anticipated discrimination, Gabbidon et al (2013) set about developing a psychometrically validated scale. Initially a 17-item scale was developed. After numerous psychometric evaluations three questions were discarded from the measure – increasing the scale's reliability. This resulted in a 14-item scale with good psychometric validity (Gabbidon, Brohan, Clement, Henderson, & Thornicroft, 2013).

2.6.3 Adaptation of the DISC and QUAD

The DISC and QUAD were adapted for this study, with the permission of Professor Graham Thornicroft. The measures are therefore known as the DISC-VI and the QUAD-VI. Questions were adapted to reflect visual impairment and visits to ophthalmologists, rather than mental illness and visits to mental health workers. The original and revised measures can be found in the appendices (appendix B1-1).

2.6.4 World Health Organisation Quality of Life (WHOQOL-BREF)

The WHOQOL-BREF is a short-form version of the WHOQOL-100 measure. The initial measure was developed to create a cross-cultural scale that is psychometrically valid. The purpose was for the World Health Organisation to create cross-cultural comparisons of quality of life (The WHOQOL Group, 1993). The WHOQOL-BREF contains 24 items relating to the 24 facets of the WHOQOL-100. The WHOQOL-100 formed a six-domain structure (Physical, Psychological, Social Relationships, Environment, Spiritual/Religion/Personal Beliefs, and Level of Independence) which contribute to an overall quality of life (Skevington, MacArthur, & Somerset, 1997; The WHOQOL Group, 1995). In

addition to the 24 items relating to the facets of the WHOQOL-100, the WHOQOL-BREF included two self-report questions assessing perceived quality of life and general health status. The WHOQOL-BREF, instead of the six-domain structure described above, formed a four-domain structure, with the spirituality/religion/personal beliefs domain being incorporated into psychological domain, and level of independence being incorporated within the physical domain. The WHOQOL-BREF can discriminate between ill and well populations effectively and has good psychometric properties (Barros da Silva Lima, Fleck, Pechansky, de Boni, & Sukop, 2005; Chen et al., 2008; Hawthorne, Herrman, & Murphy, 2006; Skevington, Lotfy, & O'Connell, 2004b; The WHOQOL Group, 1998).

2.7 Methods of Analysis

2.7.1 Qualitative Analysis

Qualitative data were analysed using an inductive thematic analysis. The intention of an inductive approach is to be driven by the data, not by extant theory (Braun & Clarke, 2013).

Braun & Clarke (2013) note that analysis will always be influenced by the researcher's knowledge and epistemology. As such I shall revert to the first person to give a brief description of my background, relevant to this study:

> As a Trainee Health Psychologist and someone who was registered as Severely Sight Impaired/Blind at the age of 30, I have an interest in the lived experience of the visually impaired. I have previously studied the lived experience of individuals with Retinitis Pigmentosa, plus the lived experience of guide dog owners. As a student of psychology I am also drawn toward phenomenological research due to the way it gives an insight into how individuals experience a multitude of conditions – something that quantitative psychology cannot always do effectively. In the recent past I have also investigated the quality of life in Britain using the World Health Organisation's WHOQOL-BREF measure. I worked closely with Professor Suzanne Skevington, who is the Director for the WHO Centre for the Study of Quality of Life in the UK.

Throughout this study I reflected upon my own experiences, but ensured that the participants voices were heard through the use of many verbatim quotations.

As the data were collected online, verbatim transcripts were collated from the downloaded Surveymonkey files. Any blank responses were deleted and all responses for each question were collated into an MS EXCEL workbook.

Braun & Clarke (2013) propose a 9-step method for thematic analysis:

1 – Transcription

In this study this is not relevant as participants typed out their own responses.

2 – Reading and Familiarisation

The transcripts were initially read through, line-by-line. A second reading through was performed, this time noting down any thoughts arising out of the reading of the data.

3 – Coding

The transcripts were read again, noting all codes that were apparent within the dataset.

4 – Search for Themes

Codes were reviewed and any relationships noted to assess what themes could be identified from the data.

5 – Reviewing the Themes

A thematic map was produced using the data identified in the search for the themes. Thematic worksheets were created with extracts of quotations fitting the themes – this required a further re-reading of the dataset.

6 – Defining and Naming Themes

During the analysis process the thematic worksheets were reviewed, along with the thematic maps, and initial theme names reviewed for appropriateness, and renamed as required.

7 – Writing up the final analysis.

Within qualitative research the researcher is an integral part of the process, using their own mind and preconceptions to create interpretations (Elliott & Williams, 2001; Morrow, 2005). It is for this reason that the disclosure of researcher background was made above. Qualitative researchers have an inherent bias; although this bias is not fixed and based on reflexion of findings in research preconceptions are potentially changeable. The disclosure of researcher's personal situation enables readers to adjust for their own perception of researcher bias. However, it has been said that a deep personal involvement in the research topic can bring a greater level of depth to the interpretations of the data (Stiles, 1993). For this reason a reflection on the research process will be included within the discussion of this thesis.

There is an on-going debate regarding the application of scientific rigour to qualitative psychology. Some believe that a focus on excellence in qualitative methodologies can be harmful to the field and its contribution to society (Gergen, 2014), with some methods constraining the ability to provide good interpretative analyses (Leary, 2014). With Health Psychology's background in the biomedical field, and some transferrable knowledge into the medical field, it has been argued that psychologists are too 'anchored' in a positivist mind-set. The concept of 'methodolatry' suggests that qualitative researchers should stop the overt focus on doing research the right way, and instead focus on a good level of interpretation (Chamberlain, 2000). Often the criteria applied to quantitative psychology is not applicable to qualitative methods and can be limiting (Yardley, 2000). One component of quantitative methodology is generalizability. It has been argued that qualitative research does not aim for generalizable conclusions due to their smaller sample sizes (Yardley, 2000) yet qualitative methods are able to produce generalisable output. Qualitative researchers, however, should be cautious in making statements regarding the generalisable nature of their studies (Goodman, 2008). In this study a large representative sample of the Visually Impaired community was used. As such, it could be argued that the results of this study are, to an extent, generalisable to the visually impaired population.

2.7.1.1 Thematic Validation

Although participation was anonymous, some participants have made themselves known, have reviewed the draft themes, and have agreed the interpretations. The themes arising out of the data have been discussed with independent researchers, and also the thematic analysis that comprises the first section of this thesis were presented as a “work in progress” at a university psychology conference, opening the thematic interpretation to questioning by a peer-audience.

2.7.2 Statistical Analysis

2.7.2.1 Data Screening & Cleaning

The dataset was reviewed in detail and any blank cases were detected. The entire dataset was reviewed line-by-line and any cases predominantly populated by zeros were removed as this indicates the participant withdrew partway through the study. For the WHOQOL-BREF the WHOQOL user manual (World Health Organisation, 1998) stipulates that cases with more than 20% of items missing be removed. Any remaining missing values should be mean-substituted. This was complied with.

2.7.2.2 *Data Coding*

Due to the high number of sociodemographic variables the following were recoded:

2.7.2.2.1 Gender

One participant identified as 'other'. This participant was incorporated into the 'male' group.

2.7.2.2.2 Relationship Status

Married/Living as Married incorporates single, cohabiting; married; and, civil partnership.

No Longer Married incorporates divorced; separated; and widowed.
Single includes both single and prefer not to say.

2.7.2.2.3 Employment Status

Employed incorporates employed 1-39 hours; employed 40+ hours contract work and self-employed.

Unemployed incorporates both unemployed looking for work and unemployed not looking for work; carer; volunteer; and full-time parent.

2.7.2.2.4 Education

Primary and Secondary Education were combined to become non-tertiary.

2.7.2.2.5 Age Groups

Age groups were created: 18-35, 36-60 and, 61+.

2.7.2.2.6 Country of Residence

UK & CI incorporates the United Kingdom and Channel Islands.

North America combines the USA and Canada.
Australasia combines Australia and New Zealand.

Europe and Rest of World combines: Romania; The Netherlands; Denmark; Greece; Sweden; Switzerland; Norway; Malaysia; South Africa; Indonesia; Mexico; and, Iran.

2.7.2.2.7 Diagnosis/Cause of Visual Impairment

RP incorporates Retinitis Pigmentosa and related retinal conditions: Leber's Hereditary Optic Neuropathy; Ushers Syndrome; Leber's Congenital Amaurosis; Alstrom Syndrome; Marfans Syndrome; Senior-Loken Syndrome, Ushers Syndrome + Macular Degeneration; Retinitis Pigmentosa + Macular Degeneration.

Kerataconus includes those who reported having Keratoconus and Macular Degeneration.

Other Retinal Dystrophies incorporates: Macular Degeneration; Rod Cone Dystrophy; Stargardt's Disease and Macular Dystrophy.

Other Causes includes: unknown; Optic Atrophy; Cataracts; Ocular Albinism; Retrolental Fibroplasia; Retinal Detachment; Nystagmus; Encephalitis; Brain Damage; Microphthalmia; Neurological Rubella; Neurofibromatosis Type 1; Hypertension; and Corneal Dystrophy.

2.7.2.3 Questionnaire Scoring

As the purpose of this study is to investigate a global experience, rather than an individual one, some scoring systems were amended for ease of interpretation.

2.7.2.3.1 QUAD-VI Scoring

The QUAD manual (Institute of Psychiatry, 2013) suggests coding 'not applicable' responses as -8. This was amended to read '0' as if the response was not applicable they would also then experience no stigma in that specific instance. The scores were then totalled to give an overall score for anticipated stigma.

2.7.2.3.2 DISC-VI Scoring

The DISC manual (Brohan, Rose, Clement, Corker, Van Bortel et al., 2013) suggests coding 'not applicable' responses as -8; 'no difference' as 0; 'a little' as 1; 'moderately' as 2; and, 'a lot' as 3. This was amended as follows: not applicable = 0; no difference = 1; a little = 2; moderately = 3; a lot = 4. These scores across all 33 items were totalled up to give an overall score for experienced stigma and discrimination.

2.7.2.4 Parametric Assumptions

Data suitable for quantitative analysis was analysed using IBM SPSS Version 21.

2.7.2.4.1 Normality

There is a debate amongst statisticians regarding the assumptions required to obtain reliable output from parametric analyses. Historically there has been a requirement for larger sample sizes (minimum of 30) and normally distributed data (Field, 2009; Norman, 2010). The use of tests of assumptions, such as Kolmogorov-Smirnov, to assess skew and kurtosis can be significant even if the data is normally, or near to normally, distributed where there is a large sample size (Field, 2009). Evidence suggests that smaller sample sizes do not affect the robustness of the parametric test, although small effect sizes may be missed. Similarly, normal distribution is not always required to ensure a the robustness of a parametric test (Norman, 2010).

Normality was assessed using box plots and probability plots. The data appeared normal. Due to the large sample size (>100) the central limit theorem alleviates concerns regarding normality (Field, 2009) and the data can be assumed to be normally distributed for this sample.

2.7.2.4.2 Independence of Errors

Independence of errors was confirmed through the review of the Durbin-Watson test result, whereby values below 1 and above 3 are serious causes for concern. Values close to 2 indicate that the residuals are uncorrelated (Field, 2009).

2.7.2.4.3 Multicollinearity

Multicollinearity was assessed by reviewing the strength of correlations between predictor variables in the regression. No relationships where R > .8 existed. Further to this, the variance inflation factors (VIFs) were assessed for each regression. Multicollinearity was assessed by reviewing the strength of correlations between predictor variables in the regression. No relationships where R > .8 existed. Further to this, the variance inflation factors (VIFs) were assessed for each regression. Whilst there are no rules surrounding the acceptable range of the VIF statistic, the guide is that if the highest VIF is greater than 10 then this causes a concern about the multicollinearity in the regression. Furthermore, tolerance statistics falling below .2 are indicative of a

potential problem. When the tolerance falls below .1 this indicates a serious problem in the multicollinearity of the test (Field, 2009). Within this sample no VIF was greater than 10 and no tolerances fell below .2.

Having reviewed the correlations and VIFs the assumption of multicollinearity can be assumed.

2.7.2.4.4 Linearity and Homoscedasticity

The assumptions of linearity and homoscedasticity were assessed using residual and partial plots and no non-linear nor heteroscedastic patterns were identified.

2.7.2.4.5 Outliers

Outliers were assessed using z-scores. One outlier ±3.26 was identified and this individual piece of data was deleted.

2.7.2.5 Analysis Plan

2.7.2.5.1 Psychometric Analyses

2.7.2.5.1.1 Internal Consistency Reliability

For each of the scales, the internal consistency reliability was assessed using Cronbach's alpha (Cronbach, 1951). The rule of thumb is an alpha coefficient of .7 indicates good internal consistency. Cronbach's alpha is one of the key methods for assessing the reliability of a scale, although should not be used as a standalone verification and should be used in conjunction with other methods of validation (Cronbach & Shavelson, 2004). For these scales the alpha coefficient shall be used to assess internal consistency reliability, with other methods for other aspects of the scale validation, as follows.

2.7.2.5.1.2 Convergent and Discriminant Validity

This was run for both the WHOQOL-BREF and the DISC-VI due to their inclusion of domains and subscales, respectively. Validity is demonstrated when all of the facets/items of a domain/subscale correlate most with their related domain or subscale (Streiner & Norman, 1992).

2.7.2.5.1.3 Exploratory Factor Analysis

There are numerous methods of performing exploratory factor analyses. For the initial development of the QUAD the authors utilized principal axis factoring

with promax rotation (Gabbidon et al., 2013) whereas for the WHOQOL-BREF a maximum likelihood approach was used with varimax rotation (Skevington, Lotfy, & O'Connell, 2004a). Gabbidon et al (2013) also suggested the use of scree plots as opposed to placing a reliance on eigenvalues. As the recommended sample size for a reliable scree plot in exploratory factor analysis is 200 (Yong & Pearce, 2013), for this study the reliance will be placed on eigenvalues.

Whilst it can still be worth performing exploratory factor analyses with smaller sample sizes, caution should be used with the interpretation of the factors arising. A sample size of 300 is recommended where communalities are not very high, and where they are low then a sample in excess of 500 could be necessary (Tabachnick & Fidell, 2012).

For this study the procedures laid out by Yong and Pearce (2013) were followed. The analyses utilised principal axis factoring with a varimax rotation. Correlation matrices were reviewed, in addition to the determinant scores, to verify an absence of multicollinearity. This was verified for all three analyses.

2.7.2.5.1.4 Discriminating Validity

For the WHOQOL-BREF one-way ANOVAS were run to verify that overall subjective QoL matched the domain scores of the measure. It was expected that higher scores would be found across all domains when respondents indicated a higher overall QoL.

2.7.2.5.2 Quantitative Analysis

2.7.2.5.2.1 Pearson's Correlation

Pearson's bivariate correlations were run to assess whether a relationship existed between participants responses to the DISC-VI measure and Average QoL (question 1 and 2 of the WHOQOL-BREF) and all domains of the WHOQOL-BREF individually; and, between participants responses to the QUAD-VI measure and Average QoL and all domains of the WHOQOL-BREF. Positive scores indicate a positive relationship, and vice-versa. As Pearson's correlations are a standardised measure the correlation coefficients can act as a quasi-effect size indicator, with a correlation of .1 being indicative of a small effect, .3 a medium effect, and .5 a large effect (Field, 2009).

Simple bootstrapping was used to create confidence intervals for the correlation, using 1000 samples. The benefit of bootstrapping to create the confidence interval is that the robustness of the test increases and mitigates any concerns regarding normality in the data (Field, 2009).

2.7.2.5.2.2 Multiple Regression

The purpose of a multiple regression is to assess how much predictor variables predict an outcome variable (Field, 2009). In this study 11 regressions were run.

1 – DISC-VI items as predictors for WHOQOL-BREF Domains (Physical, Psychological, Social Relationships, Environment), and Average QoL (Questions 1+2 of the WHOQOL-BREF, divided by 2). This made up the first 5 regressions.

2 – QUAD-VI items predictors for WHOQOL-BREF Domains (Physical, Psychological, Social Relationships, Environment), and Average QoL (Questions 1+2 of the WHOQOL-BREF, divided by 2). This made up first 5 regressions.

3 – WHOQOL-BREF items (excluding questions 1 and 2) as predictors for Average QoL (Questions 1+2 of the WHOQOL-BREF, divided by 2).

A backward stepwise method was used to remove any variables that do not significantly contribute towards the model explaining the largest variance in the outcome. There are criticisms surrounding the use of stepwise methods as they discriminate against predictors solely using statistics. This may impact on the generalizability of the analyses (Tabachnick & Fidell, 2012). Backward stepwise regression can, however, be useful when performing exploratory research (Brace, Kemp, & Snelgar, 2009). The option to report the Durbin-Watson statistic was selected, as was the option to include confidence intervals. The results from this test can be read whereby the beta represents the number of standard deviations that the outcome will change by per one standard deviation change in the predictor (Field, 2009).

3. Results

3.1 Study 1: Visual Impairment as a Differentiator

Three main themes were identified within this study: “I don’t look blind”; “I cannot fully participate in society”; and, Making the invisible, visible. These, along with their sub-themes, are presented in thematic maps below (figures 1, 2, & 3 respectively).

3.1.1 "I don't look blind"

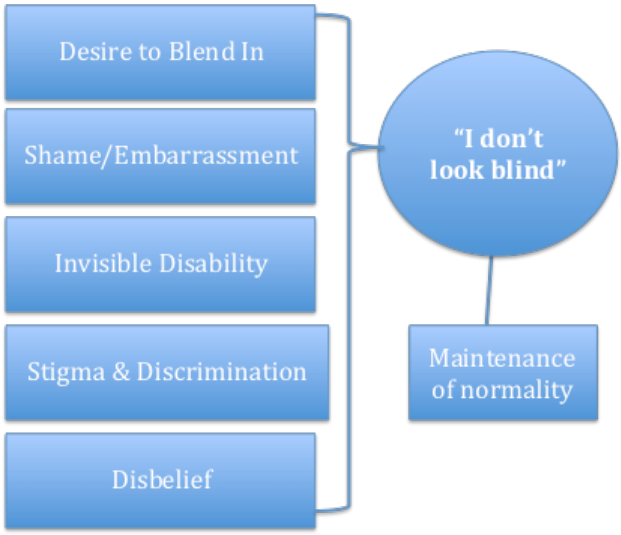

Figure 1 - Thematic Map for "I don't look blind"

Many with a VI express a desire to blend in: "*we learn to work round things*" (1). Making adjustments in daily life to live as normally as possible so as to not stand out or hide the disability: "*I try to act as if I'm not sight impaired to feel equal*" (12), and due to the varying stages in many causes of blindness it is possible to have the appearance of being sighted: "*It is not a visible disability and so superficially I appear not to be disabled*" (16). With a degenerative disorder this desire to blend in results in a constant need to re-adapt to situations that others may take for granted:

> “*My eye conditions differentiate me from others in so many ways. I'm trying to lead as normal a life as possible but the deterioration of my sight means I am constantly having to re-adapt*” (43)

Some conditions, such as Ushers syndrome, result in dual sensory loss (visual and audible) which can lead to greater difficulties in adapting to varying situations: "*Different lightings and situations affect my eyes differently and the hearing loss brings another dynamics such as I can't depend on my hearing to get about*" (3). Different situations bring their own difficulties for people with a visual impairment, resulting in some risk taking in order to blend in and appear normally sighted: "*I am very limited in what I do at night and I bump and trip over everything*" (40).

With this adaptation and the attempts to appear normally sighted bring further issues and a lack of understanding from others: "*We do jobs but people when you do this don't realise or believe u have a problem*" (1). When the invisible becomes visible this can cause confusion in people who are unaware of the various stages of blindness:

> "*people say I don't "look" blind. The fact that I use a white cane confuses them. They think that I can see a lot more than I actually can because I have learned how to function at a very high level in spite of my RP*" (10).

The constant effort to appear normally sighted, and live as normally sighted as possible, can cause tiredness having completed what would be a simple task to many:

> *"I feel it makes even simple tasks stressful, time-consuming and difficult. It makes me exhausted; even a simple trip out or somewhere crowded like a supermarket can leave me needing a lay down"* (5).

The successful adaptation to everyday life also has further repercussions with the lack of belief in others, or the lack of understanding about the assistance and accommodations that some people may need: "*when i was working people aren't patient and don't care about ones impairment*" (23). This is even the case in educational environments as students are entitled to extra time for completing examinations and coursework - with the lack of visibility of blindness in those who are making an effort to adapt to their condition further adding to the disbelief that the condition is real:

> "*one of my professors didn't seem to believe I was [not] exaggerating my vision impairment (RP) just to receive accommodations. So during a lecture - right after i met him to explain my limited peripheral visions, nightblindness, etc - he kept tossing a ping pong ball at me. Of course, I didn't couldn't see the ping pong ball so it hit me in the head each time. He had a good laugh along with the students in the class. This same professor was refusing to provide me with extra time to complete the lab practical exams - even though these accommodations were already approved in my section 504 accommodations plan*" (4).

The embarrassment of others not understanding the condition is common: "*It makes me feel clumsy, some people laugh at me*" (9) with some frustration being expressed at the reactions of others:

> "*When I need to tell someone that I am legally blind (something I weigh very carefully before disclosing) they laugh. I don [sic] not know if this is because they don't know what to say, but I am pretty sure if I told someone I had cancer they would not laugh at me.*" (24)

3.1.2 "I cannot fully participate in society"

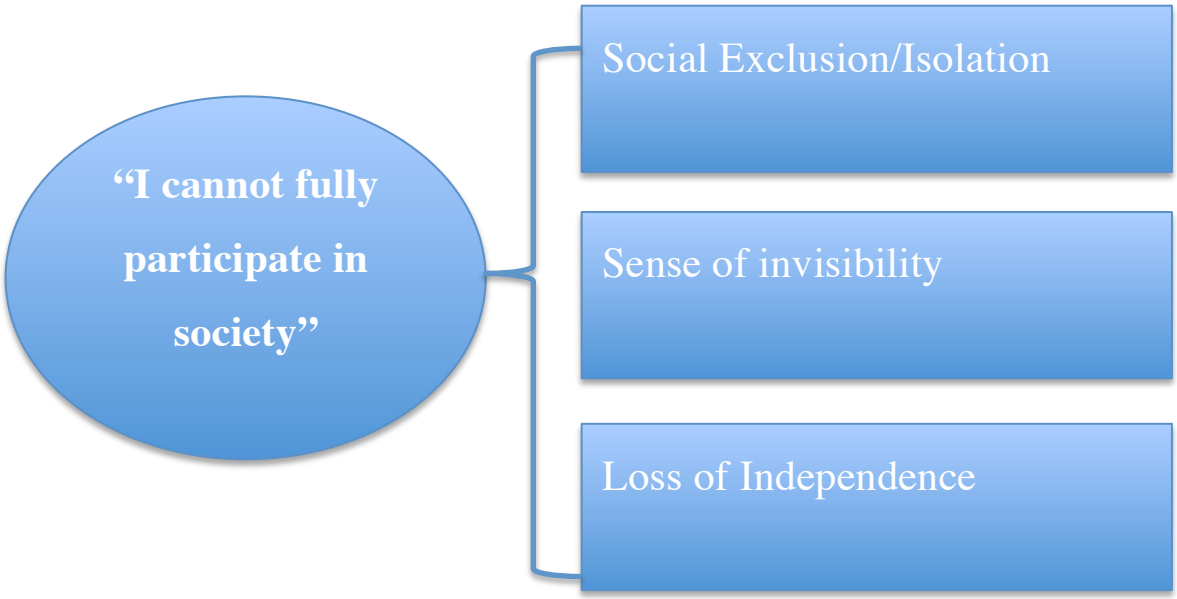

Figure 2 - Thematic Map for "I cannot fully participate in society"

People with a visual impairment develop various mechanisms to adapt and cope with their vision, and in those with degenerative sight loss their changing

vision, occasionally using humour with friends: "*It's best to spend time with good friends who laugh with me – not at me*" (4).

> "*Another funny story is when one of my roommates rearranged the living room furniture and I walked right into the couch and tumbled right over it. One of my roommates immediately made the announcement: If you're going to rearrange the furniture you have to let [name removed] know! And we all had a good laugh*" (4)

The importance and security of a supportive social network is noted: "*they help me out of embarrassing situations*" (4). Others report frustration at their reduced capacity for socializing: "*I miss out on many social opportunities because I cannot get a ride*" (22), and their reliance on others to organise social events: "*Not driving means not taking the lead in social activities*" (28). The loss of independence from not being able to drive adds to the disablement caused by visual impairment: "*losing my license has crippled me, it was the worst thing that has or could of happened to me, especially as my friends all live distances from me*" (36) leading to a sense of social exclusion and isolation: "*I cannot fully participate in society, I feel isolated and excluded*" (42).

Attempts at socializing can be stressful and lead to fear or dread over what might happen and what hazards might present themselves:

> "*I used to love socializing, but I don't always look forward to events like others can because when out I find the lighting hard to adjust to, risk tripping over steps or furniture etc and miss communication cues as I miss peoples body language and facial expressions*." (43).

Social cues and gestures become more difficult to see and the invisible nature of visual impairment can lead to misunderstanding by others who perceive the missing of these gestures and cues as rudeness:

> *"Unable to recognise people or to spot a wave or gesture such as an outreached hand can be seen as a snub so people I know no longer approach me in the street and social life becomes restricted*." (48)

There is also the sense that broadening social networks can be impinged upon by a visual impairment:

> "*Regarding people who do not know me, they are nervous when I am around because most sighted-people do not know what to do when they meet a blind person. They are afraid of saying or doing the wrong thing, so they choose to either ignore me or pretend that I am not there*" (10).

Whilst this can be a frustrating experience, it is exacerbated when this mentality ripples down to those in the extant social network:

> *"In any day 98% of the people I come into contact with pretend I am not there. Unfortunately, that includes some people who I know as friends. They will say later 'I saw you at so-an-so, but I didn't want to bother you."* (10).

The creation of new social networks is made more difficult yet by the challenges associated with starting new hobbies and social activities: "*I cannot manage to compete at chess like others… I find it impossible to have a hobby*." (48).

3.1.3 Making the invisible, visible.

This theme is split into two opposing subthemes, representing different levels of acceptance to blindness.

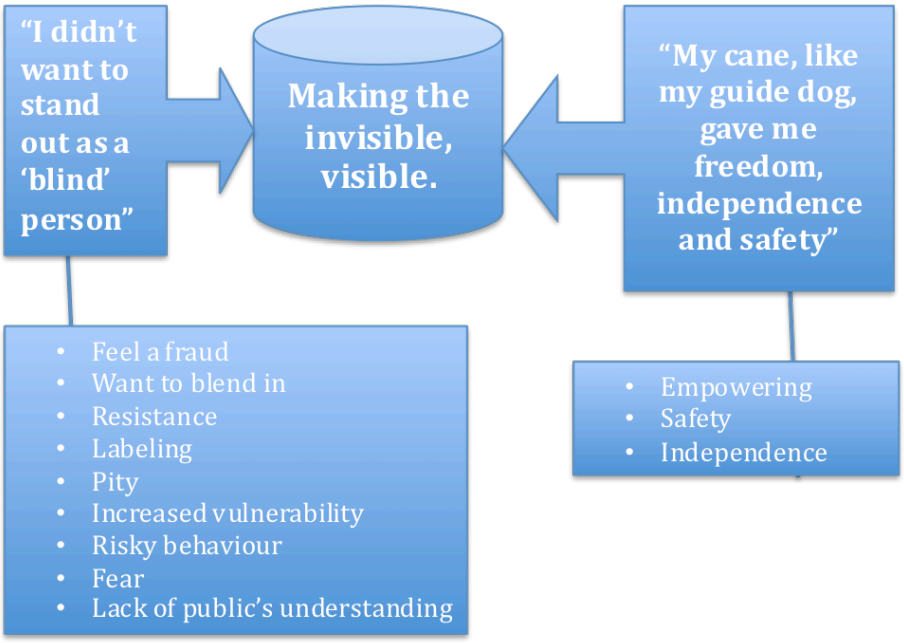

Figure 3 - Thematic Map for making the invisible, visible

3.1.3.1 "I didn't want to stand out as a 'blind' person"

Although blindness is often an invisible disability, the introduction of a mobility aid, such as a cane, instantly makes the condition visible. It can draw unwanted attention: "*I feel it draws attention to me when all I want is to be an anonymous person in a crowd*" (13).

When a disability becomes visible there's an automatic labelling process from others, which for some has negative connotations: "*I don't like people knowing im visually impaired*" (47), with a sense that it increases the sense of disablement: "*I don't like to use my cane as I feel disabled and useless*" (38), whilst others acknowledge that by raising the awareness that they have a disability can be useful: "*In general people are happy to help if they realise I cannot see and the cane helps them to know*" (49). Others demonstrate some ambivalence over the awareness raising process: "*I don't want to use it cause it puts a sign on me I am blind but sometimes think it would help to not have to explain I can't see*" (27).

This disparity on the pros and cons of making visual impairment a visible condition raises concerns in many of the participants for their own safety: "*I worry that using it, particularly at night, makes me a vulnerable target for criminals*." (34).

There is much resistance to the use of any form of cane:

> "*I feel self-conscious using a guide cane, and will sometimes put it out of view deliberately. I choose not to use it in certain situations, and feel frustrated when am forced to out of necessity*." (34)

With numerous respondents declaring hatred for having to use one:

> "*Hate it*" (14)
> "*I hate needing to use one*" (40)
> "*I hate using a symbol cane*" (13)

Whilst the use of mobility aids is not unique to people with visual impairments, one participant who has used other mobility aids in the past note that the use of a white cane is different to using a walking cane:

> "*I was using a cane before my diagnosis of RP. I have multiple Sclerosis and have mobility problems, I started using a cane for support in around 2000 so had got used to using a cane. Obviously, different issues and it did take a while to use a white cane. I didn't want to stand out as a 'blind' person*." (31).

People with visual impairments have concerns about how others perceive them. Many report being embarrassed by using a cane, with some engaging in risky behaviours whilst resisting use: "*It's embarrassing and I don't need it [unless] I'm crossing a busy street, which I still don't use it*" (21). There is an anticipation of pity: "*feel uncomfortable with some of the 'pity looks' that people don't realise I see*" (7).

Due to the varying nature of blindness, and the public's understanding of what blindness is, some people report feeling fraudulent when using a cane in public as they have some residual vision: "*I feel a fraud as I still have good central vision*" (37), with one reporting that they have heard people commenting on their use when out and about: "*People often stare and whisper why can I see certain things if I have a cane; maybe I'm faking it*." (15).

Due to the perceived issues of using a cane, the labelling of an invisible disability, some are resistant to commencing use of something that could make their life easier: "*Resisting cane training though I am at the stage of needing it*" (10); "*I am still resisting using a cane mostly because of what people think about it*" (16). With some fear about having to use one in the future: "*Scared one day I will need it*" (30).

3.1.3.2 "My cane, like my guide dog, gave me freedom, independence and safety"

Despite many people stating resistance to commencing cane training or cane use, there are some who find it gives them their once-lost independence: "*I love*

my cane… It makes me feel a lot more independent" (15), some use it with pride and treat it like an accessory rather than a mobility aid:

> *"I initially resisted using the cane. Once I began using one, I became more independent and confident in what I do. I'm not one just to sit around and do nothing, and my cane allowed me to continue doing activities that I enjoy and going places on my own. Actually, I have several canes; the typical white and red, a black cane with a red bottom (for when I dress up and go to a nice restaurant or the symphony) and a bright yellow one with red which I use to play golf. I decided when I started using the cane to have fun with the colours. I am proud of my cane because it allows me to show people that I am independent and capable"* (18).

Those who adopt the cane wholeheartedly adapt and appreciate the benefits that a cane can bring, despite initial reticence: "*I thought I would hate it, but I find it empowering*" (6). Raising awareness of the visual impairment through the use of the cane reduces frustration in the public, and reduces risk-taking behaviours: "*The cane is great as people do not get irritated with me if I do not see them. Also, it keeps me from running into or falling off of curbs*." (26).

Even those who usually use a guide dog, will occasionally revert to the cane: "*I use my cane when my pooch is not suitable form of guide – short trips, out on the pop, when company does not like dogs etc*" (52) and when the dog is an unsuitable form of aid then independence and freedom is not lost: "*I only use my cane on the very rare occasion my guide dog is unable to guide me (she's unwell). My cane, like my guide dog, gave me freedom, independence and safety*." (53).

3.2 Psychometric Analyses of the WHOQOL-BREF, DISC-VI and QUAD-VI

3.2.0 Key to Survey Questions

Q1	Quality of Life
Q2	Satisfaction with Health
Q3	Pain and Discomfort
Q4	Dependence on Medication or Treatment
Q5	Positive Feelings
Q6	Spirituality/Religion/Personal Beliefs
Q7	Thinking, Learning, Memory and Concentration
Q8	Physical Safety and Security
Q9	Physical Environments
Q10	Energy and Fatigue
Q11	Body Image and Appearance
Q12	Financial Resources
Q13	Opportunities for acquiring new information and skills
Q14	Participation and opportunities for recreation/leisure activities
Q15	Mobility
Q16	Sleep and rest
Q17	Activities of Daily Living
Q18	Working Capacity
Q19	Self-Esteem
Q20	Personal Relationships
Q21	Sex
Q22	Practical Social Support
Q23	Home Environment
Q24	Health and Social Care: availability and quality
Q25	Transport
Q26	Negative feelings

Figure 4 - Key to WHOQOL-BREF Question Numbers

Q1	Unfair Treatment in Friendships
Q2	Unfair Treatment in Neighbourhood
Q3	Unfair Treatment in Dating and Intimate Relationships
Q4	Unfair Treatment in Housing
Q5	Unfair Treatment in Education
Q6	Unfair Treatment in Marriage or Divorce
Q7	Unfair Treatment by Family
Q8	Unfair Treatment in Finding Employment
Q9	Unfair Treatment in Maintaining Employment
Q10	Unfair Treatment on Public Transport
Q11	Unfair Treatment Getting Benefits/Disability
Q12	Unfair Treatment in Religious Practices
Q13	Unfair Treatment in Social Life
Q14	Unfair Treatment by the Police
Q15	Unfair Treatment in Medical Care
Q16	Unfair Treatment in Ophthalmology
Q17	Unfair Treatment in Levels of Privacy
Q18	Unfair Treatment in Personal Safety and Security
Q19	Unfair Treatment in Starting a family
Q20	Unfair Treatment in Parental Role
Q21	Avoided or Shunned by People Aware of Visual Impairment
Q22	Stopped Self Applying for Work
Q23	Stopped Self Applying for Education or Training
Q24	Stopped Self Having a Close Personal Relationship
Q25	Concealed or Hidden Disability
Q26	Made Friends With Non-Visually Impaired People
Q27	Coping skills
Q28	Treated More Positively by Family
Q29	Treated More Positively Applying for Benefits/Disability
Q30	Treated More Positively in Housing
Q31	Treated More Positively in Religion
Q32	Treated More Positively in Employment
Q33	Treated More Positively in Other Settings

Figure 5 - Key to DISC-VI Question Numbers

Q1	Friends will treat me unfairly
Q2	Neighbours will treat me unfairly
Q3	I will be treated unfairly in dating or intimate relationships
Q4	Housing officials or landlords will treat me unfairly
Q5	Teachers, lecturers, or tutors will treat me unfairly
Q6	Family will treat me unfairly
Q7	Employers will treat me unfairly
Q8	Colleagues will treat me unfairly
Q9	Transport drivers and officials will treat me unfairly
Q10	Benefits officials will treat me unfairly
Q11	Religious officials or community will treat me unfairly
Q12	Police will treat me unfairly
Q13	Health Professionals will treat me unfairly
Q14	Children in community will treat me unfairly

Figure 6 - Key to QUAD-VI Question Numbers

3.2.1 Analysis

3.2.1.1 Internal Consistency Reliability

Internal consistency reliability of the scales was assessed using SPSS reliability analysis to determine the standardized Chronbach's alpha. Analysis of the 24 facets of the WHOQOL-BREF demonstrated an excellent internal consistency, α = .94. The four domains that make up the WHOQOL-BREF demonstrate good internal consistency overall, α = .88, and individually: Physical Domain, α = .84; Psychological Domain, α = .88; Social Relationships Domain, α = .78; and, Environment Domain, α = .86. Analysis of the DISC-VI's 33 items demonstrated an good internal consistency, α = .78, whilst the QUAD-VI's 14 items demonstrated an excellent level of internal consistency, α = .90. Tables 2 through to 4 show the importance of each facet, domain, and item in each of the respective scales.

3.2.1.1.1 WHOQOL-BREF Internal Consistency Reliability

Table 2 - WHOQOL-BREF Chronbach's Alpha Scores to Assess Whether Items Affect Internal Consistency Reliability (overall α = .94; n=169)

Facet/Domain		Item α if deleted
Q3	Pain and Discomfort	.94
Q4	Dependence on Medication or Treatment	.94
Q5	Positive Feelings	.94
Q6	Spirituality/Religion/Personal Beliefs	.94
Q7	Thinking, Learning, Memory and Concentration	.94
Q8	Physical Safety and Security	.94
Q9	Physical Environments	.94
Q10	Energy and Fatigue	.94
Q11	Body Image and Appearance	.94
Q12	Financial Resources	.94
Q13	Opportunities for acquiring new information and skills	.94
Q14	Participation and opportunities for recreation/leisure activities	.94
Q15	Mobility	.94
Q16	Sleep and rest	.94
Q17	Activities of Daily Living	.94
Q18	Working Capacity	.94
Q19	Self-Esteem	.94
Q20	Personal Relationships	.94
Q21	Sex	.94
Q22	Practical Social Support	.94
Q23	Home Environment	.94
Q24	Health and Social Care: availability and quality	.94
Q25	Transport	.94
Q26	Negative feelings	.94
Physical Domain		.84
Psychological Domain		.81
Social Relationships Domain		.89
Environment Domain		.84

3.2.1.1.2 DISC-VI Internal Consistency Reliability

Table 3 - DISC-VI Chronbach's alpha Scores to Assess Whether Items Affect Internal Consistency Reliability (overall α = .78; n=142)

Item		Item α if deleted
Q1	Unfair Treatment in Friendships	.74
Q2	Unfair Treatment in Neighbourhood	.75
Q3	Unfair Treatment in Dating and Intimate Relationships	.75
Q4	Unfair Treatment in Housing	.75
Q5	Unfair Treatment in Education	.75
Q6	Unfair Treatment in Marriage or Divorce	.75
Q7	Unfair Treatment by Family	.75
Q8	Unfair Treatment in Finding Employment	.74
Q9	Unfair Treatment in Maintaining Employment	.75
Q10	Unfair Treatment on Public Transport	.75
Q11	Unfair Treatment Getting Benefits/Disability	.75
Q12	Unfair Treatment in Religious Practices	.75
Q13	Unfair Treatment in Social Life	.74
Q14	Unfair Treatment by the Police	.75
Q15	Unfair Treatment in Medical Care	.75
Q16	Unfair Treatment in Ophthalmology	.75
Q17	Unfair Treatment in Levels of Privacy	.75
Q18	Unfair Treatment in Personal Safety and Security	.74
Q19	Unfair Treatment in Starting a family	.76
Q20	Unfair Treatment in Parental Role	.76
Q21	Avoided or Shunned by People Aware of Visual Impairment	.74
Q22	Stopped Self Applying for Work	.76
Q23	Stopped Self Applying for Education or Training	.75
Q24	Stopped Self Having a Close Personal Relationship	.75
Q25	Concealed or Hidden Disability	.76
Q26	Made Friends With Non-Visually Impaired People	.77
Q27	Coping skills	.75
Q28	Treated More Positively by Family	.76
Q29	Treated More Positively Applying for Benefits/Disability	.77
Q30	Treated More Positively in Housing	.77
Q31	Treated More Positively in Religion	.78
Q32	Treated More Positively in Employment	.77
Q33	Treated More Positively in Other Settings	.76

3.2.1.1.3 QUAD-VI Internal Consistency Reliability

Table 4 - QUAD-VI Chronbach's alpha Scores to Assess Whether Items Affect Internal Consistency Reliability (overall α = .90; n=165)

Item		Item α if deleted
Q1	Friends will treat me unfairly	.88
Q2	Neighbours will treat me unfairly	.88
Q3	I will be treated unfairly in dating or intimate relationships	.89
Q4	Housing officials or landlords will treat me unfairly	.88
Q5	Teachers, lecturers, or tutors will treat me unfairly	.88
Q6	Family will treat me unfairly	.89
Q7	Employers will treat me unfairly	.89
Q8	Colleagues will treat me unfairly	.89
Q9	Transport drivers and officials will treat me unfairly	.89
Q10	Benefits officials will treat me unfairly	.89
Q11	Religious officials or community will treat me unfairly	.89
Q12	Police will treat me unfairly	.89
Q13	Health Professionals will treat me unfairly	.89
Q14	Children in community will treat me unfairly	.88

3.2.1.2 Convergent and Divergent Validity

Tables 5 to 8 show convergent and divergent reliability across all domains of the WHOQOL-BREF with all facets being significantly, and predominantly, correlated with their parent domain. No facets are more strongly correlated with another domain. Tables 9 to 12 show convergent and divergent reliability across the subscales of the DISC-VI. Excepting the Unfair Treatment subscale, all items are significantly and predominantly correlated with their parent subscale. Two items on the Unfair Treatment subscale (Table 12) are more significantly correlated with the Overcoming Stigma subscale, possibly due to the similar nature of the questions – in particular one item within the Overcoming Stigma subscale relating to friendships. The correlations are not as strong in the DISC-VI as those in the WHOQOL-BREF.

3.2.1.2.1 WHOQOL-BREF Physical Domain Correlations

Table 5 - Correlation Matrix Showing the Correlations Between WHOQOL-BREF Facets and Domains for the Physical Domain

Facet	Physical	Psych	Social	Environ.	Q3	Q4	Q10	Q15	Q16	Q17
Q3	**.665****	.372**	.257**	.390**						
Q4	**.694****	.412**	.359**	.402**	.609**					
Q10	**.783****	.720**	.445**	.587**	.471**	.450**				
Q15	**.638****	.451**	.314**	.589**	.193**	.226**	.458**			
Q16	**.623****	.596**	.435**	.524**	.327**	.282**	.540**	.218**		
Q17	**.853****	.614**	.429**	.686**	.416**	.482**	.590**	.628**	.440**	
Q18	**.728****	.472**	.293**	.512**	.304**	.428**	.393**	.486**	.275**	.712**

** Correlation is significant at the 0.01 level (2-tailed).

3.2.1.2.2 WHOQOL-BREF Psychological Domain Correlations

Table 6 - Correlation Matrix Showing the Correlations Between WHOQOL-BREF Facets and Domains for the Psychological Domain

Facet	Physical	Psychological	Social	Environment	Q5	Q6	Q7	Q11	Q19
Q5	.527**	**.833****	.619**	.604**					
Q6	.462**	**.823****	.584**	.585**	.785**				
Q7	.565**	**.649****	.416**	.476**	.430**	.408**			
Q11	.607**	**.737****	.425**	.451**	.445**	.433**	.412**		
Q19	.679**	**.880****	.622**	.609**	.673**	.662**	.472**	.634**	
Q26	.619**	**.786****	.541**	.613**	.598**	.553**	.404**	.506**	.681**

** Correlation is significant at the 0.01 level (2-tailed).

3.2.1.2.3 WHOQOL-BREF Social Relationships Correlations

Table 7 - Correlation Matrix Showing the Correlations Between WHOQOL-BREF Facets and Domains for the Social Relationships Domain

Facet	Physical	Psychological	Social	Environment	Q20	Q21
Q20	.417**	.595**	**.881****	.509**		
Q21	.310**	.495**	**.841****	.365**	.656**	
Q22	.555**	.618**	**.771****	.583**	.541**	.409**

** Correlation is significant at the 0.01 level (2-tailed).

3.2.1.2.4 WHOQOL-BREF Environment Correlations

Table 8 - Correlation Matrix Showing the Correlations Between WHOQOL-BREF Facets and Domains for the Environment Domain

Facet	Physical	Psychological	Social	Environment	Q8	Q9	Q12	Q13	Q14	Q23	Q24
Q8	.575**	.577**	.448**	**.714****							
Q9	.524**	.600**	.491**	**.731****	.644**						
Q12	.497**	.453**	.369**	**.682****	.380**	.345**					
Q13	.607**	.487**	.289**	**.765****	.524**	.483**	.520**				
Q14	.526**	.593**	.460**	**.709****	.477**	.502**	.488**	.482**			
Q123	.386**	.424**	.485**	**.666****	.364**	.490**	.344**	.356**	.409**		
Q24	.593**	.425**	.372**	**.709****	.381**	.428**	.344**	.548**	.310**	.442**	
Q25	.470**	.452**	.372**	**.691****	.345**	.344**	.376**	.445**	.376**	.392**	.531**

** Correlation is significant at the 0.01 level (2-tailed).

3.2.1.2.5 DISC-VI Stopping Self Subscale Correlations

Table 9 - Correlation Matrix Showing the Correlations Between DISC-VI Items and Subscales for the Stopping Self Subscale

Item	Unfair Treatment	Stopping Self	Overcoming Stigma	Positive Treatment	Q22	Q23	Q24
Q22	.191*	**.449****	.030	-.159*			
Q23	.284**	**.351****	.186*	-.203**	.354**		
Q24	.190*	**.476****	.198**	-.130	.220**	.290**	
Q25	.191**	**.504****	.110	-.153*	.227**	.289**	.194**

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

3.2.1.2.6 DISC-VI Overcoming Stigma Subscale Correlations

Table 10 - Correlation Matrix Showing the Correlations Between DISC-VI Items and Subscales for the Overcoming Stigma Subscale

Item	Unfair Treatment	Stopping Self	Overcoming Stigma	Positive Treatment	Q26
Q26	.040	.040	**.300****	.000	
Q27	.204**	.165*	**.816****	-.020	.277**

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

3.2.1.2.7 DISC-VI Positive Treatment Subscale Correlations

Table 11 - Correlation Matrix Showing the Correlations Between DISC-VI Items and Subscales for the Positive Treatment Subscale

Item	Unfair Treatment	Stop Self	Overcoming Stigma	Positive Treatment	Q28	Q29	Q30	Q31	Q32
Q28	.010	-.020	.000	**.356****					
Q29	-.130	-.070	-.110	**.494****	.173*				
Q30	-.230**	-.269**	-.080	**.635****	.150	.552**			
Q31	-.177*	-.130	-.220**	**.605****	.060	.294**	.588**		
Q32	-.225**	-.307**	-.110	**.507****	.231**	.276**	.393**	.338**	
Q33	-.090	-.110	.030	**.396****	.190*	.328**	.296**	.120	.363**

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

3.2.1.2.8 – DISC-VI Unfair Treatment Subscale

Table 12 - Correlation Matrix Showing the Correlations Between DISC-VI Items and Subscales for the Unfair Treatment Subscale

Item	Unfair Treatment	Stop Self	Overcoming Stigma	Positive Treatment	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
Q1	.261**	.185*	**.278****	-.090										
Q2	**.383****	.171*	.120	-.080	.374**									
Q3	**.311****	.030	.249**	-.206**	.359**	.276**								
Q4	**.363****	.130	.180*	-.152*	.140	.337**	.316**							
Q5	**.294****	.253**	.213**	-.130	.440**	.372**	.258**	.163*						
Q6	**.336****	.090	.251**	-.110	.261**	.154*	.533**	.395**	.120					
Q7	**.244****	.040	.110	-.070	.345**	.245**	.301**	.294**	.291**	.314**				
Q8	.345**	**.378****	.247**	-.197**	.287**	.272**	.345**	.237**	.410**	.243**	.196**			
Q9	**.346****	.195**	.171*	-.120	.191*	.291**	.247**	.193**	.179*	.241**	-.030	.299**		
Q10	**.340****	.060	.153*	-.100	.304**	.304**	.205**	.263**	.216**	.279**	.218**	.270**	.120	
Q11	**.328****	.080	.206**	-.020	.270**	.218**	.229**	.301**	.223**	.269**	.217**	.211**	.292**	.342**
Q12	**.456****	.090	.229**	-.151*	.268**	.208**	.228**	.224**	.265**	.306**	.284**	.209**	.120	.218**
Q13	.165*	.060	**.195***	-.020	.475**	.280**	.263**	.169*	.265**	.202**	.320**	.275**	.202**	.299**
Q14	**.379****	.050	.236**	-.120	.154*	.325**	.285**	.376**	.201**	.211**	.192**	.271**	.060	.217**
Q15	**.337****	.010	.120	-.130	.251**	.295**	.173*	.290**	.202**	.176*	.218**	.225**	.270**	.434**
Q16	**.298****	.080	.120	-.040	.060	.120	.110	.164*	.159*	.157*	.153*	.289**	.225**	.223**
Q17	**.186***	.060	.167*	-.110	.080	.281**	.159*	.279**	.147*	.130	.231**	.273**	.110	.413**
Q18	.249**	.090	**.302****	-.070	.339**	.421**	.290**	.271**	.424**	.233**	.277**	.365**	.214**	.230**
Q19	**.515****	.197**	.150	-.233**	.010	.040	.140	.120	.130	.246**	.140	.333**	.169*	.120
Q20	**.494****	.198**	.080	-.226**	.070	.040	-.030	.070	.030	.060	.120	.174*	.199**	.050
Q21	**.283****	.050	.270**	.010	.548**	.435**	.349**	.316**	.332**	.220**	.388**	.332**	.140	.274**

** Correlation is significant at the 0.01 level (2-tailed). * Correlation is significant at the 0.05 level (2-tailed).

Item	Unfair Treatment	Stop Self	Overcoming Stigma	Positive Treatment	Q11	Q12	Q13	Q14	Q15	Q16	Q17	Q18	Q19	Q20
Q1	.261**	.185*	**.278****	-.090										
Q2	**.383****	.171*	.120	-.080										
Q3	**.311****	.030	.249**	-.206**										
Q4	**.363****	.130	.180*	-.152*										
Q5	**.294****	.253**	.213**	-.130										
Q6	**.336****	.090	.251**	-.110										
Q7	**.244****	.040	.110	-.070										
Q8	.345**	**.378****	.247**	-.197**										
Q9	**.346****	.195**	.171*	-.120										
Q10	**.340****	.060	.153*	-.100										
Q11	**.328****	.080	.206**	-.020										
Q12	**.456****	.090	.229**	-.151*	.110									
Q13	.165*	.060	**.195***	-.020	.397**	.120								
Q14	**.379****	.050	.236**	-.120	.207**	.402**	.050							
Q15	**.337****	.010	.120	-.130	.434**	.286**	.356**	.365**						
Q16	**.298****	.080	.120	-.040	.314**	.100	.244**	.070	.321**					
Q17	**.186***	.060	.167*	-.110	.267**	.100	.150	.268**	.347**	.340**				
Q18	.249**	.090	**.302****	-.070	.240**	.264**	.324**	.439**	.384**	.248**	.425**			
Q19	**.515****	.197**	.150	-.233**	.080	.213**	-.070	.232**	.070	.256**	.245**	.212**		
Q20	**.494****	.198**	.080	-.226**	.110	.200**	-.080	.040	.100	.223**	.090	.070	.509**	
Q21	**.283****	.050	.270**	.010	.344**	.233**	.474**	.242**	.349**	.239**	.197**	.517**	.030	.080

** Correlation is significant at the 0.01 level (2-tailed). * Correlation is significant at the 0.05 level (2-tailed).

3.2.1.3 Construct Validity

The WHOQOL-BREF has a four domain structure, although in this study an exploratory factor analysis using principal axis factor analysis (with varimax rotation, Kaiser Normalisation) a five domain structure was found (Kaiser-Meyer-Olkin = .917, Bartlett's test of sphericity χ^2 = 2450.21, df = 276, p < .001) with each factor having eigenvalues >1. The five factor model (Table 13) explains 58.45% if the variance. In this structure there is evidence of a psychosocial domain, with all facets of the social relationships domain being linked to the psychological domain. The second factor is made up of physical and environmental facets, although incorporating activities of daily living, working capacity, finances, there's considerable similarities within the facets depending on the interpretation of the questions posed. The third factor consists of the remaining psychological facets and are largely bodily and body function related. The fourth factor is a purely environmental domain, with the final being very obviously linked to physical health and the experience of health. Due to the WHOQOL-BREF being an international instrument, it is expected that interpretation of the facets of the scale will alter depending on the audience.

The DISC scale has a 4-factor structure. This revised DISC-VI scale has been utilized on the basis of a 4-factor structure. An exploratory factor analysis using principal axis factor analysis (varimax rotation with Kaiser normalization) on a sample smaller than ideal (n = 142) found a ten-factor structure (Kaiser-Meyer-Olkin = .702, Bartlett's test of sphericity χ^2 = 1548.46, df = 528, p <.001) as shown in table 14. For this analysis the factor loading was eliminated to explore the reasons for a negative correlation on factor 7, although alternative correlations were too weak to consider utilizing. The unfair treatment subscale is large, and makes up much of the scale, incorporating 21 items. As such, a larger sample would be required to have more conclusive suggestions on the existence of new factors. There are some logical groupings, such as religion and family; work and training; and, marriage and dating. The positive treatment subscale was almost wholly agreed, with the exception of the new question 33.

The QUAD has no subscales or domains, although a previous study suggested a two factor model (Gabbidon et al., 2013). An exploratory factor analysis using principal axis factor analysis (varimax rotation with Keiser normalization) with a

small sample (n = 165) identified a three-factor structure (Kaiser-Meyer-Olkin = .869, Bartlett's test of sphericity = χ^2 972.81, df = 91, p < .001) as shown in Table 15. The factors are reminiscent of those found in Gabbidon et al., (2013)'s study, with factor 1 indicating a interpersonal relationships within the local community; factor 2 relating to institutions and services; and the third factor relating to employment.

3.2.1.3.1 WHOQOL-BREF Exploratory Factor Analysis

Table 13 - Exploratory Factor Analysis of the WHOQOL-BREF Facets

Facet	Domain	Factor				
		1	2	3	4	5
Q20	Social	0.763				
Q21	Social	0.674				
Q5	Psychological	0.674				
Q6	Psychological	0.632				
Q19	Psychological	0.573				
Q22	Social	0.534				
Q9	Environment	0.400				
Q18	Physical		0.728			
Q17	Physical		0.720			
Q15	Physical		0.582			
Q13	Environment		0.511			
Q14	Environment		0.456			
Q8	Environment		0.401			
Q12	Environment		0.355			
Q10	Physical			0.752		
Q11	Psychological			0.595		
Q26	Psychological			0.531		
Q16	Physical			0.481		
Q7	Psychological			0.461		
Q25	Environment				0.630	
Q24	Environment				0.576	
Q23	Environment				0.547	
Q4	Physical					0.791
Q3	Physical					0.635
	Eigenvalues	3.81	3.15	3.01	2.33	1.74
	Variance (%)	15.84	13.13	12.54	9.69	7.26

3.2.1.3.2 DISC-VI Exploratory Factor Analysis

Table 14 - Exploratory Factor Analysis of the DISC-VI Items

Item	Subscale	Factor									
		1	2	3	4	5	6	7	8	9	10
Q1	Unfair Treatment	0.723									
Q21	Unfair Treatment	0.685									
Q18	Unfair Treatment	0.625									
Q5	Unfair Treatment	0.583									
Q2	Unfair Treatment	0.520									
Q13	Unfair Treatment	0.416									
Q27	Overcoming Stigma	0.311									
Q30	Positive Treatment		0.808								
Q31	Positive Treatment		0.642								
Q29	Positive Treatment		0.622								
Q32	Positive Treatment		0.518								
Q6	Unfair Treatment			0.769							
Q3	Unfair Treatment			0.560							
Q11	Unfair Treatment				0.584						
Q9	Unfair Treatment				0.547						
Q10	Unfair Treatment				0.351						
Q20	Unfair Treatment					0.907					
Q19	Unfair Treatment					0.609					
Q22	Stopping Self						0.648				
Q22	Stopping Self						0.492				
Q8	Unfair Treatment						0.424				
Q24	Stopping Self						0.376				
Q25	Stopping Self						0.322				
Q4	Unfair Treatment							0.634			
Q14	Unfair Treatment							0.504			
Q15	Unfair Treatment							0.414			
Q12	Unfair Treatment								0.545		
Q28	Positive Treatment								0.456		
Q33	Positive Treatment								0.452		
Q26	Overcoming Stigma									-0.539	
Q7	Unfair Treatment									0.536	
Q16	Unfair Treatment										0.506
Q17	Unfair Treatment										0.360
	Eigenvalues	3.25	2.16	1.59	1.58	1.53	1.49	1.45	1.13	1.04	.90
	Variance (%)	9.83	6.54	4.82	4.80	4.64	4.51	4.40	3.41	3.16	2.72

3.2.1.3.3 QUAD-VI Exploratory Factor Analysis

Table 15 - Exploratory Factor Analysis of the QUAD-VI Items

Items		Factor		
		1	2	3
Q2		0.637		
Q1		0.596		
Q6		0.586		
Q3		0.561		
Q12		0.503		
Q4		0.481		
Q11		0.474		
Q14		0.462		
Q9			0.789	
Q13			0.561	
Q10			0.528	
Q5			0.516	
Q7				0.872
Q8				0.605
	Eigenvalues	2.89	2.40	1.64
	Variance (%)	20.65	17.16	11.70

3.2.1.4 Discriminating Validity

As demonstrated in table 16 there is a statistically significant relationship between the quality of life scores (assessed using the mean of questions 1 and 2 of the WHOQOL-BREF) and the WHOQOL-BREF domains, whereby for each increase in subjective quality of life the scores across the domains also increase. This indicates that the domains are reflecting a true picture of the quality of life within the sample.

3.2.1.4.1 Discriminating Validity of the WHOQOL-BREF

Table 16 - Discriminating Validity of the Domains of the WHOQOL-BREF Against General Quality of Life Scores

		Physical Domain		Psychological Domain		Social Relationships Domain		Environment Domain	
		F(4,181) = 52.95**		F(4,181) = 74.36**		F(4,181) = 30.24**		F(4,181) = 48.82**	
General QoL	n	M (SD)	95% CI	M (SD)	95% CI	M (SD)	95% CI	M (SD)	95% CI
Very Poor	18	9.30 (3.10)	[7.76,10.85]	7.30 (1.84)	[6.38,8.21]	7.11 (3.54)	[5.35,8.87]	9.08 (3.02)	[7.58,10.59]
Poor	48	11.42 (2.67)	[10.64,12.19]	11.08 (2.16)	[10.46,11.71]	10.64 (3.35)	[9.67,11.61]	11.87 (2.39)	[11.18,12.57]
Neither Poor Nor Good	47	13.92 (2.44)	[13.21,14.64]	13.21 (2.52)	[12.47,13.95]	13.57 (3.40)	[12.58,14.57]	13.81 (2.30)	[13.13,14.48]
Good	55	15.94 (1.92	[15.42,16.46]	15.74 (2.37)	[15.09,16.38]	14.78 (3.17)	[13.92,15.63]	15.33 (1.79)	[14.85,15.82]
Very Good	14	18.45 (1.33)	[17.68,19.22]	18.00 (1.55)	[17.11,18.89]	17.33 (3.27)	[15.45,19.22]	18.08 (1.47)	[17.23,18.93]

**p<.001

3.2.2 Psychometric Summary

The internal consistency reliability of the WHOQOL-BREF, DISC-VI, and QUAD-VI demonstrate that these measures are sufficiently valid for use with this visually impaired population. The WHOQOL-BREF also demonstrates good convergent and divergent validity, good content validity and good discriminating validity. The QUAD-VI demonstrates good divergent and convergent validity and good content validity. The DISC-VI does not demonstrate good divergent and convergent validity or good content validity. The use of this measure with this population shall be done with caution and the subscales shall not be used within the analysis.

3.3 Quantitative Analysis – Does Stigma and Discrimination Affect Self-Reported Quality of Life?

Table 17 - Means And Standard Deviations

Variable		n	Average QoL M (SD)	Physical M (SD)	Psychological M (SD)	Social M (SD)	Environment M (SD)	DISC-VI Total M (SD)	Quad-VI Total M (SD)
Gender									
	Male	62	2.81 (1.16)	13.72 (3.44)	13.04 (4.25)	12.40 (3.29)	13.40 (3.29)	52.09 (11.62)	12.31 (8.52)
	Female	120	3.09 (1.11)	13.78 (3.51)	13.27 (3.71)	13.01 (4.28)	13.73 (3.12)	53.16 (11.91)	11.27 (7.12)
Marital Status									
	Single	57	2.87 (1.20)	13.76 (3.74)	12.97 (3.77)	11.60 (4.49)	13.55 (3.41)	53.46 (11.76)	13.88 (7.65)
	Married/Living as	101	3.09 (1.06)	13.79 (3.18)	13.48 (3.33)	13.89 (3.69)	13.92 (2.97)	51.95 (11.76)	10.48 (7.65)
	No Longer Married	24	2.88 (1.26)	13.62 (4.13)	12.53 (4.64)	11.17 (4.86)	12.53 (3.35)	54.68 (12.24)	11.27 (6.64)
Employment Status									
	Employed	75	3.27 (1.11)	14.83 (2.89)	13.94 (3.75)	13.03 (4.17)	14.29 (2.72)	51.78 (13.44)	10.44 (6.71)
	Student	24	3.38 (1.01)	14.98 (3.55)	14.03 (3.48)	14.22 (3.81)	14.46 (3.25)	53.20 (9.81)	13.10 (8.07)
	Retired	13	3.00 (1.29)	13.63 (2.75)	13.64 (2.70)	13.69 (3.72)	14.68 (3.31)	50.13 (6.85)	10.00 (7.80)
	Disability	36	2.44 (1.08)	11.10 (3.88)	11.61 (3.74)	10.94 (4.84)	11.94 (3.31)	55.36 (12.15)	12.06 (9.32)
	Unemployed	34	2.71 (1.00)	13.43 (2.92)	12.45 (3.29)	12.92 (3.21)	12.91 (3.21)	52.92 (10.04)	13.27 (7.11)
Age Group									
	18-35	61	3.25 (1.16)	14.34 (3.56)	13.76 (3.78)	13.18 (4.59)	13.99 (3.05)	53.10 (11.38)	12.38 (7.37)
	36-60	105	2.89 (1.09)	13.54 (3.54)	12.90 (3.77)	12.65 (4.21)	13.42 (3.29)	52.93 (12.36)	11.07 (7.46)
	60+	16	2.75 (1.18)	13.00 (2.42)	13.01 (2.62)	12.46 (3.40)	13.54 (2.99)	49.75 (8.66)	12.57 (9.86)

Variable		n	Average QoL M (SD)	Physical M (SD)	Psychological M (SD)	Social M (SD)	Environment M (SD)	DISC-VI Total M (SD)	Quad-VI Total M (SD)
Visual Impairment									
	Retinitis Pigmentosa	109	3.07 (1.11)	13.99 (3.27)	13.33 (3.50)	13.00 (4.23)	13.80 (2.93)	51.39 (10.63)	11.43 (6.47)
	Keratoconus	21	3.14 (1.15)	13.99 (3.14)	13.97 (3.59)	13.65 (4.34)	14.48 (3.25)	49.56 (13.31)	6.55 (6.56)
	Other Retinal Dystrophies	19	2.74 (1.10)	12.61 (3.91)	12.04 (4.23)	11.44 (4.08)	12.53 (3.03)	52.93 (10.03)	13.72 (8.10)
	Other Causes	33	2.79 (1.19)	13.54 (4.05)	12.93 (3.87)	12.44 (4.42)	13.10 (3.84)	59.84 (13.14)	14.64 (9.94)
Education Level									
	Professional Qualification	27	2.81 (1.27)	13.82 (3.41)	12.77 (3.92)	12.22 (4.06)	13.56 (3.31)	53.95 (6.88)	11.44 (8.05)
	Postgraduate	39	3.28 (1.15)	15.18 (2.81)	14.80 (3.04)	13.91 (4.31)	14.18 (3.23)	49.70 (12.47)	11.55 (8.69)
	Undergraduate	62	3.00 (1.13)	13.38 (3.55)	12.82 (3.80)	12.41 (3.93)	13.56 (3.26)	54.76 (12.02)	11.41 (7.30)
	Non-Tertiary	54	2.87 (1.03)	13.14 (3.66)	12.68 (3.54)	12.78 (4.66)	13.31 (3.01)	52.30 (12.79)	12.06 (7.06)
Current VI Status									
	Registered SSI	91	2.90 (1.20)	13.01 (3.72)	12.56 (4.36)	12.09 (4.36)	13.17 (3.10)	55.28 (11.25)	12.90 (7.86)
	Registered SI	44	2.91 (1.08)	14.29 (3.14)	12.95 (3.54)	12.97 (3.81)	13.20 (2.98)	55.06 (11.23)	11.93 (6.61)
	Chosen not to register	13	2.85 (1.07)	13.76 (2.62)	13.69 (3.42)	13.44 (4.50)	14.92 (2.90)	53.50 (11.87)	8.31 (6.26)
	Not yet registered	34	3.41 (1.05)	15.10 (3.06)	15.02 (2.91)	14.31 (4.22)	14.86 (3.90)	43.86 (9.71)	9.35 (8.18)
Help completing survey									
	Yes	11	2.45 (1.036)	11.85 (3.20)	12.24 (3.81)	12.79 (4.31)	11.49 (2.38)	50.88 (13.38)	12.44 (8.52)
	No	170	3.03 (2.99)	13.89 (3.48)	13.27 (3.66)	12.82 (4.29)	13.77 (3.16)	52.89 (11.76)	11.65 (7.60)

3.3.0 Key to Abbreviations In Analyses

UT = Unfair Treatment in SS – Stopping Self TMP – Treated More Positively by

TMU – Will Treat Me Unfairly QoL – Quality of Life

3.3.1 Correlation Analysis

Table 18 - Correlations Between the DISC-VI (n = 141) and QUAD-VI (n = 165) totals and WHOQOL-BREF Domains and Average QoL

	Physical Domain	Psychological Domain	Social Relationships Domain	Environment Domain	Overall QoL
DISC-VI	-.354** [-.494,-.208]	-.291** [-.456,-.116]	-.305** [-.465,-.125]	-.359** [-.500,-.197]	-.376** [-.542,-.193]
QUAD-VI	-.487** [-.600,-.357]	-.501** [-.610,-.384]	-.450** [-.566,-.314]	-.648** [-.732,-.541]	-.496** [-.619,-.351]

**p<.001.
BCa bootstrap 95% CIs reported in brackets

As can be seen in Table 18 there are statistically significant correlations between the DISC-VI scores and all four domains of the WHOQOL-BREF, and average QoL. These indicate a negative relationship, whereby higher scores on the DISC-VI scale relate to lower QoL scores.

The QUAD-VI measure, which measures anticipated stigma also has statistically significant correlations with all four domains of the WHOQOL-BREF, and average QoL. Again, the correlation indicates a negative relationship between anticipated stigma and QoL. The strongest relationship is between anticipated stigma and the environment domain of the WHOQOL-BREF.

3.3.2 Predictors of Quality of Life

3.3.2.1 Which DISC-VI items best predict average quality of life?

Using the backward method, a significant model emerged: $F(13, 128) = 9.256$, $p < .001$. The model explains 43.2% of the variance (Adjusted $R2 = .432$). Table 19 gives information for the predictor variables that are included in the model.

As shown in Table 19 the stigma items that most predict overall QoL are related to friends and family relationships, employment and being on benefits, and interactions with health care professionals.

Table 19 - Unstandardized and Standardised Regression Coefficients, Plus 95% Confidence Intervals Reported in Parentheses, for the Predictors of Average QoL in the Model (n = 142)

	b	SE b	β	p
(Constant)	4.213	0.377		.000
	[3.47, 4.96]			
Q1 - UT Friends	-0.256	0.081	-0.240	.002
	[-.42, -.10]			
Q8 - UT Employment	0.206	0.065	0.236	.002
	[.08, .33]			
Q11 – UT Getting Benefits/Disability	-0.208	0.071	-0.226	.004
	[-.35, -.07]			
Q15 – UT Medical Care	-0.283	0.089	-0.234	.002
	[-.46, -.11]			
Q16 – UT Ophthalmology	-0.198	0.084	-0.163	.020
	[-.37, -.03]			
Q23 – SS Education or Training	-0.165	0.067	-0.179	.015
	[-.30, -.03]			
Q24 – SS Close Personal Relationship	-0.344	0.070	-0.346	.000
	[-.48, -.21]			
Q26 – Made Non-VI Friends	0.201	0.069	0.198	.004
	[.06, .34]			
Q27 – Coping Skills	0.09	0.052	0.123	.087
	[-.01, .19]			
Q28 – TMP Family	0.158	0.064	0.167	.015
	[.03, .29]			
Q29 – TMP Benefits/Disability	-0.147	0.071	-0.159	.040
	[-.29, -.01]			
Q32 – TMP Employment	-0.154	0.072	-0.157	.036
	[-.30, -.01]			
Q33 – TMP Other Settings	0.156	0.079	0.151	.052
	[.00, .31]			

3.3.2.2 Which DISC-VI items best predict Physical QoL

Using the backward method, a significant model emerged: $F(10, 131) = 11.81$, $p < .001$. The model explains 43.4% of the variance (Adjusted R2 = .434). Table 20 gives information for the predictor variables that are included in the model.

Table 20 indicates that the stigma items that predict physical QoL are in the realms of family and social networks, plus employment.

Table 20 - The Unstandardized and Standardised Regression Coefficients, Plus 95% Confidence Intervals Reported in Parentheses, for the Predictors of QoL in the Physical Domain in the Model (n = 142)

	b	95% CI	SE b	β	p
(Constant)	15.894	[13.80, 17.99]	1.060		.000
Q7 – UT Family	-0.516	[-.98, -.06]	0.233	-0.165	.028
Q8 – UT Finding Employment	0.800	[-.81, -.01]	0.208	0.301	.000
Q9 – UT Maintaining Employment	-0.414	[-.81, -.01]	0.202	-0.146	.043
Q10 – UT Public Transport	-0.501	[-.97, -.04]	0.235	-0.158	.035
Q15 – UT Medical Care	-0.801	[-1.36, -.24]	0.283	-0.217	.005
Q17 – UT Levels of Privacy	0.984	[.22, 1.74]	0.384	0.175	.012
Q21 - Avoided/Shunned	-0.734	[-1.22, -.25]	0.244	-0.242	.003
Q22 – SS Apply for Work	-0.511	[-.89, -.13]	0.192	-0.194	.009
Q24 – SS Close Personal Relationship	-0.514	[-.94, -.09]	0.217	-0.169	.019
Q26 – Made Non-VI Friends	0.731	[.31, 1.15]	0.212	0.236	.001

3.3.2.3 Which DISC-VI items best predict Psychological QoL

Using the backward method, a significant model emerged: $F(12, 129) = 8.28$, $p < .001$. The model explains 38.2% of the variance (Adjusted R2 = .382). Table 21 gives information for the predictor variables that are included in the model.

Table 21 indicates that the stigma items that predict physical QoL are in the realms of family and social networks, plus employment and transportation.

Table 21 - The Unstandardized and Standardised Regression Coefficients, Plus 95% Confidence Intervals Reported in Parentheses, for the Predictors of QoL in the Psychological Domain in the Model (n - 142)

	b	95% CI	SE b	β	p
(Constant)	13.663	[11.22, 16.11]	1.237		.000
Q1 – UT Friends	-0.515	[-1.11, .08]	0.301	-0.143	.089
Q2 – UT Neighbourhood	0.694	[.01, 1.38]	0.347	0.164	.047
Q7 – UT Family	-0.694	[-1.24, -.14]	0.278	-0.201	.014
Q8 – UT Finding Employment	0.594	[.12, 1.07]	0.239	0.202	.014
Q9 – UT Maintaining Employment	-0.607	[-1.09, -.13]	0.243	-0.194	.014
Q10 - UT Public Transport	-0.628	[-1.16, -.09]	0.271	-0.179	.022
Q17 – UT Levels of Privacy	1.095	[.15, 2.04]	0.477	0.177	.023
Q18 – UT Personal Safety/Security	-0.861	[-1.51, -.22]	0.325	-0.223	.009
Q20 – UT Parental Role	0.941	[.23, 1.66]	0.361	0.186	.010
Q22 – SS Applying for Work	-0.407	[-.85, .03]	0.223	-0.14	.070
Q24 – SS Close Personal Relationship	-0.727	[-1.22, -.24]	0.248	-0.217	.004
Q26 – Made Non-VI Friends	0.953	[.47, 1.44]	0.245	0.278	.000

3.3.2.4 Which DISC-VI items best predict Social Relationships QoL

Using the backward method, a significant model emerged: F (7, 134) = 9.75, p < .001. The model explains 30.3% of the variance (Adjusted R2 = .303). Table 22 gives information for the predictor variables that are included in the model.

Table 22 indicates that the stigma items that predict physical QoL are those relating, unsurprisingly, to friends and family, social life, and employment.

Table 22 - The Unstandardized and Standardised Regression Coefficients, Plus 95% Confidence Intervals Reported in Parentheses, for the Predictors of QoL in the Social Relationships Domain in the Model (n = 142)

	b	95% CI	SE b	β	p
(Constant)	14.56	[11.92, 17.20]	1.336		.000
Q1 – UT Friends	-0.677	[-1.34, -.02]	0.333	-0.167	.044
Q6 – UT Marriage/Divorce	-0.611	[-1.16, -.07]	0.276	-0.166	.029
Q8 – UT Finding Employment	0.535	[.03, 1.04]	0.256	0.161	.038
Q13 – UT Social Life	-0.803	[-1.37, -.23]	0.288	-0.225	.006
Q24 – SS Close Personal Relationship	-1.225	[-1.79, -.66]	0.287	-0.324	.000
Q26 – Made Non-VI Friends	0.574	[.02, 1.13]	0.279	0.149	.042
Q28 – TMP Family	0.494	[-.01, 1.00]	0.255	0.137	.055

3.3.2.5 Which DISC-VI items best predict Environmental QoL

Using the backward method, a significant model emerged: F (8, 133) = 13.01, p < .001. The model explains 40.5% of the variance (Adjusted R2 = .405). Table 23 gives information for the predictor variables that are included in the model. Table 23 indicates that the stigma items that predict environmental QoL are those relating to friends and family, training, and benefits.

Table 23 - The Unstandardized and Standardised Regression Coefficients, Plus 95% Confidence Intervals Reported in Parentheses, for the Predictors of QoL in the Environment Domain in the Model (n = 142)

	b	95% CI	SE b	β	p
(Constant)	13.472	[11.58, 15.40]	0.972		.000
Q11 – UT Benefits/Disability	-0.695	[-1.07, -.32]	0.191	-0.275	.000
Q15 – UT Medical Care	-0.920	[-1.39, -.45]	0.238	-0.277	.000
Q23 - SS Education or Training	-0.394	[-.75, -.04]	0.180	-0.155	.030
Q24 – SS Close Personal Relationship	-0.576	[-.95, -.21]	0.187	-0.211	.002
Q26 – Made Non-VI Friends	0.961	[.60, 1.33]	0.185	0.345	.000
Q28 – TMP Family	0.483	[.13, .83]	0.176	0.186	.007
Q29 – TMP Benefits/Disability	-0.426	[-.81, -.04]	0.194	-0.168	.030
Q33 – TMP – Other Settings	0.425	[.02, .83]	0.204	0.150	.039

3.3.2.6 Summary of the DISC-VI predictors of Quality of Life

Across all five regressions it is shown that relationships are important in predicting QoL. Overcoming stigma by having friends who are not visually impaired is a predictor of improved QoL across all of the domains of the WHOQOL-BREF.

3.3.3 Which QUAD-VI items best predict average QoL?

Using the backward method, a significant model emerged: F (5, 159) = 17.43, p < .001. The model explains 33.4% of the variance (Adjusted R2 = .334). Table 24 gives information for the predictor variables that are included in the model.

As shown in Table 4 the anticipated stigma items that most predict overall QoL are related to friends and family relationships, employment and education, and interactions with health care professionals.

Table 24 - The Unstandardized and Standardised Regression Coefficients, Plus 95% Confidence Intervals Reported in Parentheses, for the Predictors in the Model (n = 165)

	b	95% CI	SE b	β	p
(Constant)	4.067	[3.80, 4.33]	0.135		.000
Q1 – Friends TMU	-0.566	[-.80, -.33]	0.120	-0.365	.000
Q5 – Education TMU	0.248	[.03, .47]	0.112	0.171	.028
Q6 – Family TMU	-0.204	[-.39, -.02]	0.092	-0.159	.028
Q7 – Employers TMU	-0.126	[-.28, .02]	0.076	-0.114	.097
Q13 - Health Professionals TMU	-0.396	[-.62, -.17]	0.112	-0.269	.001

3.3.3.1 Which QUAD-VI items best predict physical QoL?

Using the backward method, a significant model emerged: F (3, 161) = 26.64, p < .001. The model explains 31.9% of the variance (Adjusted R2 = .319). Table 25 gives information for the predictor variables that are included in the model.

As shown in Table 25 the anticipated stigma items that most predict physical QoL are related to social relationships and interactions with health care professionals.

Table 25 - The Unstandardized and Standardised Regression Coefficients, Plus 95% Confidence Intervals Reported in Parentheses, for the Predictors of QoL in the Physical Domain in the Model (n = 165)

	B	95% CI	SE b	β	p
(Constant)	16.341	[15.61, 17.07]	0.369		.000
Q1 – Friends TMU	-1.246	[-2.01, -.49]	0.385	-0.258	.001
Q3 - Dating and Relationships	-0.611	[-1.15, -.07]	0.273	-0.172	.027
Q13 - Health Professionals TMU	-1.363	[-2.02, -.71]	0.330	-0.297	.000

3.3.3.2 Which QUAD-VI items best predict psychological QoL?

Using the backward method, a significant model emerged: F (5, 159) = 19.02, p < .001. The model explains 35.5% of the variance (Adjusted R2 = .355). Table 26 gives information for the predictor variables that are included in the model.

As shown in Table 26 the anticipated stigma items that most predict physical QoL are related to social relationships and interactions with health care professionals.

Table 26 - The Unstandardized and Standardised Regression Coefficients, Plus 95% Confidence Intervals Reported in Parentheses, for the Predictors of QoL in the Psychological Domain in the Model (n = 165)

	B	95% CI	SE b	β	p
(Constant)	15.623	[14.92, 16.33]	0.358		.000
Q1 – Friends TMU	-1.603	[-2.36, -.85]	0.383	-0.316	.000
Q5 – Education TMU	0.981	[.25, 1.71]	0.371	0.207	.009
Q6 – Family TMU	-0.772	[-1.36, -.18]	0.298	-0.184	.011
Q11 – Religion TMU	-0.673	[-1.46, .11]	0.397	-0.123	.092
Q13 - Health Professionals TMU	-1.580	[-2.30, -.47]	0.365	-0.328	.000

3.3.3.3 Which QUAD-VI items best predict social relationships QoL?

Using the backward method, a significant model emerged: F (5, 159) = 15.44, p < .001. The model explains 30.6% of the variance (Adjusted R2 = .306). Table 27 gives information for the predictor variables that are included in the model.

As shown in Table 27 the anticipated stigma items that most predict physical QoL are related to social relationships and interactions with health care professionals.

Table 27 - The Unstandardized and Standardised Regression Coefficients, Plus 95% Confidence Intervals Reported in Parentheses, for the Predictors of QoL in the Social Relationships Domain in the Model (n = 165)

	b	95% CI	SE b	β	p
(Constant)	15.572	[14.63, 16.52]	0.479		.000
Q1 – Friends TMU	-2.163	[-3.09, -1.24[	0.470	-0.364	.000
Q5 – Education TMU	1.504	[.60, 2.40]	0.456	0.271	.001
Q11 – Religion TMU	-1.081	[-2.03, -.14]	0.478	-0.170	.025
Q13 – Health Professionals TMU	-1.181	[-2.07, -.30]	0.449	-0.210	.009
Q14 – Children in Community TMU	-0.796	[-1.49, -.10]	0.353	-0.177	.026

3.3.3.4 Which QUAD-VI items best predict Environment QoL?

Using the backward method, a significant model emerged: F (5, 159) = 28.16, p < .001. The model explains 45.3% of the variance (Adjusted R2 = .453). Table 28 gives information for the predictor variables that are included in the model.

As shown in Table 28 the anticipated stigma items that most predict physical QoL are related to social relationships and interactions with health care professionals.

Table 28 - The Unstandardized and Standardised Regression Coefficients, Plus 95% Confidence Intervals Reported in Parentheses, for the Predictors of QoL in the Environment Domain in the Model (n = 165)

	b	95% CI	SE b	B	p
(Constant)	16.863	[16.16, 17.56]	0.354		.000
Q1 – Friends TMU	-1.176	[-1.78, .57]	0.308	-0.268	.000
Q6 – Family TMU	-0.817	[-1.28, -.35]	0.235	-0.225	.001
Q7 – Employers TMU	-0.655	[-1.04, -.27]	0.193	-0.209	.001
Q9 – Transport TMU	-0.486	[-1.02, .05]	0.269	-0.125	.073
Q13 - Health Professionals TMU	-0.743	[-1.34, -.15]	0.301	-0.178	.015

Which WHOQOL-BREF items best predict average QoL?

Using the backward method, a significant model emerged: F (10, 158) = 59.97, p < .001. The model explains 77.8% of the variance (Adjusted R2 = .778). Table 29 gives information for the predictor variables that are included in the model.

As shown in Table 29 the WHOQOL-BREF items that most predict overall QoL are related to social relationships, positive feelings, transportation and access to leisure, and dependence on medication.

Table 29 - The Unstandardized and Standardised Regression Coefficients. Plus 95% Confidence Intervals Reported in Parentheses, for the Predictors of Average QoL in the Model (n = 169)

	b	95% CI	SE b	β	p
(Constant)	-0.756	[-1.41, -.37]	0.195		.000
Q4 - Dependence on Medication	0.171	[.09, .25]	0.041	0.185	.000
Q5 - Positive Feelings	0.178	[.06, .29]	0.058	0.176	.003
Q9 - Physical Environments	0.095	[-.01, .20]	0.051	0.087	.063
Q12 - Financial Resources	0.084	[.01, .16]	0.040	0.096	.037
Q14 - Participation and opportunities for recreation or leisure	0.090	[-.01, .19]	0.051	0.090	.078
Q16 - Sleep and rest	0.066	[-.01, .14]	0.039	0.076	.092
Q18 - Working Capacity	0.077	[.00, .15]	0.039	0.094	.051
Q19 - Self-Esteem	0.208	[.10, .32]	0.056	0.234	.000
Q20 - Personal Relationships	0.131	[.05, .21]	0.041	0.149	.002
Q25 - Transport	0.083	[.01, .16]	0.037	0.097	.025

3.3.4 Summary of Multiple Regressions

Throughout the multitude of regressions performed, the predictors of QoL are relatively consistent. The impact of stigma through interactions with health care professionals is a common predictor.

As shown through regressions using items in all three measures, QoL is frequently predicted by relationships with friends, family, and the neighbours.

Working and benefits are also predictors that have appeared regularly within these analyses. It is interesting to note that having friends who are not visually impaired predicts an improved QoL across all domains of the WHOQOL-BREF.

3.4 Do Stigma and Discrimination affect the Quality of Life in the Visually Impaired: A Thematic Analysis

Overarching Theme	Theme	Subtheme
Barriers to Life	Blindness as a Disease	
	Unfair Treatment	Abuse (financial, verbal, physical, emotional); Lack of Consideration; Disclosure of Visual Impairment; Accommodations and Privacy
	Environmental Challenges	Transportation; Environmental Barriers
Coping Skills	Humour	
	Positive Traits	Supportive Networks; Adaptation & Resilience
	Educating Others	
	Use of Concessions	
	Adaptation by Others	

Figure 7 - Thematic Table

3.4.1 Barriers to life

3.4.1.1 Blindness as a Disease

This theme discusses the consideration of blindness as a disease. The definition of a disease is:

> *"A disorder of structure or function in a human, animal, or plant, especially one that produces specific symptoms or that affects a specific location and is not simply a direct result of physical injury"*

And:

> *"A particular quality or disposition regarded as adversely affecting a person or group of people"*
>
> (Oxford University Press, 2014c)

Although a VI is a disease in the more traditionally considered 'functional' and 'structural' sense, affecting, in this instance, the eyes (a very specific location), some of the peculiarities of individuals with a VI can impact upon how a VIP is perceived by the sighted public. In some instances it can adversely affect the lived experience, and traits of the VIP, such as the white cane, can become an integral part of the individual. This therefore suggests that both above definitions of disease can apply to the individual with a VI and these shall be discussed in more depth below.

It is not uncommon for VIPs to hypothesise about the motives of others' actions. In particular, VIPs describe the notion that some members of the sighted population deem blindness to be a contagious disease that must be avoided at all costs:

> "*People who ride on the bus are reluctant to sit next to me and act like I have some kind of disease*" (21)
>
> "*Sometimes people cross the road to avoid being close to someone with a white cane*" (294)
>
> "*People would act like I had something they could catch*" (199)

Although blindness is not a contagious disease it can, if caused by a genetic condition, be passed onto offspring. There is a perception that the VI is a justification for not dating a VIP, although some report an apparent fear existing within the sighted population:

> *"He did not want to stay with someone losing their sight"* (39)
>
> "*Many did not want to marry me and have children because they were scared the children could be blind too*" (19)
>
> "*I've had dates tell me that they didn't think they could handle 'that' anymore*" (272)

It was frequently reported that VIPs experience a reticence to dating due to poor historic experiences, and a fear of judgment and rejection:

> "*I find it hard to meet prospective partners because of low lights in restaurants and pubs, I am worried about looking silly in front of someone who does not know me and I am afraid of being rejected just because I have RP*" (276)

> "*Its [sic] always in my mind that he won't be around forever, so try not to get too attached*" (285)

Some VIPs have adjusted to a perceived notion that they are an unnecessary burden and that it is unfair to expect others to make adjustments in their lives:

> "*I don't think it is fair for someone to commit to a relationship with the me who can see some just to have to help a me that can't see later*" (306)

> "*I have stopped myself from developing many new personal relationships, as I think it is unfair on other people to have to compensate for my poor vision"* (272)

One VIP reported that even an individual whom she considered to be her best friend acted in a hurtful and discriminatory manner due to the shame of being seen with a 'blind girl':

> "*My supposed best friend who turned around and said 'Going to prom with you would ruin my reputation, I cannot be seen with a blind girl. I'm sorry.'"* (135)

The same VIP explains how a similar incident occurred whilst at university:

> "*Another time, I had become rather close to someone while at university and he said 'I cannot do the whole cane thing. I mean, yu [sic] cant even drive, what good is that. I just can't be with you. I tried to be different, but I just cant live my life with a blind girl holding me back.'"* (135)

Some of the VIPs reported that not only did they experience negative reactions from friends and potential romantic partners, but also from professionals in public services.

It is not always potential partners that have concerns regarding offspring. Medical professionals occasionally air their concerns to future parents regarding their chances of passing on the relevant gene:

> "*Don't have children, they will be born blind*" (276)

One VIP reported that some of their colleagues in law enforcement have negative thoughts towards people with disabilities, noting disgust:

> "*I work in Law Enforcement and as far as working with them, that can be a little difficult as they do feel a bit repulsed by disabled persons*" (115)

Reinforcing the concept of blindness being a disease, some VIPs have also reported discriminating and demeaning behaviour by the church:

> "*Church leaders have treated me unfairly by trying to 'heal' me without asking and also by implying that my faith must not be strong enough if I have not been 'healed'*" (39)

> "*They believe if I prayed and believed enough I'd be healed and that I don't need to depend on aids like my cane*" (280)

3.4.1.2 Unfair Treatment

As described above, it is not uncommon for VIPs to experience challenges creating new relationships, and it can be equally challenging maintaining extant relationships. Within this theme we shall explore some of the ways that VIPs describe experiencing treatment that differentiates them from the sighted population.

3.4.1.2.1 Lack of Consideration

A commonly reported phenomenon amongst the VIPs in this study was that old friends start reconsidering their friendship once a VI becomes apparent:

> "*Friends that my wife and I have had for many years, once my eyesight started to fail, they started distancing themselves from us*" (21)

> "*A few old friends and some family members have avoided me because of my vision*." (146)

Several VIPs expressed some frustration at sighted friends' perceptions of disability, and their lack of contemplating a VI's ability. This can lead to the VIP being excluded from social events and activities that they may have been able to partake in, even if not fully able to participate:

> "*Not being invited to participate with the explanation of 'I didn't think you could do it'*" (204)

> "*There have been times when friends were doing something that they felt I couldn't participate in (going sailing) so I was never asked and they tried to keep it secret from me*." (199)

> "*Sometimes friends don't [sic] always invite me to certain social events but I know my limits and would have enjoyed watching them from the sidelines (i.e. go karting etc)*." (177)

It can be difficult for VIPs to describe to friends what they can or cannot see, and also what activities are doable. This can make it difficult for VIPs to engage in social activities:

> "*Some friends have stopped inviting me to do things due to their assumption that I will not be able to go… making it harder to maintain friendships*" (39)

One VIP described their perception of a "power dynamic" in friendships, where the VIP has a weaker position within the social group and must therefore set their own needs aside to maintain their position within the group:

> "*There is what I call a 'power dynamic' in all friendships/relationships where one feels like one must put aside one's own needs, preferences, and desires so as not to 'rock the boat' or jeopardize the friendship/relationship… often people refuse to help because they don't take the time to understand the limitations*." (89)

This ‘power dynamic’ is further described by other VIPs who, when attending social events, experience challenges interacting with others. Some VIPs explained how at social gatherings they have struggled to be included:

> “*At social occasions I have been ignored or shunned by some people because I am blind but these are people who I don’t know well…*” (133)

> “*When we have outings or parties and they will just sit me in a chair and leave me alone. Sometimes, they will just forget about me until someone else will Ecknowledge [sic] that I’m there*.” (149)

The sense of abandonment, described above, does not only exist within formal social settings. One VIP described the challenges of keeping up with friends whilst being risk averse and aware due to their VI:

> “*Difficult to keep up with people while being active sometimes, especially in situations when I was in my early 20s where someone would rush across a busy road or jaywalk, and I would be left waiting for the lights to change*” (183)

Even though, as seen above, VIPs are often frustrated at being deemed disabled, with others forgetting to consider what they may be able to do, there is also considerable frustration expressed at the general lack of consideration regarding the needs, disability, and existence of a VI.

Above we have seen instances where friends have lacked some consideration towards the VIP. Many VIPs also reported a lack of understanding and consideration from various family members:

> “*In the initial months after my diagnosis, there was not [sic] understanding from my close family in regards to my limitations, even told once that I was exaggerating my limitations, pretending to be more blind of what [sic] I actually was*.” (190)

Occasionally this lack of understanding can lead to VIPs being pushed toward unsafe activities, and being made to feel fussy:

> "*My family doesn't understand how my vision loss can actually affects me, after all I'm not blind. Things like encouraging me to drive, saying things like 'oh that's right you don't like to do things after dark'*." (216)

And this VIP describes how her parents pushed her to do household chores with the expectation that the end result should be to their satisfaction, and not meeting their standards equates to laziness:

> "*My parents sometimes told me I'm lazy. Example: as a child when they show you some housework. They told me, how to clean something. I tried to clean it but obviously it wasn't clean at all cause [sic] I didn't see there was more dirt. They showed me again and again and after a while they became impatient and me too. They said 'try again' and I respond 'I can't' And their conclusion was, that I'm a lazy girl and I could just do it if I want to. That made me very angry all the time*." (260)

One VIP also reported how a lack of willingness to understand the challenges of living with a VI and make requested adaptations within the home, can cause rifts in familial and marital relationships:

> "*Because my wife and my daughters can see, clutter and a disorganized house is not an issue for them. I tried to get them to help me keep things organized and clutter free, but I lost this battle. Needless to say, this unwillingness to help me out in this way and the constant clutter causes stress for me and there have been some relationship issues that have resulted from the situation*." (290)

Many VIPs also described various situations when out and about they would be deemed to be 'snobby' or 'rude' by acquaintances and neighbours for not acknowledging social cues:

> "*A friend started working in the same office as me and often said hello in passing but I never noticed her because I didn't know to be looking for her, she emailed me about it and told me I was being very rude and didn't believe me when I explained*." (264)

> "*I cannot see when neighbors wave, and I can see to approach them if they are outside [sic]. Hence, it seems that many neighbors believe I am 'snobby' because I do not wave back or approach for friendly conversation… The first few neighbors I have met, I have explained to them that I'm visually impaired and asked them to say hello if they see*

me outside, and to tell me who they are until I recognize their voice. But NONE of them have grasped this or acted on my request. So while I can hear that my neighbors are friendly with each other, and help each other from time to time, I remain isolated and misunderstood." (89)

Further to the above, VIPs report considerable lack of consideration from public service professionals. Some treat VIPs as though a VI is indicative of mental health problems:

"*I have had a few run-in's with teachers for my deaf and autistic grandson. Due to my blindness they seem to want to talk to me, like I'm an idiot. I can't count how many times I've reprimanded them by saying that I don't appreciate being talked to in that manner, and besides I also hold a Master of Education degree in Special Education, and I live with a child with disabilities, so don't talk to me like I'm stupid*." (21)

"*People trying to talk to me as if I am remedial or disregard my input as a parent and let my 11-13 yr old play a role as an adult able to make decisions*" (42)

Some VIPs report experiencing troubles with police officers:

"*On a couple of occasions I have found the street blocked by police when trying to get to a tube station. When I ask what is going on one said 'are you blind?' in a very offensive way. When I said 'yes' he pushed me away. On another occasion I was trying to go shopping on Oxford Street but was forced by police into Hyde Park because there was some kind of event going on.*" (92)

"*One VIP had even been arrested: 'the police never understand, I was sober reading a ATM machine very closely. The officer thought I was toast and arrested me for public intoxication.'*" (311).

Two of the VIPs reported concerns regarding vehicles parked on pavements. One of which describes attempts to report this to the police:

"*I have had some contact with the police regarding dangerous parking outside my previous address. The attitude from the police and traffic wardens (all bar one officer) was that pavement parking wasn't a problem as any 'normal' person (that's a direct quote from a police officer) would walk in the road around cars. Also, none of the officers*

(except one) who visited my address in the two years that the problem was going on identified themselves by name." (62)

Thankfully, for the above, the issue was resolved:

"*Eventually one female officer visited after two years, told me who she was and gave me her contact details… listened to the issues I'd been having, agreed that it was not acceptable and needed to stop, and then ticketed the offending cars… They never did it again*." (62)

Even in medical settings, where VIPs should feel most understood, they occasionally experience staff that do not take into account their abilities and their impairment:

"*Many do not know how to work with people who cannot read an eye chart*" (19)

"*Several years ago I was told by an ophthalmologist… that I should not go there again for yearly check-ups as 'I want to keep this clinic for people who can be treated*'". (92)

One VIP reported experiencing a derogatory behaviour when visiting her local dentist:

"*My dentist told myself and my children to wait outside the surgery buildings because I had my guide dog with me. I refused and complained. Now we all go inside but its [sic] awkward. And unable to find another NHS dentist so can't avoid going*" (332)

Some VIPs note that some medical staff are lacking some communications skills: "*they add smiling 'you will lose your eyesight'*" (8); "*I think the ophthalmologist who broke the bad news to me did not have advanced communication skills*" (39).

Many of the VIPs describe their pride in maintaining some level of independence. A key factor in achieving this is successfully navigating the public transportation system. Some VIPs, however, explain some of the challenges they face:

"*I once had a bus driver refuse my disabled bus pass because he stated that I was not disabled and that I was lying*." (68)

"*Bus drivers refuse to tell me where my stop was, put me off at the wrong stop without telling me, divert the route without making me aware – the list goes on!*" (62)

"*On more than one occasion, when asking the driver what number bus they were driving they would refuse to answer and tell me to look at the sign. I'd try to tell them that I couldn't read it, but they did not seem to care*" (55)

One VIP describes an ordeal on the London underground:

"*I frequently got trapped in Underground ticket barriers when using my freedom pass because ticket staff had switched off access to disabled people. This only stopped when I complained several times to London Underground Limited and threatened to sue them under the equality act. They claimed it was a measure to trap people fraudulently using a disabled person's pass during rush hour, but it actually prevented disabled people from validly using our cards."* (92)

One VIP explains how he has given up going to church:

"*I have a very strong Christian faith but have recently stopped going to church. More often thatn [sic] not, I will go to church and not a single person will come up to me and say hello. I realize this is because people are uncomfortable around blind people, but one would think that at church this might be a little different. Actually I am engaged by others more at the gym I go to than at my church*." (290)

Despite this positive endorsement for the sociability and higher levels of acceptance amongst gym-goers, the same VIP described an instance in the gym where another gym use became threatening, despite his impairment being overt due to the use of the cane:

"*I did have an incident at my gym once. I walked up to a set of weights trying to make out the numbers on the end. I did not know there was a lady standing very close by (she made no sound). She must have thought I was too close to her. She screamed at the top of her voice 'what the hell is the matter with you. Can't you see I'm right here?' I was*

carrying my cane as usual. I humped back and began apologizing profusely. I told her I was blind and that I was sorry. She interrupted me and said 'You can't be that blind, I'm not that small.' Then she made a gesture with the weight she was holding like she was going to throw it at me. Instinctively I dropped my cane to prepare for the blow. Just as she started to throw it, she stepped aside and slammed it into the weight rack, then stormed off." (290)

3.4.1.2.2 Abuse

Some of the VIPs mentioned they have experienced abuse in many forms, some have experienced verbal abuse from strangers on the street: "*Abuse shouted, Told I didn't look very disabled*" (90); "*verbal abuse is not uncommon*' (113); "*people yell at me I'm not blind*' (280); "*comments shouted when guide dog relieving itself*" (330).

When VIPs are not overt with their condition, and it's invisible to the general public, they open themselves up to a greater risk of verbal abuse, and potential physical abuse: "*I've been verbally abused when I've bumped into people*" (193); "*With an invisible disability people can get impatient as they see it as dithering*" (185).

Two of the VIPs reported experiencing abusive behaviour from cyclists:

> "*The most aggressive people are cyclists, usually when breaking the law riding on the footpath, jumping red lights or going the wrong way down one-way streets. They shout foul-mouthed abuse if I get in their way or don't jump out of their way fast enough. A couple of years ago I was hit by a cyclist jumping both red traffic lights and a Pelican red light. I was thrown several feet by the impact, and he broke two ribs. The hospital doctor assumed it had been a motor-cyclist who hit me until I explained."* (92)

> "*I was called a fucking spastic in front of my 3 year old when I didn't move out of the way of a cyclist speeding down the pavement that I hadn't seen or heard*." (156)

Another VIP reported experiencing the wrath of a mother:

"*Often both my husband and I receive abuse and unfriendly treatment by people where we live. Just this morning we were walking with our guide dogs (we both have guide dogs) in single file along a narrow path. Suddenly we heard a woman shout 'Matthew! Get back on the path!' We heard a child say something and as the woman passed us she said 'For god's sake, get out of the way, he's just a kid,' We didn't even know he was there obviously until she spoke, and plainly she either didn't care that a guide dog means a person can't see others, or didn't care.*" (62)

Some of the VIPs reported some instances of physical threats, and abuse: "*Threatened physically in street [sic]. Punched once*." (90); "*Severely bullied, abused, intimidated & assaulted @ school*." (164). These instances can leave VIPs in a "*constant fear for personal safety*" (330):

"*There is always the fear of being mugged when you are in the street. Someone in my village always deliberately walks into me in the street but they never speak*." (133)

One VIP described how her previous partners have disbelieved her condition and would test her using highly dangerous, and cruel, methods:

"*Various boyfriends have either doubted my visual impairment (I am very independent) or in some cases deliberately put obstacles or dangers in my way to see if I would be come injured (for example, walking me into things when guiding me, or leaving sharp objects like razors or knives in places where they know I would be feeling around for things)."* (62)

Another VIP recounts an instance of bullying:

"*When I was in high school, I attended a public school and had to take a school bus to get to school. The school bus stop at the corner of my street was such that at least one child would be in each seat, and none of them would let me sit beside them. So I had to stand up all the way to school. This was very humiliating. I decided to try to 'solve' the problem by walking to the bus stop that was one ahead of mine so that I could get a seat. When I did this I was bullied by a boy who physically assaulted me. He grabbed me and threw me to the ground, jumped on top of me, and began strangling me around the neck. The other kids did not intervene. The bus arrived and all the other kids boarded the bus, leaving me with my attacker still strangling me in full view of the bus driver. The bus driver did not get out to intervene, simply drove away. It was very likely that I could have been killed by the strangling, except that*

> *I was able to get one of the boy's fingers in my mouth and bite it… I was so traumatized by the incident that I* ***refused*** *to ride the school bus again*." (89)

A few VIPs reported experiencing financial abuse, with taxi drivers occasionally taking longer routes to their destination to milk a larger fare: "*a 15 minute drive took 45 minutes*" (163); "*cab drivers try to take advantage of my not knowing where my home is*" (43). Further to this exploitation, some taxi drivers flout the disability discrimination laws and attempt to extort additional payments from guide dog owners for carrying the guide dog: "*charged more for using taxis because of my guide dog*" (62); "*Taxi tried to charge me extra for dog*" (143).

One VIP described how he was the target of an abusive partner, who he felt lulled him into a relationship under false pretences. Soliloquizing over how all a VIP wants is to be in a loving relationship, but can be the target for malicious abusers:

> "*I met and married a British woman, and moved from the US to the UK for 10 months. To my horror, I found out that the woman lied to me about many things, was taking advantage of me financially, and her behavior escalated to domestic violence. My observation is that people who are visually impaired or blind are 'easy targets' for unscrupulous partners because finding a partner who accepts and understands the disability is difficult*" (89)

3.4.1.2.3 Disclosure of Visual Impairment

Many of the VIPs reported a change in the way they were treated within the workplace when they 'came out' as VI: "*was made redundant after an eye operation*" (100); "*It was made clear to me that I would not be welcome back after my initial time off [after sudden vision loss]*" (62).

Some describe a perception that employers employ underhand tactics to elicit a resignation from their VI employees – constructive dismissal: "*Some managers liked to assign me the worst tasks all the time instead of everybody taking turns*" (102); "*I reduced my work hours from 40 to 30 because physically strained/tired. Workload did not change even though hours different*" (11).

Some have found that when they do manage to retain employment, they become stagnant. Unable to achieve promotion: "*I suspect it has impacted upon promotion*" (185), whilst one VIP reported that he was demoted when he stopped driving in the dark: "*the company I worked for demoted me due to not being available during all times of day to train new employees*" (245).

Although, some struggle to even obtain gainful employment. Some VIPs reported challenges getting through the interview stage when their VI was apparent, even though on occasion a telephone interview was very successful:

> "*I spent 20 years as a computer programmer and consultant. Whenever I interviewed for a new position as a consultant, I have experience [sic] the same thing over and over. I would have a phone interview and the person would say 'oh you are just what we are looking for. Come in for a face-to-face interview. It's only a technicality. We really want you to work for us.' Then I went in for the interview, I could tell the interview was over when they saw the white cane. The interviewer did not even bother to ask me very good questions. There was always a list of skills they wanted starting with the most important… No one ever had all the skills. When they called to tell me I did not get the job, they would pick one of the really obscure skills and would say they really needed someone with this and that… The first time this happened, I didn't think much about it, but after it happened several times I began to see a pattern.*" (290)

Another VIP reported being treated like a timewaster by an interviewer:

> "*I have always had trouble finding employment and I could fill a book with examples of mistreatment. One example, I was told by the interviewer that 'my third eye' (monocle) on my reading glasses would be too disturbing for clients to see so I couldn't get the job. Another time I was told by the interviewer to make it quick because she had real people to interview and that she had no time to waste*." (199)

3.4.1.2.4 Accommodations and Privacy

VIPs reported numerous instances where simple accommodation/adaptation requests were not acted upon:

> "*I have had numerous problems with my local GP surgery, including correspondence arriving by letter concerning a confidential matter that I specifically asked them not to write to me about as a sighted member of my family would get to see the letters when they read my post to me (and to add insult to injury, on the letter that did arrive concerning this issue 'do not write to patient, telephone only!' was written on the top of the letter!)*." (62)

In addition to this lack of consideration of a simple request by the above VIP, they have had further reasonable requests, such as accessible braille medication labels, obscured by pharmacy staff: "*printed labels stuck over the braille on the box for my medications (despite being asked not to do this)*" (62).

There were several issues raised by VIPs regarding the new technology installed at GP practices in the UK: "*I do occasionally need to get a friend to fill out all the paperwork. And sign in on the screen thing*" (109); "*GP reception has a board telling you when your appointment is ready and which room to go which needs reading – no good when you can't see*." (133). Some of the VIPs reported asking the receptionist to advise them when their GP was ready to see them: "*they didn't*" (133); "*they forget and I am just left sitting there*" (174).

Several VIPs also reported that staff in ophthalmic hospitals do not consider their accessibility needs: "*I've experienced doctors and nurses saying 'follow me' and walking off quick*" (118); "*being told to go and sit and place your chin on the equipment when you can't see to do it is a bit thoughtless*" (195). One VIP explains how his wife guides him during visits to the eye hospital, yet staff questions her presence:

> *"You go in to take an eye test, and they just tell you to take a seat, don't guide you and then question the presence of my partner when she guides me – sometimes telling me she is not allowed in."* (192)

Further issues were highlighted from many of the VIPs regarding difficulties experienced in the education sector:

> "*Before my health and eyesight worsened, I was working full-time and taking master's level courses in computer science at a university in the evenings. One professor put all his lecture notes on an overhead*

> *projector. When I asked him if he could please print up a copy of his notes since I was unable to see the overhead projector, he refused. Even after several requests, I ended up having to hire an attorney to force him to comply with my request for accommodation. This was so distressing that I ended my attempt to get an MS degree in computer science*." (89)

The lack of adaptations in some educational environments is a concern for many of the VIPs: "*The request for Braille on standardized texts was rarely met*" (132); "*I was not able to access a subject material until week ten of a 14 week term*" (163); "*Teachers often forget to create a larger print copy*" (302).

Another situation where, in order to have the same opportunities as sighted people, VIPs often require some accessible adaptations within the workplace. Unfortunately, these are not always forthcoming:

> "*I was working near a window and when the sunshine was really bright it caused eye watering and pain. Eventually blinds were fitted, but only after five years*." (76)

Lack of adaptations can be harmful to the VIP, as described in this example:

> "*When I took the new job, I was given a desk and chair that were NOT adjustable. As a result, I had to sit in a contorted position to see the monitor, with my head turned to the left so that I could see the screen with my better right eye. The net result was that I developed severe chronic neck pain which required several months of intensive physical therapy. But still no accommodations were made, and so I was forced to resign*." (89)

Some VIPs reported issues with accessibility of forms, both for accessing employment as well as benefits: "*interview information not being provided in an accessible format*." (156); "*forms ten miles long are not very 'blind person friendly'*" (36). The following VIP explains how they had to persist in order to receive accessible forms from the government to amend their benefits:

> "*I recently changed from incapacity benefit and had to ask 10 times for a form in braille. It took 29 weeks & then I was not permitted to fill it in in my chosen format but had to read out my answers to a stranger!*" (51)

Another situation where VIPs report a lack of accessibility is within the church: "*No accessible prayerbooks, no visual descriptions*" (274); "*no large print or braille bulletins for the service*" (89).

Some of the VIPs note how venues are very good at accommodating some physical disabilities, such as those involving a wheelchair. They note, however, that sensory disabilities are often not understood, or not considered:

> "*Social events cater for the wheelchair disabled but rarely the sensory disabled. Braille is rare to find. Lighting is poor. Venues poorly laid out. I prefer to do my hobbies at home because socializing is like a battle against my eyes*." (332)

When there are disabled facilities, they are not always usable and staff can display hostility at being asked to provide some assistance:

> "*I attended a pub karaoke night a couple of months ago. It was a Saturday night and the pub was very busy. To get to the ladies toilet was difficult due to the crowds, and part-way through the evening my friend noticed a disabled toilet near to where we were sitting. However when I got there I found the door locked. I went to the busy bar and asked for the key. On opening the toilet I found the light in the toilet was switched off and could not find the switch. Some lads playing pool nearby came to my assistance but couldn't find the lightswitch either. I put a note on the bar, as the staff were very busy. I politely asked could the disabled toilet light be switched on and the door be left unlocked. The manager came over to my table 5 minutes later and angrily retorted that the door would remain locked. She was extremely rude and despite me explaining about my difficulties and my cane being visible at the time, she refused my request.*" (319).

3.4.1.3 Environmental Challenges

3.4.1.3.1 Transportation

Some VIPs reported the inability to drive affecting many facets of life. Some who were able to drive before their condition worsened, then lost their driving license and their employers re-evaluated their position, as seen earlier, plus in this example:

> "*The company I worked for decided on a reorganization when they knew I could no longer drive – this was a large part of the job but I had arranged help via Access to Work. I was put through a process that had the deck stacked against me and then made redundant. 6 months later the post I had was resurrected under another name but with the same duties*." (322)

In some areas VIPs report difficulty accessing public transport: "*living in the US where public transportation is not very prevalent, I think that a person with a visual impairment and unable to drive is at a great disadvantage*" (250). This means that to remain active reliance is placed on others, which can result in the VIP feeling like a 'burden', and can place a strain on relationships:

> "Changed circumstances because I depend on my husband now" (11)

> "*Me not driving and not being able to help out with my own and children's transportation has been a huge stressor for their dad*." (91)

There is also an apparent struggle to get friends to comprehend this and provide transportation to enable VIPs to continue engaging in social activities: "attending events is hard because of transportation" (178); "*since I can not drive I have often not [been] invited to events or cannot attend (no rides offered)*" (129). Some report that friends are not forthcoming or easy to make when they are aware that the VIP is unable to drive, and therefore not able to contribute towards the friendship to the same degree as those who are sighted: "*people are reluctant to make friends with someone who they know will always need a ride*." (306).

3.4.1.3.2 Environmental Barriers

VIPs report facing challenges due to their condition: some conditions causing VI can result in night blindness and a highly restricted peripheral field of vision, making some environments extraordinarily challenging. Often, however, these environments are the social haunts of the normally sighted:

> "*It is difficult to attend some social events, particularly late at night in dark situations (eg clubs, bars etc). Given my age group it is difficult because that is a significant part of the social scene*." (171)

Similarly, some VIPs reported concerns regarding dating due to the difficulty coping in the usually frequented environments, such as pubs and restaurants, leading to a sense of isolation: "*It is hard to meet new people as I cannot cope in low light… so I am nervous to say yes to an invitation… I sometimes feel isolated…*" (276). This particular VIP expressed concerns about dating due to being negatively judged: "*I am worried no one will want to date me because of my RP*" (276).

The neighbourhood environment is also important to the VIP, with pavements occasionally being blocked causing mobility challenges, and increasing risk of injury:

> "*Late at night, when the street lights are turned off, I have difficulty walking home, especially the night before bins are collected. I often walk into a lot of bins on my way home*." (171)

Even shopping can be a challenge, with some of the more fashionable brands opting to plunge their retail outlets into darkness to create the atmosphere they desire: "*some shops like Hollister are so dimly lit I can't use them*" (265).

3.4.2 Coping Mechanisms

3.4.2.1 Positive Wellbeing

VIPs reported a sense of pride in displaying a level of normalcy. Maintaining some independence and showing off ability, rather than being disability focused:

> "I always maintain dignity and never let things bother me too much… I also show people that I am independent and can do most things for myself." (103)

> "*I can still sing or do other activities that are valuable. If normal people can do it, I can do it too (only the method is different*)." (130)

Being ability focused and doing one's best enables realistic expectations to be met. By also accepting that it is reasonable to make mistakes or to have

accidents, the VIP is demonstrating a greater level of psychological flexibility when accidents do happen:

> "*I am a naturally optimistic person. Determined and independent. There are many situations I find difficult or challenging because of my eyesight but I do the best that I can. If I knock or bump into something I try to see the funny side, or accept that it is part of my condition*." (184)

One VIP had an interesting insight into the stigma they experience, reframing the situation: "*I am not stigmatized because I have a disability I am stigmatized because of others' attitudes towards disability*" (224).

3.4.2.2 Humour

As the VIP above highlighted, often it is healthy to have a sense of humour about the quirks of the condition. This seems to be a commonly used coping mechanism amongst VIPs: "*I have a really good sense of humour. When I feel like I'm the victim of stigma I try to laugh it off as much as I can*" (132); "*A sense of humour is essential*" (119).

Some VIPs report that whilst humour helps them to cope, it can also relax others who may be uncertain how to react when meeting a VIP:

> "*I am very comfortable with my visual impairment, and I don't mind telling people – what makes me uncomfortable is when others become uncomfortable upon finding out and they just don't know how to react to it. I always try to make light of it and maybe even make a joke about it to try and show them I am okay with it…*" (68)

3.4.2.3 Education

Some of the VIPs reported a general lack of understanding amongst the sighted population and therefore opt to take on the role of an educator. Educating the curious and naïve; challenging stereotypes:

> "*I always find there is something underlying stigma and discrimination – such as misunderstanding, assumptions, fear – I frequently use my own communication skills to find out what is underlying it and kindly challenging that…*"(39)

> "*The major issue I encounter is people trying to figure our what the white cane is for (some think it is a ski pole). Where possible I educate them in a friendly/non-threatening way. I especially like to help children become familiar with the cane, how it works and let them try it so they will be more comfortable with visually impaired folks they meet later in life*." (148)

A few VIPs also reported using new media to educate a wider audience through blogging about their lived experiences: "*I can do a good job of communicating what it is like to be visually impaired in writing – as on the internet*" (89). Others may take a more active role promoting VI related matters in the local community. One VIP explains how she used her knowledge and experience to educate local authorities and champion change, which will have a benefit for many within her local community:

> "*I recently successfully advocated to have the city change a design of items built all over the city that are hazardous to blind and visually impaired people. The city will fix one in my neighbourhood and have changed their design for all future ones across the city*." (274)

3.4.2.4 Concessions

Whilst personal resources are valuable for facilitating coping with a VI, there are some concessions available to make life a little easier for VIPs. Several VIPs reported excellent treatment when travelling through airports: "*Airlines have taken exceptional care at times*" (90); "*avoiding lines at airports, priority boarding*" (250). In some countries VIPs are also entitled to free bus travel: "*I use a free bus pass*" (184); "*the only benefit of registering has been to get a free bus pass…it's hugely beneficial to me in getting to and from my children's school*" (245).

Similarly to concessionary travel, and preferential treatment at airports, VIPs are often able to park in more accessible locations: "*A 'disability' parking tag allows me to get good parking at public locations*" (249). Entertainment venues often also have concessionary rates and favourable seating options for VIPs: "*Front row seats at a BBC TV show filming*" (82); "*Theatres very helpful 2 for 1 tickets so carer goes free*" (133).

3.4.2.5 Maladaptive Coping Strategies

Above VIPs have discussed methods of coping with VI. Some methods, although the VIP may be quite content with them, could be deemed to be maladaptive coping mechanisms, such as avoidance.

With some forms of blindness being an invisible disability, it is easy for VIPs to hide their disability, or to refrain from making their disability overt: "*I doubt that anyone in my immediate neighbourhood has any idea I'm registered blind or even that I may have a sight impairment*" (193); "*I conceal it to look NORMAL*" (115); "*I kind of 'hide' it*" (91); "*I use my 10 degrees remaining vision to 'fake' it in daily life*" (53).

Many reasons are given for concealing a VI. In some there is a sense of shame or embarrassment: "*I don't want them to see me*" (43); "*I don't want other people to think that I'm weak*" (236). In others, they hide it due to frustration at having to try and explain their condition to others: "*it becomes so tedious to constantly have to explain what KC is…*" (98); "*it's easier than trying to explain RP sometimes*" (267).

One VIP reflects upon nearly 10 years of hiding their condition:

> "*I didn't actually 'come out' as VIP until the day that I was registered blind. I had struggled for nearly a decade prior to that. It took me years to regain my confidence and be comfortable with my condition but my registration was a bit of an epiphany. I just thought that I can't carry on like nothing is wrong anymore I need to help myself. I had been very concerned about peoples reactions and the longer I left telling them the harder it got to bring it up*" (332)

4. Discussion

This study was designed to establish whether there was a link between stigma, discrimination, visual impairment and QoL. In order to achieve this three scales were used, two quantitative and one mixed-methods. Two open-ended qualitative questions were also posed. During the data collection phase there were some difficulties with participant recruitment, in particular with participants dropping out due to the sheer volume of questions posed. In order to streamline the study two questions, regarding how participants felt that their visual impairment differentiates them from others, and how they feel about using a cane as a mobility aid, were removed from the study. This data was utilised in a small qualitative component of this study and will be used to enhance the depth of understanding within this discussion. The remainder of the study was focussed on the research question posed:

Does Stigma and Discrimination affect the Quality of Life (QoL) of the Visually Impaired (VI)?

To answer this question three scales were used. To measure experienced stigma the Discrimination and Stigma Scale (DISC) was revised to cover a VI (DISC-VI) as opposed to Mental Illness. To measure anticipated stigma the Questionnaire on Anticipated Discrimination (QUAD) was revised to cover a VI (QUAD-VI). To measure QoL the WHOQOL-BREF was used. The results demonstrate that there is a significant relationship between both experienced and anticipated stigma and QoL in VIPs. Analysis of the WHOQOL-BREF found that the facets most predicting a better QoL are, in order: Self-Esteem; Positive Affect (mood); Dependence on Medication or Treatment; Personal Relationships; Financial Resources; and Transport.

To explore further how the aforementioned facets of the WHOQOL-BREF are related to the impact of stigma and discrimination on the QoL of the visually impaired we shall review discuss the findings below: Starting with a review of the demographic properties of the studies; psychometric properties of the three

scales used; before exploring the findings from the remainder of the study, using the qualitative findings to give meaning to the quantitative results.

4.1 Demographic Considerations

To enhance understanding and interpretation of the proceeding discussion, we shall first consider how representative the sample is of VIPs.

4.1.1 Marital Status

Within this sample those married and living as married equate to 55.5% of the population, with single people making up another 31.3%. The married/living as married respondents reflect United Sates Government estimates of adults living with sight loss. Single people, however, appear to be over-represented within this sample, whilst those reporting being divorced or widowed are under-represented, in comparison with US estimates (Blackwell, Lucas, & Clarke, 2014).

4.1.2 Employment Status

A larger than expected proportion of the sample were in employment, be it full-time, part-time, or self-employment. At 41%, however, this is not dramatically different to the UK estimates of 33% of working age VIPs being in employment (Action for Blind People, 2014). When we consider this as a study with an international population, an explanation for a higher proportion of employment could be differences between countries. For example, in Canada they consider the level of the legally-blind who are unemployed to be low, yet report 46.1% of legally-blind people of working age are in employment (Benoit, Jansson, Jansenberger, & Phillips, 2013).

4.1.3 Geographic Location

The majority of participants were from the UK, followed by those from North America. The World Health Organisation suggests that the majority of people with a VI live in developing countries (WHO, 2014b). This is a limitation regarding the representative nature of the data collected, due to the methodology used. It is less likely that people living in developing countries will

have the equivalent access to the Internet as people living in developed countries. It is possibly even less likely that those who are blind to the point of light-perception only, or unable to read, will have access to adaptive technologies to enable participation in the study. It is, however, surprising that there were no participants from India, with approximately 243 million people having access to the internet (The Times of India, 2013).

4.1.4 Diagnosis

In this study 59.9% of participants had a diagnosis of Retinitis Pigmentosa (RP) and related syndromes, whilst 11.5% had a diagnosis of Keratoconus. Neither of these two conditions represent the main causes of blindness, those being: Age-Related Macular Degeneration (AMD); Cataracts; Glaucoma; and Diabetic Retinopathy (Action for Blind People, 2014). Whilst the above is for a UK population, a review of the literature suggests these are the most common causes of blindness across the globe, along with refractive error (Bourne, Stevens, White, Smith, Flaxman et al., 2013; Pascolini & Mariotti, 2012; Stevens, White, Flaxman, Price, Jonas et al., 2013; Thylefors, Négrel, Pararajasegaram, & Dadzie, 1995). Refractive error is less common in developed countries due to the availability of corrective lenses. This is a limitation in this study, caused by the method of data collection and participant recruitment. As discussed in the method section, participants were recruited through Facebook and LISTSERV support groups, largely populated by UK and North American individuals. A large proportion of the support groups also appear to be targeted at people with a diagnosis of RP. A small number of the groups were not specifically disorder-targeted, but were for general blindness. It is likely that the 18.1% of participants with “other” causes of their VI were recruited through these groups. It is uncertain why AMD and Diabetic Retinopathy VIPs are so under-represented within this study.

4.1.5 Status of Visual Impairment

Current UK estimates of the split between those registered blind and partially sighted is 50:50 (Action for Blind People, 2014). Within this sample the proportion of those registered as blind is 50%. On the face of it those registered partially sighted are under-represented. It is not clear whether this is,

or is not, the case. The difference could merely be a semantic one as those awaiting registration, or whom opted out from being registered, are somewhere on the VI spectrum. It is, therefore, not possible to tell whether they are registered blind, or making up the remainder of the partial-sighted population.

4.1.6 Gender

In this study there was a gender split of 2:1 (F:M). This matches UK estimates (Action for Blind People, 2014). It has been shown that as few as 4% of those with a medical condition engage in online peer support groups (Van Uden-Kraan, Drossaert, Taal, Smit, Bernelot et al., 2011). As could be expected, female participants, who are in early to mid-adulthood, dominated this study. This is in-line with research identifying that females are more likely to use Facebook support groups (Shpigelman & Gill, 2014). It is not surprising, as the overall demographic of social networking sites are skewed toward young and mid-adulthood females (Madden & Zickuhr, 2011). This makes it more challenging to access males and garner their opinions, as they are not as readily accessible as their female counterparts. It is not known how many VIPs engage with social networking support sites, but given the additional challenges of using a computer with visual impairments, there could be other views that we have not had access to.

4.2 Psychometric Properties

4.2.1 WHOQOL-BREF

The WHOQOL-BREF has already been validated on cross-cultural samples (Skevington et al., 2004b), providing confidence in its utility in this cross-cultural study. This study involved participants from across the globe, albeit predominantly developed countries. All of the participants had some form of visual impairment, whether they are registered blind or partially sighted. As there were no sighted participants included as a control measure, it is not possible to state whether the WHOQOL-BREF can distinguish between VI or non-VI individuals. The WHOQOL-BREF has been shown to distinguish between ill and non-ill populations in the past (Skevington et al., 2004b) but this analysis fell outside the scope of this study. No test-retest analyses were

performed during this study, although the measure has been shown to be adequate in test-retest analyses (Min, Lee, Kim, Suh, & Kim, 2000; O'Carroll, Smith, Couston, Cossar, & Hayes, 2000; The WHOQOL Group, 1998). The present study found that the internal consistency reliable was excellent (>.9) and provides confirmation that the WHOQOL-BREF is a suitable tool for measuring the QoL of the VI population. All of the domains had very good internal consistency (>.8). This is unusual as the social relationships domain is often lower than the other domains due to there being fewer facets within that domain (Colbourn, Masache, & Skordis-Worrall, 2012; Skevington et al., 2004b). In this study social relationships had the highest alpha. Again, this study confirmed the findings of Skevington et al., (2004b), with all items of the WHOQOL-BREF correlating most strongly with its parent domain. There are current disagreements within the research over the domain structure of the WHOQOL-BREF, with both a 4 and 6 factor structure being found to be valid (Castro, Hökerberg, & Passos, 2013; Skevington et al., 2004b; Trompenaars, Masthoff, Van Heck, Hodiamont, & De Vries, 2005). Neither a 4 nor 6 factor structure was confirmed within this study, although a 5-factor structure was identified.

The first factor consisted of psychosocial items, suggesting that within the study population there is an interrelatedness between self-esteem, spirituality, positive affect, and the social relationships items (personal relationships, sex, and practical social support). Interestingly the physical environment is incorporated into this factor suggesting that environment impacts upon the social life and positive affect of this population. As this population consists wholly of VIPs this could be due to the environmental barriers to socializing that are discussed in the analyses above.

The second factor is a physical/environment factor. The factor consists of items relating to the ability to get about and work (Activities of daily living, working capacity, mobility), and very related items regarding accessibility to recreation and education.

The third factor incorporated psychophysical items; again these could all be related due to the impact of sleep and energy on negative affect, and memory.

Body image falling within this factor is interesting, although cannot be explained within the context of this study.

The next factor is made up of three environment items, whilst the last factor is made up of two physical items, linking together pain and discomfort, and medication.

These differences do not invalidate the WHOQOL-BREF as it is expected that different cultures, or groups, interpret the items in different ways (Skevington, Gunson, & O'Connell, 2012). The above demonstrates that the WHOQOL-BREF is a valid and reliable measure for use in both epidemiological studies of VIPs, as well as with individual clinical patients.

4.2.2 DISC-VI

The DISC measure is relatively new and was designed to measure the level of discrimination and stigma experienced in people with mental illness (Brohan et al., 2013). This scale was adapted to fit the needs of those with a VI. Internal consistency reliability analysis demonstrated that the DISC-VI is an acceptable tool for measuring discrimination and stigma in VIPs and echoed the results of Brohan et al., (2013). Exploring correlations between items and domains, all items correlated most with their own domain, excepting two items. "Have you been treated unfairly in making or keeping friends?" and "Have you been treated unfairly in your personal safety and security?" were more correlated with Overcoming Stigma than Unfair Treatment. The differences in the correlations are not large and could be caused by the large number of items falling within this domain, or the need for a larger sample size. Factor analysis was not performed in the development of the DISC due to sample size (Brohan et al., 2013). In this study an exploratory factor analysis was performed but fell short of the recommended sample size (Tabachnick & Fidell, 2012). The structure of the DISC-VI could not be confirmed and therefore within the analyses the individual items were used, as was the total of the entire scale, but the 4-domain structure was not. Other than the domain structure of the DISC-VI, the measure is acceptable for use for this population.

4.2.3 QUAD-VI

Similarly to the DISC, the QUAD is a relatively new measure designed to evaluate the anticipated discrimination in populations with a mental illness (Gabbidon et al., 2013). Psychometric analyses were performed to assess whether a revised version of the QUAD is valid for use with a VI population. Internal consistency reliability was excellent (.9), marginally better than that reported within the initial development of the QUAD (Gabbidon et al., 2013). The initial developmental study demonstrated that the QUAD has good test-retest reliability, although this was not assessed within this study for the QUAD-VI. There is no domain structure for the QUAD. An exploratory factor analysis showed three factors: one encompassing friends, family, and community (inclusive of police officers, religious leaders and housing officials); another on institutions and services; the third being work based. This deviates from the factor analysis of the QUAD measure on a mental illness population, whereby there were two factors found. Gabbidon et al., (2013) found an interpersonal/professional relationships factor, encompassing the 6 items relating to friends, family, neighbours, and colleagues. This was different to the current study, as colleagues were not grouped with other interpersonal relationships but formed a new factor along with employers. There is a possibility that VIPs have a different perception of people whom make up their local community and social circle to people with a mental illness.

4.3 Hypothesis

The findings of this study show a significant relationship between both experienced and anticipated stigma and QoL, across all domains of the WHOQOL-BREF, as well as overall QoL. This study reinforces the findings of previous studies on stigma and QoL in conditions such as chronic illnesses and HIV, whereby the actual experience of stigma has less of an impact on QoL than anticipated stigma (Earnshaw, Lang, Lippitt, Jin, & Chaudoir, 2014; Earnshaw, Quinn, & Park, 2012; Earnshaw & Quinn, 2012; Kent, 1999).

4.4 Predictors of Quality of Life

4.4.1 Interpersonal Relationships

The visually impaired in this study report a significant impact on their social lives, noting instances where friends are not sure how to behave around them once their condition deteriorates. The impairment becomes a barrier to social inclusion and can result in a sense of isolation. Even when the VIPs are included, there can be a sense of dread at the prospect of socializing in an unknown environment riddled with hazards.

This study shows that being treated unfairly by friends and family has a negative predictive value on QoL, however whilst this only impacts upon psychological and physical QoL when experienced via family members, negative treatment by friends has a broader impact, affecting, not surprisingly, social relationships QoL in addition to psychological and physical QoL. Contra to these findings, there is a positive relationship between having sighted friends, and QoL across all domains of the WHOQOL-BREF. This could be due to the sighted friends providing a supportive network, which has been shown in other conditions to help improve coping and QoL (Sibitz et al., 2011; Slater et al., 2013). Similarly, experiencing positive treatment from family members can positively impact upon environment QoL.

Participants reporting the experience of social exclusion, or being shunned, report reduced QoL in the physical domain. The extant literature links social exclusion to increased depressive symptoms (Üçok, Karadayı, Emiroğlu, & Sartorius, 2013) and therefore this finding is unexpected as we would anticipate social exclusion to be a predictor of psychological QoL. This warrants further investigation, although from comparing the qualitative responses with the facets making up psychological QoL, the reason for this finding could be due to the level of dependence on others to include the VIP. Physical QoL incorporates the facets of mobility and activities of daily living. If VIPs are being shunned by those who formerly socialised with them, took them to events, then their perception of not being able to complete tasks and be mobile could be impacted. Not unexpectedly, experiencing unfair treatment in one's social life

impacts upon social relationships QoL. Another factor predicting worsening social relationships QoL is unfair treatment during marriage or divorce. However, those who report unfair treatment in close personal relationships are more likely to report a worse QoL in all domains. Similar to the above, anticipated discrimination from friends and family have an affect across most QoL domains, whilst anticipated discrimination in dating predicts a poor physical QoL.

It was found that unfair treatment from neighbours predicted a better psychological QoL. This is inexplicable and could be caused by the large number of participants reporting that they have not experienced this at all. Only a small number reported experiencing discriminating treatment from their neighbours. This phenomenon would need more exploration to assess the validity of this finding. Anticipated discrimination from children in the neighbourhood predicts a worse social QoL, so it would be expected that a similar impact would be experienced from adult neighbour discrimination.

When the WHOQOL-BREF facets were reviewed to assess what most predicts QoL with this sample, two of the facets were personal relationships and opportunities to participate in recreation and leisure activities. This could be one reason why both positive and negative experiences with friends and family are such important factors for predicting QoL, as they can facilitate leisure activities.

A recent report found that two thirds of the British public are uncomfortable talking to disabled people, fearing they may say or do something wrong; one fifth of people aged 18-34 reported actively avoiding a disabled person. This report found that the British public actively avoid the disabled and have the perception that disabled people are less capable, more dependent on others, and are less productive (Scope, 2014). This could explain why within this study there were numerous reports of VIPs being avoided in public, or shunned by old friends. This finding supports previous findings of overt disabilities increasing the risk of social distancing (Shiloh et al., 2011). Conversely, the Scope (2014) report stated that individuals with a sensory impairment were less likely to be avoided than people with concealed disabilities, such as mental illness. Whilst

this study does not compare VIPs with any other condition, it is apparent that people with a VI do experience stigma and discrimination, and it impacts upon their QoL.

The Scope (2014) report can be used to explain the anticipated stigma experienced within the VIPs in this study. Should such a large proportion of society deem the disabled less productive than non-disabled, and are patently struggling to communicate with the disabled, these are likely to influence how VIPs experience interactions with others, and perceive the attitudes of others. We must be cautious, however, as Scope's report is based on the opinions of people within the UK and may not be representative of the views of the non-disabled in other countries.

Interpersonal relationships were heavily featured within the qualitative responses to the study. Many participants reported that they have actively been avoided when out in public, people have crossed the street to avoid them, or refused to sit next to them on the bus. Whilst this has been shown in the literature for disability, it would be expected that people with an overt disability, such as a visual impairment, are less likely to experience avoidance from the general public (Scope, 2014). The findings do provide some support to the notion that, per Goffman (1984), blindness is a stigmatizing condition that makes someone "*not quite human*" (Goffman, 1984, p. 15) who represents a danger. In addition to members of the public overtly avoiding VIPs in this study, people formerly considered friends were often reported to have drifted away. People who regularly meet for meals suddenly stop inviting the VIP. This either reinforces Goffman's concepts above, or confirms theories posed by VIPs within this study that due to lack of transportation, challenges participating in some social activities, and the perception that the VIP will be, or become a burden as the condition progresses, friends do not want to have to deal with this. Within this study there were a fairly high proportion of single people.

The qualitative responses on dating and relationships suggest that many VIPs have adopted avoidant strategies due to historic rejection experiences, or abusive partners. They avoid new relationships due to the anticipation of a repeat performance of past poor treatment. It is difficult to state the causal

factor for the normally sighted rejecting the VIPs. One possible explanation is stigma by association, which is where those accompanying the stigmatized also become objects of stigma and are deemed less socially attractive (Ostman, 2002; Pryor, Reeder, & Monroe, 2012). There is also a possible explanation within evolutionary psychology. Some of the reports from participants were regarding potential partner and parental concerns over the passing of the blindness-causing gene onto offspring. It has been suggested that all animals, humans included, are primarily interested in ensuring the longevity of their genes for future generations (Barrett, Dunbar, & Lycett, 2002; Dawkins, 1979). It is therefore possible to conclude that those without a blindness gene may perceive the reduced likelihood of their offspring being fit, healthy, and able to pass on their genes to further generations and decide that the risk is not worth taking. A limitation within this study is that we can only consider the perspective of the VIPs, therefore are unable to explore partner reactions to the impairment. As VIPs occasionally experience some negative attitudes towards their ability to have offspring, whether they are competent enough to be parents or whether they are passing on defective genes, it can explain how unfair treatment in the parental role could negatively impact upon the psychological QoL.

The above findings are not inline with the findings of Scope (2014). Although there is no comparative group within this study, VIPs still experience actual and anticipatory stigma in interpersonal relationships. We cannot state whether this is to a greater or lesser degree than other disabling conditions. A finding that was corroborated within this study was the perception of others considering VIPs rude or snobby due to their inability to see people when out and about (Bennion et al., 2012). The abilities of the VIPs within this study appear to confuse family, friends and acquaintances. This is potentially due to the difficulty that many VIPs have explaining what they can and cannot see, the difficulty that the sighted have in understanding how someone can be blind, yet still see some things. This lack of understanding how blindness can affect VIPs differently can lead to exclusion from activities that VIPs may be able to partake in, even if not fully. There is a perception of a power dynamic in friendships whereby VIPs have to try and adapt to the needs of the sighted. This could be explained through the concept of ‘stigma-power’, whereby people can be marginalized by people who want to maintain a higher position within the social

hierarchy. In research into mental illness stigma-power relationships are often covert (Link & Phelan, 2014). It could, however, also be due to a lack of understanding of how the VIP would cope in a given situation, and not have any malicious intent. Despite the possibility that it may not be malicious, or intentionally stigmatizing, the VIP may perceive this action as being stigmatizing and in-turn anticipate future discriminatory behaviour. A limitation within this study is that we can only assess the VIPs understanding of the social exclusion.

4.4.2 Discrimination in Religion

Religion intersects both the interpersonal, and the professional spheres of relationships. With the religious officials, whether they are pastors, priests, imams, rabbis etc., being professionals, and the congregation being the interpersonal/social relationships. Within this study it was found that anticipated stigma in religious settings contributed to a lower psychological and social relationships QoL. The extant literature on stigma within the church is limited, however can be explained by considering the paradoxical manner in which religion views disability. Some within religion view disability as a sign of sin: whether that be the sin of the self, or one's parents (Lowe, 2012); conversely, some view the blind as more gifted as they have enhanced abilities and perceptions (Webster, 2007).

The literature supports the concept that spirituality and personal beliefs can improve QoL of individuals with mental illness (Katsuno, 2003) and those on haemodialysis (Saffari, Palpour, Naderi, Koenig, Baldacchino, et al., 2013); or, help to moderate depressive symptoms in people with HIV (Chaudoir, Norton, Earnshaw, Moneyham, Mugavero, et al., 2012) and heart failure (Sacco, Park, Suresh, & Bliss, 2014). Whilst religiosity is not always associated with a better self-reported QoL, it can be associated with factors that improve QoL, such as mental health and social functioning (Heydari-Fard, Bagheri-Nesami, Shirvani, & Mohammadpour, 2014). In this study, however, the findings suggest that the anticipation of being stigmatized can impact the psychological wellbeing of VIPs, and therefore as some VIPs attend church for socializing, there is also an impact on social relationships. The qualitative findings support the notion that some aspects of the church still deem disability, and VI, as a disease of the

sinner, that can be cured through prayer and religious healing. This could further add to the psychological persecution and shame of the VIP for not being a strong-enough believer to be cured. Those who reported these behaviours from the church, and religious leaders, demonstrated some scepticism in the healing abilities of the church. There were further reports of social isolation within the church community, being shunned by others. This goes against what most would deem the core concept of religion, and the preceding 'golden rule' of "do unto others as you would have them do unto you" (ancient tradition).

4.4.3 Welfare/Benefits, Unemployment, and Employment

Within this population it would appear that people who deal with benefits or welfare staff report a lower environment QoL. Unexpectedly, even when people report favourable treatment from staff in welfare services, the QoL is still impacted. The likely reason for this is the environment QoL domain encompasses facets such as financial resources; home environment; opportunities for acquiring new skills and information; and participation in leisure activities. Being on benefits means that VIPs are likely to be unemployed, or in a lower paid job role. As such, the funds may not be available to partake in some further education or skill building courses, some leisure activities could be out of reach, financially, and it is possible that the home environment is not ideal for the needs of a VIP. Transportation could also be impacted if housing in a less well-connected part of town is more affordable. The finding that environment QoL is impacted is not novel, and supports evidence that unemployment can increase stress; increase negative health consequences; and, due to financial constraints, reduce the environment and overall QoL – becoming worse the longer the unemployment continues (Worach-Kardas & Kostrzewski, 2014). Being on welfare benefits was not highly discussed within the qualitative findings, although many discussed that inaccessibility of the forms for VIPs and the difficulty experienced when requesting forms in an accessible format. It is not possible from the current findings to assess any causal link between the experience of inaccessible forms for VIPs and stigma.

Research has shown that those with a visual impairment receive more positive, less over-protective, social support when they are employed. This can result in experiencing less anxiety symptoms and is linked to improved life satisfaction (Cimarolli & Wang, 2006). In this study a marginally higher than expected proportion of the participants reported being employed. Unexpectedly, unfair treatment when looking for work is a predictor of a better QoL. This could be due to the increased level of empowerment having eventually found employment, in spite of experiencing unfair treatment. People may be more likely to experience discriminatory treatment if they are actively looking for work, than those to whom this question is not applicable to, and who do not work for reasons of disability or lifestyle choice. Struggling to maintain employment and stopping oneself from applying for work have similar effects, albeit on psychological and physical QoL. Physical QoL incorporates the facet of work capacity and activities of daily living, whilst psychological QoL incorporates thinking, learning, memory and concentration; self-esteem; and, positive and negative affect. As discussed above, employability can impact upon stress and feelings of anxiety; and, being employed is associated with better QoL and improved psychological wellbeing (Cimarolli & Wang, 2006; Worach-Kardas & Kostrzewski, 2014).

Anticipated stigma from work colleagues appears to impact upon different aspects of life, with this being a predictor of poor environment QoL. One of the biggest predictors of poor environment QoL is anticipated stigma from friends. Work colleagues could be incorporated into a broader “social network” category: a group of people you spend much time around, and with whom you are likely to attend recreational activities, socialize with.

Many of the VIPs within this study reported numerous instances of being judged incapable once their disability was discovered. This, in some instances led to a VIP giving up looking for work. Whilst it has been noted that in Britain those with a disability are more likely to report being unfairly treated within the workplace, many do not perceive this as being related to their disability. Potentially due to the covert methods used to avoid discrimination laws (Fevre, Robinson, Lewis, & Jones, 2013). In Canada the perception of stigma within the workplace has resulted in low rates of employment within the legally-blind

population (Benoit et al., 2013). It is estimated that 90% of employers in the UK perceive the employment of VIPs to be either difficult or impossible (Baker & Simkiss, 2004). This could account for some of the reported experiences of the VIPs in this study, whereby they have either been fired for not being able to drive, been made redundant, have been deemed un-promotable, or have perceived themselves as being constructively dismissed through an unfair workload or not having reasonable adaptions made to the workplace to enable them to continue within the role.

It has been found that some employers are unaware of schemes, such as the UK Government's Access to Work scheme, that helps to fund adaptive equipment, taxis to and from work, and other required adaptations to ensure that people with disabilities have an equal opportunity for employment. It has also been found that employers who are experienced in employing people with a VI are less discriminating in employing other people with a disability (FMR Research, 2006). This lack of awareness of the availability of support for employing disabled people could provide some explanation as to why some participants reported negative feedback during the interview stage, or following a positive telephone interview, became repellent as a candidate. A limitation within this study is its international nature. Had this study been focused on one particular country then legal implications and protections could have been explored; however, as this study involved VIPs from multiple legal jurisdictions this was not feasible and would have resulted in a confused discussion.

4.4.4 Health Professionals

It has been noted that some ophthalmologists can lack empathic communications skills and quite harshly advise people that they are going blind, with very little additional detail (Hayeems, Geller, Finkelstein, & Faden, 2005). This finding was corroborated by this current study, whereby people reported ophthalmologists who were smiling whilst advising them they would go blind; and made them feel like a timewaster for attending with an incurable eye condition. As with other findings in this study, we have to consider only the perspective of the VIP, therefore cannot comprehend what the ophthalmologist is thinking or feeling at the time they advise someone that they are going blind.

This is potentially due to the ophthalmologist being ill-equipped to deal adequately with communicating bad news to his patients, or his professional frustration with there being no treatment options available (Brown, 2012). The quantitative findings in this study suggest that unfair treatment by the medical profession in general is a greater predictor of poor QoL than unfair treatment by ophthalmologists alone, with both physical and environment QoL being affected by experienced stigma from health professionals. Anticipated stigma from health professionals appears to have a broader impact on predicting QoL in all domains: physical, psychological, social relationships, and environment. This supports research into the impact of anticipated stigma by healthcare professionals in Irritable Bowel Syndrome sufferers (Taft et al., 2014).

A recently published clinical review highlighted the challenges that VIPs face when they meet health professionals, laying out a list of tips for improving healthcare for VIPs, including: ascertaining the level of impairment; describing what is happening during the consultation; speaking directly to the VIP, not their companions; when giving directions, be very specific; offer assistance, guidance to another department; and many more (Cupples, Hart, Johnston, & Jackson, 2012). The current study suggests that these issues raised are still a concern for VIPs, particularly when dealing with technician, nursing, and reception staff, as there appears to be little consideration of the visual impairment, even when attending eye hospitals. Particular concerns raised are when staff gives directions, or ask a VIP to 'follow' them, before they rapidly vanish out of the small amount of useful remaining sight. Further concerns that are not raised in Cupples and colleagues' article are the new technologies being used within GP waiting rooms. Within UK GP waiting rooms patients are now required to check-in using a touch-screen monitor, before seating themselves and awaiting a sound and their name to appear on an LED screen. VIPs in this study reported finding this challenging, in particular if they have no useful vision. When some VIPs have asked for support from the reception staff, they have forgotten to advise the patient that the GP is ready to see them. Technology like this is great and helps boost cost efficiencies, but for patients who are VI they are not accessible and therefore should either be reconsidered, or an alternative be provided for those unable to benefit from the new systems. Whilst privacy was not a strong predictor of QoL, and there were few reports of

privacy concerns, the concerns raised were largely related to requests being ignored by healthcare providers, such as sending highly confidential documents in an inaccessible format to VIPs with no useful vision, forcing them to have their family read out their private information. All of the above can belittle the VIP, increasing the risk of anticipating and reinforcing stigmas, reducing self-esteem. Stigma in the healthcare system can lead to individuals avoiding healthcare providers, increasing the risk of other health concerns (Earnshaw & Quinn, 2012).

4.4.5 Education

The quantitative exploration suggests that stopping oneself from applying for training is a negative predictor of environment QoL. Two of the facets of the environment QoL domain are financial resources and access to information and skills. As skills development could contribute to employment opportunities and development, it is not surprising that this is a predictor of environment QoL. More surprising, however, is that anticipated stigma from education professionals predicts better psychological and social relationships QoL. An explanation for this is that the majority of respondents had not experienced stigma from education professionals. This could also be accounted for by previous findings that more education can result in a better self-reported QoL (Skevington, 2010).

From the qualitative findings it is suggested that even in educational environments the VIP is forced to fit into a sighted world, and adaptations can be deemed concessionary rather than a way of aiding the VIP in integrating into the life of academia. With the possibility that a small concession may not be the most effective method for the VIP to learn – the VIP is also marked out as different during this process (Byrne, 2014).

This study has demonstrated that within academia there is still considerable work to do on mitigating student exposure to stigmatizing and discriminating behaviours from academics and teaching staff. As some teaching staff are open to ridiculing disabled students through a disbelief of their condition it may be beneficial if academics and teaching staff were given training in disabilities to

enhance their understanding of the difficulties that students with a VI have when in education. This could improve the VIP's student experience, and academic achievement.

4.4.6 Transportation

The WHOQOL-BREF facet of transport is a predictor of overall QoL in this study. It is therefore no surprise that those who experience unfair treatment when using public transport are more likely to experience a worse QoL. Although, the domains of QoL affected are potentially unexpected. Physical health could be explained due to the impact of transport on the VIPs ability to perform the activities of daily living, be mobile, and to work. Within the qualitative results VIPs report some discriminatory treatment when using public transport, in particular the bus network. There were reports of being judged as ineligible for the free bus pass by drivers as the VI was not obvious; drivers not advising passengers what number bus they are on; and not calling out when they arrive at the required bus stop. This latter point is becoming less of a concern. Some parts of the UK have buses with a visual and voice announcement system, declaring the name of the road or stop that the bus is coming up to, and stopping at. The Royal National Institute Of Blind People is campaigning for the implementation of talking buses throughout the UK (Royal National Institute Of Blind People, 2014a). Whilst the judgment laid down by some bus drivers is a new finding, the experience of bus drivers being inconsiderate of the needs of VIPs is supported in a recent survey on buses, reporting that buses drive away before VIPs have taken their seat; bus drivers are not forthcoming with information about their required stops; and, can stop in places where VIPs are exposed to obstacles that they collide with on disembarkation (Royal National Institute Of Blind People, 2014c). Alongside the judgment over qualification for the disabled person's bus pass, the Royal National Institute Of Blind People (2014) survey fails to mention issues regarding bus drivers refusing to advise the VIP what number the bus is. This could be implied in the survey, as there is a high proportion that state that they have missed buses due to them not stopping in the right place, but behind another bus.

As mentioned above, transportation is an important consideration for VIPs within this study. Some have lost employment due to the loss of their driving license, and others report that not being able to drive can place a strain on relationships, both social and marital. This could explain why anticipation of stigma from public transport officials is a predictor of poor environment QoL, albeit a statistically insignificant one.

4.4.7 Personal Safety, Security, and Abuse

The analysis showed that unfair treatment with personal safety is a predictor of psychological QoL. This suggests that threats, abuse, and violence may affect body image, self-esteem, and levels of depression and anxiety. Within the VIP population a cane can be used for personal safety – prevent trip hazards, walking into people etc., but this turns the invisible, visible. Potentially affecting body image. The findings of VIPs feelings about cane use demonstrate a dichotomy regarding the use of mobility aids.

Overall it appears that Visually Impaired Persons (VIPs) go out of their way to blend in with others, putting themselves at risk, confusing people around them, and all at considerable effort. The constant adaptation to changing situations requires energy that some VIPs can ill afford. There appears to be shame and embarrassment and whilst there is acceptance of blindness, the societal labelling of being blind is avoided.

The dichotomy presents itself when we consider the attitude toward using a cane (also known as the white cane, guide cane, awareness cane, long cane). There is a split when some experience the cane as a limiter: something that marks them as visibly different; worthy of pity; and, a target for criminals. A stigma. There is also the cane as a tool that elicits the label of blindness. Something that is more difficult to accept than other forms of mobility aid for other physical disabilities. This perception in VIPs may be exacerbated by the feeling and experience that the public, sighted, community has scant understanding of what blindness is. Do the sighted public have awareness of the new labels designed to clear the muddy water of the terms “blind” and “partially sighted”? Currently the sighted public appears confused when

someone registered as sight impaired or significantly sight impaired, or using a cane, is able to see something, rather than having no vision at all. This can lead to a sense of being a fraud in the VIP.

The polemic opposite of this dichotomy is the experience of those who feel the cane is an awesome tool to allow them to maintain their independence. Their interpretation of the cane as a useful tool as opposed to a tool for ridicule allows a different perspective and greater acceptance. This allows the VIP to become empowered.

The concern of participants that they are more vulnerable to criminal acts when using a cane is reinforced in the popular media, with reports of VIPs being attacked in the past year (BBC News, 2014b; Ulster Herald, 2014); similarly, there are also reports of people ignoring the white cane and running VIPs over on pedestrian crossings (BBC News, 2014a, 2014d); and, a police officer mistaking the cane for a weapon and tasering an innocent VIP (BBC News, 2014e). This could be a reinforcer of the negative attitude towards the cane that many VIPs report. Whilst it is probable that the two instances of VIPs being run over on pedestrian crossings would have happened to sighted or visually impaired people, the VIPs are less likely to see dangers and take evasive action: in these two instances the cane provided no protection for the VIP.

In addition to concerns over the cane putting VIPs at risk, the public frequently misunderstands VIPs. The BBC's Ouch series reported relatively new terms describing attitudes towards the disabled. Ableism being an Americanism denoting preferable treatment of the more able-bodied in society, whereas the British use the term Disablism, denoting prejudicial behaviour against those with a disability (BBC News, 2014c). It has been shown that disablism is more prevalent where people have little experience of visual impairment – environments and individuals who are better informed have less of an ableist attitude (Wedgwood, Smith, Shuttleworth, & Llewellyn, 2013). Should someone be treated similarly due to their gender, sexuality, or ethnicity, there would be outrage and severe consequences; and, it has been posited that disablism should be classified as a hate crime, alongside the aforementioned forms of discrimination (Roulstone, Thomas, & Balderston, 2011). With these examples

of prejudice and discriminatory behaviour, it is barely surprising that some VIPs choose to hide their impairment and live as if there was no impairment.

On the other hand, those who report acceptance of the cane have a different attitude. They may be naïve of the news reports, or have awareness that a few people are treated with discriminatory behaviour out of the many who lead rather uncomplicated lives with the use of their mobility aids. Are they more enlightened? Or are they at a different stage on their journey to full acceptance? In a model of adjustment to progressive vision loss, it was suggested that people can go down two paths, from identification as sighted where one conceals the condition, avoids assistive devices, and becomes dependent; or, to identification as visually impaired, where one is open about the condition, utilize assistive devices, and live more independently. Whereby through the stages of the stages of change model, it is possible to shift from acting as sighted, to acceptance of the self as visually impaired (Hayeems et al., 2005). This model can explain the dichotomy; although, whether the split is so definitive, or whether everyone can be a different person in a different situation, could warrant further exploration.

Cane use is not the only attractor of abuse for VIPs. Some participants within this study reported instances of cyclist-rage: being run-over and experiencing explicit verbal abuse. VIPs can also be prone to judgmental shouts of abuse from strangers with accusations of faking their blindness. VIPs are vulnerable to a plethora of abuse. Within this study alone there are reports of financial abuse from spouses and taxi drivers; bullying whilst at school, incorporating both verbal and violent physical violence; threatening behaviours; domestic violence; and, even mild physical abuse from the police. This is supported in the extant literature, with studies showing that disabled women are 4x more likely to experience sexual assault than non-disabled women (Martin et al., 2006), and similarly, men also report significantly higher rates of intimate partner violence (Mitra & Mouradian, 2014). A study on people with low vision reported high rates of belittling, labelling as inferior, bullying and physical harm (Kelly & Moore, 1999).

4.4.8 Coping Strategies

Within this study it was found that the use of personal skills as a coping mechanism were a marginal, non statistically significant, predictor of overall improved QoL. The qualitative responses highlight that VIPs use a variety of methods for coping with their condition. Some constructive, some not:

> "*A phantom acceptance is thus allowed to provide the base for a phantom normalcy. So deeply, then, must he be caught up in the attitude to the self that is defined as normal in our society, so thoroughly must he be part of this definition, that he can perform this self in a faultless manner to an edgy audience that is half-watching him in terms of another show*."
>
> (Goffman, 1984, p. 148)

As suggested by Goffman many VIPs take pride in living a 'normal' life rather than defining their lives by their disability. Some even note that disability is a social construction, and therefore is something that is beyond their control. Whilst some take this philosophical approach to their disability, others use personality traits, such as humour, to make others feel easier about the disability. Breaking the silence, breaking the ice, shattering the awkwardness that some report when communicating with VIPs. VIPs may also use humour to laugh off incidents that may, otherwise, cause embarrassment. This has been reported in the literature, albeit humour was not a key coping mechanism (Boerner & Wang, 2011). It has been suggested that humour may be helpful for improving the QoL of people with a chronic illness, or disability, but the results are currently inconclusive (Bennett et al., 2014; Merz, Malcarne, Hansdottir, Furst, Clements, et al., 2009), although humour coping may help boost self-efficacy (Marziali, McDonald, & Donahue, 2008).

Some of the VIPs within this study have opted to share their experiences of VI with the internet-connected world through the use of blogging. This has enabled VIPs to educate some initially naïve sighted-people as to what living with a VI is like. Blogging, however, can also be used as a therapeutic tool where individuals can express themselves and release some of the stresses of

life (Zareie & Selamat, 2014). Others take more traditional approaches to educating others about the difficulties that VIPs are confronted with. This educational approach is an effort to humanise the VIP so that normally sighted people feel more comfortable communicating with the visually impaired. Some report feeling that they have a duty to other VIPs to educate the sighted public, especially the young. This is their way of mitigating the risk of stigma for future generations of VIPs.

Others report utilizing the few concessions available to VIPs, such as the disability parking badge, free bus travel, concessionary rates for carers at venues and priority boarding when travelling by air. These concessions enable VIPs to be able to resist social isolation, the use of the carer cards for the cinema, and concessionary rates for the theatre enable carers or friends to join the VIP at the cinema, making it beneficial having a VIP friend should you enjoy watching the latest West-End or Broadway production, or the latest Blockbuster movie.

Not everyone in the study had fully accepted their condition, and were going through "course A" per Hayeems et al., (2005), whereby they were actively concealing their condition, avoiding assistive devices such as canes, expressing a sense of shame and embarrassment over the condition and 'fake it'. The term 'coming out' as blind is used when one fully accepts the condition. These individuals provide some confirmation to Hayeem's findings, however, as mentioned above, it is possible that people present themselves differently in different situations. Each situation is a different stage, upon which we play a different role (Goffman, 1990). This would benefit from further investigation.

4.5 Limitations of the current study

As discussed earlier, some of the demographic properties of this study are a limitation within this study. There is a risk of participant bias due to the recruitment method involving VIPs from Facebook support groups. Within these groups there are many discussions regarding struggles to cope with VI, discussions regarding current, past, and upcoming research, as well as a wealth of support for those who are going through challenges. This could mean

the participants in this study are better informed than the 'average' VIP, have a greater understanding of their condition, and of the concerns of other VIPs. As the research topic was overt, there is the possibility of participants responding in a desirable manner to enhance the results of the research. This also implies there is a risk of social desirability bias, whereby the participants do not want to appear stigmatized or disabled and give answers accordingly. It has been shown that the risk of social desirability bias can be increased with the use of web surveys (Brenner & DeLamater, 2013).

There is also a risk of bias from the sample through self-selection bias. As noted within the demographic discussion the population was recruited from largely developed countries with high rates of Internet access. Countries involved, such as Iran, are largely underrepresented, as are many of the developing countries. It is possible that those who clicked on the link had some motivation to do so. It is possible that their motivation to participate was to discuss a particular incident they experienced; to state that they are not objects of stigma; or, they are keen to participate in any research that may benefit people with their condition. We cannot know why people did not participate. There are tens of thousands of people who are members of the support groups this study was advertised in, yet only a few hundred clicked on the link, and less participated. Without knowing the viewpoints of the large population who did not participate, the sample will be at risk of bias. It has been suggested that people are from significantly different demographic backgrounds than those in a traditional research methodology (Loosveldt & Sonck, 2008), although these differences are not consistent and within some areas there are very few demographic differences noted (Evans, Wiggins, Mercer, Bolding, & Elford, 2007). These demographic differences are discussed above, although in this study ethnicity was not recorded, and there were no explicit socioeconomic (SES) demographics collected. SES could be implied through employment and educational achievement.

Sample size may put some of the findings of this study at risk of Type 1 error. Whilst the sample size is considered large (Field, 2009) it is still not suitably large for effective factor analysis. With the DISC-VI measure having so many items, this could weaken the strength of any analysis.

The study takes into consideration solely the perspectives of the VIPs questioned. This results in only half of the story being told. Whilst this is important for understanding the link between perceived experiences and anticipated stigma, we cannot put the experiences into a context to gain a deeper understanding of what the true meaning of certain interactions were. As such, this study is one-sided.

The method of qualitative data collection centred predominantly on questions in the DISC-VI survey. This results in more specific answers relating to the areas of stigma being explored. Whilst some participants were given the opportunity to describe what differentiates them from the normally sighted, this opportunity was not afforded to the entire sample. This could result in some key issues not being raised. Furthermore, the DISC and QUAD scales were developed for measuring Stigma and Discrimination in people with mental illness. There is a risk that VIPs have stigmatising issues that were not featured on the scales. This would have been ascertained through a re-development of the scales using focus groups to gain a better understanding of the exact needs of a measure for VIPs.

As this study was exploratory the differences between demographic groups was not explored. Reviewing the difference between Mean scores for QoL and Stigma it is apparent that there are differences between demographic groups, in particular the following demographic groups stand out: Marital Status; Employment Status; Education Level; and VI Status.

4.6 Researcher's Reflection on The Research Process

As this is the researcher's personal reflection, it has been written in the first person.

The initial plan was to assess whether there was a relationship between stigma, discrimination and QoL in VIPs. Having tried to review the field of literature it became apparent to me that this was an un-researched area. I have studied the lived experience of VI in the past, and was aware of much of the literature on health-related QoL, but I felt this was too limiting. For this reason I opted to

use the WHOQOL-BREF. Having used the WHOQOL-BREF within my MSc dissertation I was aware of much of the QoL literature, and the background of the measure. The knowledge of the development came to having the fortune of working with one of the psychologists involved in the development of the WHOQOL scales, Professor Suzanne Skevington. When reviewing the field of literature for stigma scales I came across one that had been recently developed for use in mental illness. Having reviewed the questions it was apparent that some small semantic changes could be made without significantly impacting the questions of the scale. For this reason I contacted the developer of the scales (Professor Graham Thornicroft) and received his permission to amend the scales. The scales were amended appropriately and received his approval. Once I had received ethical approval for the study I entered all of the data onto Surveymonkey.co.uk. From the outset I had unrealistic expectations of the number of participants that would respond. My preliminary estimations would be to get around 300 participants within a month, possibly two. This, I believed, would give me a good sample size, plus sufficient time to analyse the data. As there were over 7,000 members in the groups that I initially marketed my study I was confident in my projections. It became quickly apparent that initial confidence was naïve.

I had some feedback from participants that the surveys were too long to complete, one taking two hours to complete all of the questions, although another (who was light perception only and completing the survey on an iPad) took just over half an hour. Reviewing the response rate from the Surveymonkey statistics it appeared that over 50% of the participants gave up having completed the consent and looked at the number of questions requiring answering. Given this feedback, and the need to get more participants to have some valid statistical data, two qualitative questions were removed. Whilst these questions added some extra dimension to the study, they were not a core element for answering the research question. Reviewing the way the surveys had been laid out, I opted to not have each survey on a separate page, but to include all of them on one page on the Surveymonkey site. The only time a participant had to click “next” was to agree to consent, and to submit their results. The survey was repeatedly re-marketed. I am not certain whether the

removal of the two questions did help boost participation, as the completion rate was still only 49% at the conclusion of the recruitment process.

The positive aspect of a slow uptake is that I researched many more Facebook support groups for VIPs and received approval to advertise my study from the majority of them. Advertising the study on bank holiday weekends, such as the Easter weekend, proved fruitful. The majority of participants were recruited over the Easter weekend. The benefit of this was the inclusion of more Australian VIPs due to finding a group based there, plus a wide range of conditions. Initially the marketing was predominantly to groups for people with Retinitis Pigmentosa. In the end I was content with the sample size, although it was much lower than I had hoped, and the recruitment process took 9.5 months. This was 7 months longer than initially envisaged.

In past studies I have used either wholly qualitative, or wholly quantitative methodologies. Another reason why I chose the DISC measure for stigma was the mixed-method questions. Often I am concerned with assessing causality by using solely quantitative measures, so having qualitative responses to gain a deeper understanding of why the statistics look the way they do appealed to me. In reality, however, the process of mixed-method research was a large learning curve. Drafting the individual sections was no different to past studies; however creating a synthesized view within the discussion caused sleepless nights. It was a challenge to create a coherent picture and involved reading other mixed-methods papers to assess how they achieved this, before working out my own way to integrate all of the findings.

Quantitative research is one of my weaknesses. Whilst I am competent with quantitative methods, and my MSc dissertation received a good mark, I am often concerned with the many processes involved, such as ensuring assumptions are met. During the process of analysing the quantitative data I was in danger of overthinking the analyses, creating MANOVAs to assess the impact of the demographic variables on various facets of stigma and QoL. Having taken a step back, thought about the research question posed, and the vast amount of qualitative data yet to analyse, I came to the conclusion that the quantitative analysis should be kept more simple. As such, the correlations

were chosen as they directly answer the research question. To add some further understanding to what may impact QoL the multiple regressions were run. I feel that this was the right decision, although a considerable amount of time was wasted concerning myself with the idea that I needed more detailed quantitative analysis. In future I will be more confident in my analytical decisions and ensure I stick to the plan, which was devised as it answers the question at hand.

As a researcher who is passionate about qualitative methodologies, largely because I enjoy reading them more than I do quantitative research, I was looking forward to the analysis of the qualitative data. In this study I found it to be a monumental task. Whilst I was fortunate with having no transcribing to do, there was a considerable amount of work required to organize the data into an analysable format. All of the findings were pasted into MS Excel workbooks: one page for each question. This resulted in hundreds of pages of transcripts. The pages were read over and over. There was so much data that there was a danger of becoming confused. I took a step back and summarized the findings from each question, then started developing the themes. This process took considerably longer than initially anticipated. Numerous times I re-read the guidance on performing thematic analyses (Braun & Clarke, 2006, 2013). I had experience of thematic analysis, and in my undergraduate degree had been taught thematic analysis by Dr. Victoria Clarke, so despite being confident in the method, the sheer size of the project was the issue. After much consolidation and re-reading, I finally reduced the data into themes and selective quotes for analysis. As recommended by Braun & Clarke (2013), the data was not analysed question-by-question, but in a holistic manner. This meant that it did not matter which question a response came from, it was coded and used to develop a theme. If the data were gathered in a different manner and every question had an equal number of responses then it would be possible to analyse question-by-question but there would be the risk of repetition.

When I am conducting research into visual impairments I am often concerned whether I shall bias the results with my own personal experiences as someone who is registered as Significantly Sight Impaired/Blind. In the past I have bracketed my personal opinions, or been interviewed by a colleague to

ascertain my views on the subject, enabling me to compare and contrast. As discussed within the method section, it can be beneficial having a VI and studying VI. In this instance I was able to acknowledge how some responses reflected my own experience, and enjoy reading contrasting experiences, however horrific some may have been. I feel that this study benefitted from having a VI researcher as I have reflected on the analysis as I have progressed.

Another challenge arose when it came to writing the introduction. There is no literature that overtly discussed the impact of stigma on QoL in VIPs. Again, I reviewed the guidelines for writing qualitative reports by Braun & Clarke and discovered that brevity is acceptable. During my previous studies I had learned the funnelling effect of the introduction so drafted a plan to frame the topic, starting with defining the key terms of Blindness, Stigma, and QoL, before moving into a discussion of how Stigma affects people with other conditions, how QoL is affected in other conditions, then how stigma affects QoL in other conditions. The intention was to create a readable and informative introduction that provided the initial framework for my study. It was initially frustrating not being able to find the research to write a more detailed introduction, but this highlighted to me the importance of the study I had undertaken.

The process of completing this study has helped me develop considerably as a researcher. It has taught me to remain focused on the planned goal. That the process of research, even when planned out, takes much longer than anticipated and this should be factored into future time projections. Even when using online methods it can be challenging to recruit participants, and online methods can result in too international a sample. Sometimes it may be more beneficial to have a more homogenous sample. This research has also confirmed my preference for qualitative methodologies, and my appreciation of quantitative methodologies.

4.7 Recommendations for Practice

This research has indicated a link between the way healthcare providers treat, and are anticipated to treat, VIPs and QoL. It is therefore recommended that healthcare providers, including Doctors, Nurses, Receptionists and anyone

within the medical field whom may come into contact with a VIP receive adequate training in how to deal with VIPs, or at the very least review the paper written by Cupples et al., (2012).

There is evidence that self-esteem and mood can facilitate a better QoL, therefore it would be beneficial for VIPs to have access to psychosocial support, with practitioners developing interventions to help VIPs boost self-esteem, give confidence to utilize mobility aids, and help to develop social skills.

It is also apparent that VIPs would benefit from a wider understanding of the real definition of blindness, or a redefinition of the term blindness. A public health education campaign to raise awareness of blindness as a condition that does not always equate to light perception or total blindness only could also be beneficial, possibly through the media, such as the inclusion of a VIP character within a soap opera.

4.8 Areas for Further Research

The purpose of the study was to assess whether there was a link between stigma and QoL in VIPs. It was shown that there is a significant negative relationship between both anticipated and experienced stigma and QoL, plus the qualitative components of this study added some comprehension of how these stigmas are experienced. This study is intended to start a conversation on how the QoL of VIPs is affected, and therefore further research is required to consider how demographic variables may impact the stigma experienced and anticipated. In particular, socioeconomic differences, differences between the levels of severity of condition, the condition diagnosed with, marital status, and employment.

Furthermore, investigations into national differences in the stigma experience are required to assess whether in VIPs stigma and discrimination is a cultural phenomenon, or whether there are other potential factors related to these experiences. Larger studies would also be beneficial to give more power to quantitative analyses.

Finally, it would be beneficial for the development of studies assessing interventions to increase self-esteem in VIPs to measure QoL, rather than just health-related QoL or Vision-Related QoL to gain a perspective of the overall life improvements of any interventions that are investigated, and to consider whether self-esteem helps to moderate the negative impact of stigma on QoL in VIPs.

4.9 Conclusion

The purpose of this study was to assess whether there was a relationship between stigma, QoL, and visual impairment. If a relationship was found then it was anticipated that this study would provide the foundations for future researchers to build on. Currently this is an un-researched area. Many other conditions have researchers assessing the impact of stigma on QoL, yet VI has not received the same attention. Whilst some past studies into VI have discussed elements of stigma and discrimination, and many studies have focused on the vision and health related QoL of VIPs. This study was the first to combine these phenomena. It was shown that there is a significant negative relationship between stigma and QoL in VIPs. This confirmed the study hypothesis. Further analysis demonstrated that anticipated stigma has a stronger negative relationship with QoL than experienced stigma.

What was evident in this study is that not everyone has the same experience. Whether that is caused by cultural differences; differences in perceptions of the self; different public attitudes to disability; different social situations; or, differences in levels of acceptance. What is apparent is that people do still experience discriminatory behaviour, and it could be argued that being disabled in an ableist world is a challenge. Some have the psychological flexibility to reframe the situation and get on with it; others find it more of a challenge.

Further research is now required to develop a more detailed picture of the current situation, and aid the development of interventions to support VIPs who are experiencing, or anticipating, stigma to ensure that QoL is not diminished.

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APPENDICES

B1-1 – Information Sheet, Consent Form, Surveys

Stigma and Quality of Life in the Visually Impaired

Information Sheet

PSYETH(UPTD) 13/14 11

Investigating the stigma associated with visual impairment, and its impact on quality of life

We would like to invite you to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

There is evidence to suggest that people with disabilities experience stigma and discrimination in their daily lives. The purpose of this study is to survey visually impaired persons (VIPs) to understand whether they do experience stigma and/or discrimination in their lives, and whether this affects their quality of life.

Why have I been invited?

You have been invited to participate in this research as you are a VIP and your input into this research will be hugely valuable.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. Due to the nature of the study, it is not possible to withdraw once you have submitted your responses.

What will happen if I take part?

The information will be collected through a series of three online questionnaires, plus one open question. The questionnaires should take approximately 20-30 minutes to complete and the open question can take as long as you like. It would be envisaged that the maximum time to complete would be around 1 hour. The time to complete may take longer using accessible software such as JAWS or Zoomtext.

What do I have to do?

I would appreciate it if you could complete the DISC-VI questionnaire with as much detail as possible. The other two questionnaires, the QUAD-VI and WHOQOL-BREF should be completed as quickly as possible to give a first instinct response. With the open question, please give as much detail as possible.

What are the possible disadvantages and risks of taking part?

There should be no risks of participating, although thinking about issues surrounding stigma and discrimination due to being a VIP may be upsetting.

What are the possible benefits of taking part?

There are no direct benefits to participating, although the findings of this research will be disseminated to the scientific community to enhance understanding of how VIPs are affected by their condition and whether VIPs experience stigma and discrimination in daily life.

What will happen when the research study stops?

When the research is complete, published, and my doctorate submitted, data will be destroyed. Responses to the WHOQOL-BREF will be stored by the World Health Organisation Centre for the Study of Quality of Life.

Will my taking part in the study be kept confidential?

• You will not be asked to provide any identifying information and your responses will be wholly anonymous.
• IP addresses will not be collected.

What will happen to results of the research study?

The results of this study will be used as the main thesis of my Professional Doctorate in Health Psychology. Results will be further disseminated through an appropriate publication, such as an ophthalmological or health journal (i.e. British Journal of Health Psychology).

What will happen if I don't want to carry on with the study?

You can withdraw anytime during the study simply by closing your browser or navigating to another website. Once you have submitted the information then due to the total anonymity of participation there is no ability to withdraw.

What if there is a problem?

Should you experience distress during this study due to your visual impairment the RPFighting Blindness helpline will be able to give you advice and support - 0845 123 2354

If you would like to complain about any aspect of the study, City University London has established a complaints procedure via the Secretary to the University's Senate Research Ethics Committee. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is: Investigating the stigma of Visual Impairment and its impact on Quality of Life

You could also write to the Secretary at:

Anna Ramberg
Secretary to Senate Research Ethics Committee
Research Office, E214
City University London
Northampton Square
London
EC1V 0HB
Email: [redacted]

Who has reviewed the study?

This study has been approved by City University London School of Arts & School of Social Sciences Research Ethics Committee

Comments, concerns or observations procedure:

This project has been approved by the Research and Ethics Committee of the Department of Psychology of City University London (project approval number PSYETH(UPTD) 13/14 11). If you have any comments, concerns or observations about the conduct of the study or your experiences as a participant, please contact the Secretary to the Committee Mrs Carmai Pestell, quoting the above project approval number:

Telephone: [redacted]

Email: [redacted]

Postal Address:
Mrs Carmai Pestell
Secretary to Psychology Department Research and Ethics Committee
School Office A129
Schools of Arts and Social Sciences
City University
Northampton Square
London
EC1V 0HB

Further information and contact details

Researcher:
Tim Mahy
[redacted]

Supervisor
Dr Clare Eldred
[redacted]

Stigma and Quality of Life in the Visually Impaired

Interim Supervisor
Dr Parmpreet Kalsi
[redacted]

Thank you for taking the time to read this information sheet.

PSYETH(UPTD) 13/14 11

*1. Consent

	Yes	No
I agree to take part in the above City University London research project. I have had the project explained to me, and I have read the participant information sheet, which I may keep for my records. I understand this will involve complete questionnaires asking me about my experience of stigma and discrimination, and my quality of life.	○	○
This information will be held and processed for the following purpose(s): I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party. No identifiable personal data will be published. The identifiable data will not be shared with any other organisation.	○	○
I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw at any stage of the project without being penalized or disadvantaged in any way.	○	○
I agree to City University London recording and processing this information about me. I understand that this information will be used only for the purpose(s) set out in this statement and my consent is conditional on the University complying with its duties and obligations under the Data Protection Act 1998.	○	○
I agree to take part in the above study.	○	○

Please click "next" to continue

Demographic Questions

***2. What is your gender?**

- Female
- Male
- Other (please specify)

3. Which of the following best describes your current relationship status?

- Married
- Widowed
- Divorced
- Separated
- In a domestic partnership or civil union
- Single, but cohabiting with a significant other
- Single, never married

Other (please specify)

4. Which of the following categories best describes your employment status?

- Employed, working 40 or more hours per week
- Employed, working 1-39 hours per week
- Student
- Not employed, looking for work
- Not employed, NOT looking for work
- Retired
- Disabled, not able to work

Other (please specify)

5. What is the highest level of education you have completed?

Other (please specify)

***6. In what year were you born? (enter 4-digit birth year; for example, 1976)**

***7. In what country do you currently reside?**

- ○ United Kingdom
- ○ United States
- ○ Other (please specify)

***8. What is your eye condition?**

- ☐ Retinitis Pigmentosa
- ☐ Ushers
- ☐ Macular Degeneration
- ☐ Glaucoma
- ☐ Other (please specify)

***9. What is your current status?**

- ○ Registered blind/ Severely sight impaired
- ○ Registered partially sighted/ Sight impaired
- ○ Not yet registered
- ○ Chosen not to register
- ○ Other (please specify)

10. In what year were you diagnosed? (enter 4-digit birth year; for example, 1976)

Discrimination and Stigma Scale for the Visually Impaired (DISC-VI)

Introduction:
Discrimination and stigma occur when people are treated unfairly because they are seen as being different from others. This questionnaire asks about how you've been affected by discrimination and stigma because of your visual impairment.

There are four parts to this questionnaire:
1 – The first part will ask you about times when you have been treated unfairly because of your visual impairment.

2 – The second part will ask you about times when you have stopped yourself from doing things because of how others might respond to your visual impairment.

3 – The third part will ask about how you may have overcome stigma and discrimination because of your visual impairment.

4 – The fourth part will ask you about any times where you have been treated more positively because of your visual impairment.

At each part of the questionnaire you will be asked whether each event has happened not at all, a little, moderately, or a lot. You will also be asked to give an example. It would be appreciated if you could give as much detail as possible.

For each question, please think about events which have happened at any stage of your life since being classified as sight impaired or severely sight impaired, or your visual impairment was acknowledged.

*11. Section 1

In this section, I would like to ask about times when you have been treated unfairly because of your visual impairment. There are 21 questions in this section. Please choose only one answer for each question.

	Not at All	A Little	Moderately	A Lot	N/A
1 – Have you been treated unfairly in making or keeping friends?	○	○	○	○	○

Please give an example

	Not at All	A Little	Moderately	A Lot	N/A
2 – Have you been treated unfairly by the people in your neighbourhood?	○	○	○	○	○

Please give an example

	Not at All	A Little	Moderately	A Lot	N/A
3 – Have you been treated unfairly in dating or intimate relationships? (excluding treatment by a	○	○	○	○	○

spouse or co-habiting partner as covered in Q6)

Please give an example

4 – Have you been treated unfairly in housing? (including becoming homeless)

Please give an example

5- Have you been treated unfairly in your education? (including school, college, university, on the job training, and vocational courses)

Please give an example

6 – Have you been treated unfairly in marriage or divorce? (including co-habiting or civil partnerships. How has your visual impairment impacted your ability to find a partner or spouse, has it caused any problems within the relationship, or impacted upon any divorce settlements?)

Please give an example

7 – Have you been treated unfairly by your family? (excluding spousal or co-habiting relationships. Including parents, siblings, and other relations, including any children).

Please give an example

8 – Have you been treated unfairly in finding a job? (full or part-time paid work)

Please give an example

9 – Have you been treated unfairly in keeping a job?

Please give an example

10 – Have you been treated unfairly when using public transport? (including free travel cards, passengers, drivers)

Please give an example

11 – Have you been treated unfairly in getting welfare benefits or disability pensions? (how was the application process for benefits such as income support and disability allowances, and the support provided by the benefits system and the levels of benefits provided).

Please give an example

12 – Have you been treated unfairly in your religious practices? (if you attend church, are you still able to do so? Your treatment by fellow parishoners and church leaders)

Please give an example

13 – Have you been treated unfairly in your social life? (how do you find socialising, hobbies, attending events, and leisure activities).

Please give an example

14 – Have you been treated unfairly by the police? (have you have any contact with the police and how has your visual impairment impacted this contact?).

Please give an example

15 – Have you been treated unfairly when getting help for physical health problems? (i.e. GP, dentist, nurses, emergency treatment)

Please give an example

16 – Have you been treated unfairly by Ophthalmology staff? (how have they treated you? Have you ever felt disrespected or humiliated by contact with the ophthalmological staff? How have the staff behaved towards you?)

Please give an example

17 – Have you been treated unfairly in your levels of privacy? (including in hospital or community settings i.e. phone calls or private letters, medical records and criminal records checks, disclosure and barring service checks).

Please give an example

18 – Have you been treated unfairly in your personal safety and security? (i.e. verbal or physical abuse, assult etc)

Please give an example

19 – Have you been treated unfairly in starting a family or having children? (how have you experienced the behaviour of health professionals, friends and family, and how were you or your partner treated during pregnancy and/or childbirth).

Please give an example

20 – Have you been treated unfairly in your role as a parent to children? (how have other parents, teachers, family or health professionals behaved towards you?)

Please give an example

21 – Have you been avoided or shunned by people who know you have a visual impairment?

Please give an example

***12. Section 2**

In this section, I would like to ask you about times when you have stopped yourself from doing things that are important to you because of how others might respond to your visual impairment. There are 4 questions in this section. Please choose only one answer for each question.

	Not at All	A Little	Moderately	A Lot	N/A
22 – Have you stopped yourself from applying for work?	○	○	○	○	○

Please give an example

23 – Have you stopped yourself from applying for education or training courses?	○	○	○	○	○

Please give an example

24 – Have you stopped yourself from having a close personal relationship?

Please give an example

25 – Have you concealed or hidden your visual impairment from others?

Please give an example

***13. Section 3**

In this section, I would like to ask you about examples of overcoming stigma and discrimination because of your visual impairment. There are 2 questions in this section. Please choose one answer only for each question.

	Not at All	A Little	Moderately	A Lot	N/A
26 – Have you made friends with people who are not visually impaired?	○	○	○	○	○

Please give an example

27 – Have you been able to use your personal skills or abilities in coping with stigma and discrimination?	○	○	○	○	○

Please give an example

*14. Section 4

In this section, I would like to ask you about times when you have been treated more positively because of your visual impairment. Being treated "more positively" means receiving special or favourable treatment. If you have a degenerative condition that has become worse over the years, I would like to know whether you have experienced any favourable treatment compared with how you were treated when your condition was not so advanced, or compared to how people who do not have a visual impairment are treated. There are 6 questions in this section. Please choose only one answer for each question.

	Not at All	A Little	Moderately	A Lot
28 – Have you been treated more positively by your family? (including parents, siblings, spouse, partner, children or relatives)	○	○	○	○

Please give an example

	Not at All	A Little	Moderately	A Lot
29 – Have you ever been treated more positively in getting welfare benefits or disability pensions?	○	○	○	○

Please give an example

30 – Have you been treated more positively in housing?

Please give an example

31 – Have you been treated more positively in your religious activities?

Please give an example

32 – Have you been treated more positively in employment? (i.e. in finding work, keeping work and adjustments in the workplace)

Please give an example

33 – Have you been treated more positively in any other settings? (i.e. public transport, social activities, public events etc)

Please give an example

Questionnaire on Anticipated Discrimination in the Visually Impaired

Stigma and Quality of Life in the Visually Impaired

***15. Below you will find a list of sentences. For each one, please indicate the answer that best suits you by selecting the number that is most appropriate. Please do not spend too much time thinking about your answer as your first impression is most important.**

	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A
1 – If friends know about my visual impairment they will treat me unfairly	○	○	○	○	○
2 – if people in my neighbourhood know about my visual impairment they will treat me unfairly	○	○	○	○	○
3 – if a person I want to date or have an intimate relationship with knows about my visual impairment, they will treat me unfairly	○	○	○	○	○
4 – if housing officials or landlords know about my visual impairment, they will treat me unfairly.	○	○	○	○	○
5 – If teachers, lecturers, or tutors know I have a visual impairment, they will treat me unfairly.	○	○	○	○	○
6 – If my family knows about my visual impairment, they will treat me unfairly	○	○	○	○	○
7 – if employers know about my visual impairment, they will treat me unfairly	○	○	○	○	○
8 – If work colleagues know about my visual impairment, they will treat me unfairly	○	○	○	○	○
9 – If transport drivers and officials (i.e. bus driver, ticket inspector, taxi driver) know about my visual impairment, they will treat me unfairly.	○	○	○	○	○
10 – If benefit officials know I have a visual impairment, they will treat me unfairly.	○	○	○	○	○
11 – If religious officials or the community (i.e at church, mosque or temple) know about my visual impairment, they will treat me unfairly.	○	○	○	○	○
12 – If the police know about my visual impairment, they will treat me unfairly.	○	○	○	○	○
13 – If health professionals (GP, nurse, dentist, ophthalmologist) know I have a visual impairment, they will treat me unfairly.	○	○	○	○	○
14 – If children and teenagers in my community know I have a visual impairment, they will treat me unfairly.	○	○	○	○	○

Please click "next" to continue

World Health Organisation Quality of Life Scale - Brief Version

This questionnaire asks how you feel about your quality of life, health, and other areas of your life. Please answer all the questions. If you are unsure about which response to give to a question, please choose the ONE that appear most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last two weeks.

*16. Overall Quality of Life

	Very dissatisfied	Dissatisfied	Neither Satisfied nor Dissatisfied	Satisfied	Very Satisfied
How would you rate your quality of life?	○	○	○	○	○
How satisfied are you with your health?	○	○	○	○	○

*17. The following questions ask about how much you have experienced certain things in the last two weeks.

	Not at all	A Little	A moderate amount	Very much	An extreme amount
How much do you feel that pain prevents you from doing what you need to do?	○	○	○	○	○
How much do you need medical treatment to function in your daily life?	○	○	○	○	○
How much do you enjoy life?	○	○	○	○	○

*18. The following questions ask about how much you have experienced certain things in the last two weeks.

	Not at all	A little	A moderate amount	Very much	Extremely
To what extend do you feel life to be meaningful?	○	○	○	○	○
How well are you able to concentrate?	○	○	○	○	○
How safe do you feel in your daily life?	○	○	○	○	○
How healthy is your physical environment?	○	○	○	○	○

*19. The following questions ask about how completely you experience or were able to do certain things in the last two weeks.

	Not at all	A little	Moderately	Mostly	Completely
Do you have enough energy for everyday life?	○	○	○	○	○
Are you able to accept your bodily appearance?	○	○	○	○	○
To what extent do you have enough money to meet your needs?	○	○	○	○	○
How available to you is the information that you need in your day-to-day life?	○	○	○	○	○
To what extend do you have the opportunity for leisure activities?	○	○	○	○	○

***20. The following question asks you how good you felt about aspects of your life over the past two weeks.**

	Very poor	Poor	Neither poor nor good	Good	Very good
How well are you able to get around?	○	○	○	○	○

***21. The following question asks you how satisfied you felt about various aspects of your life over the past two weeks.**

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
How satisfied are you with your sleep?	○	○	○	○	○
How satisfied are you with your ability to perform daily living activities?	○	○	○	○	○
How satisfied are you with your capacity for work?	○	○	○	○	○
How satisfied are you with yourself?	○	○	○	○	○
How satisfied are you with your personal relationships?	○	○	○	○	○
How satisfied are you with your sex life?	○	○	○	○	○
How satisfied are you with the support you get from your friends?	○	○	○	○	○
How satisfied are you with the conditions of your living place?	○	○	○	○	○
How satisfied are you with your access to health services?	○	○	○	○	○
How satisfied are you with your transport?	○	○	○	○	○

***22. The following question refers to how often you have felt or experienced certain things in the last two weeks.**

	Never	Seldom	Quite often	Very often	Always
How often do you have negative feelings, such as blue mood, despair, anxiety, depression?	○	○	○	○	○

23. Did someone help you complete this survey?

○ Yes

○ No

Please click "next" to continue

Thank you for taking the time to participate in this research, your participation is much appreciated.

The Lived Experience of Guide Dog Ownership

Systematic Review of Cognitive Behavioural Therapy Programmes for Smoking Cessation

An Updated Systematic Review of Cognitive and Behavioural Therapy Programmes for Smoking Cessation

Abstract

Whilst the global prevalence of smoking is falling, current estimates are that 1.3bn people smoke, with one person dying every six seconds from smoking related illness. The cost of smoking is rising, therefore cheaper alternatives such as rolling tobacco, are sought, with possibly worse health implications than factory made cigarettes. With the significant health and economic costs of smoking, and estimates that 1bn people will die through smoking in this century, it's important to find effective methods to help smokers become abstinent.

Aims

The aim of this review was to update Pires-Yfantouda & Sykes' review to 2013. This review specifically looks at Cognitive Behavioural interventions, including third wave therapies (Mindfulness and Acceptance and Commitment Therapy) for smoking cessation. We also aimed to consider the components of CBT incorporated into each study.

Search Strategy

Studies led by a health professional that had a cognitive and behavioural component were included in the analysis. Psychinfo, Web of Science, EMBASE, SCOPUS, and the Psychology & Behavioural Sciences Collection databases were searched for 2005-2013.

Selection Criteria

A selection criterion was drawn (participants, interventions, outcomes, study design). Studies that did not meet the criteria were excluded.

Search terms: were employed using the Psychinfo, Web of Science, EMBASE, Scopus, and the Psychology and Behavioural Sciences Collection databases.

Quality Assessment

Studies were quality assessed and scored 0 to 1 on each of the different categories. The maximum score a study could score was 10. The cut-off point for inclusion was 5.

Results

Table B3 1 - Included Study Results

Trial		Intervention Group		Control Group		Difference %
Author/Year	Quality Rating	Quiters	%	Quiters	%	
Webb et al, 2010	6	24/77	31	11/77	14	17
Prapavessis et al, 2007	5	23/53	43	18/68	26	17
Wittchen et al, 2011	7	27/129	21	13/44	30	-9

Discussion

Of the two thousand, five hundred and fifty three studies, of which eighteen were reviewed: only three were eligible for inclusion and quality assessment. This review suggests that CBT based interventions, run by a health professional, alongside nicotine replacement, is an effective treatment even at twelve-month follow-up.

Background

It is estimated that should people continue to smoke then 1 billion people will die this century from smoking related disease (World Health Organisation, 2013). It is estimated that there are currently 1.3bn smokers in the world, and 6 trillion cigarettes are smoked per year: 2 trillion of which are smoked in China (Jha & Peto, 2014), where only 23% of adults believe that smoking is a causal factor for lung cancer and heart disease and only 16% of current smokers have some intent to quit within a 12 month period (Global Adult Tobacco Survey, 2010).

Global smoking prevalence is extremely varied, with an estimated 51% of males over 15 in pacific rim being smokers, whilst Europe has the highest prevalence of female smokers, at 22% (World Health Organisation, 2009a). On an individual basis, Kiribati and Greece report the highest rates of male smokers, 71% and 63% respectively, with Ethiopia reporting the fewest at 8%. The highest prevalence of female smokers is in Naura, with 50% of females over 15 being smokers, closely followed by Austria and Greece, with 45% and 41% respectively. Some of the countries with the lowest prevalence of female smokers are Saudi Arabia, Benin, and Kenya, at 1% (World Health Organisation, 2009b). In the USA currently 18% (21% male: 16% female) of the population smoke: 42 million Americans.

One of the biggest smoking related killers, however, is respiratory disease. Approximately 1 in 5 deaths in those aged 35 and over in the UK are smoking related (2011), with a third of those being related to respiratory disease and 30% being cancer (Health and Social Care Information Centre Lifestyles Statistics, 2012). In the USA it is estimated that 16 million people are currently suffering with a smoking related illness, with 480,000 deaths per annum. Furthermore, it is estimated that over the past 50 years, 2.5 million Americans have died due to illnesses caused by second hand smoke (U.S. Department of Health and Human Services, 2014). On a global scale it is thought one person dies every six seconds due to smoking, with an estimated annual global death toll of

approximately 5 million due to smoking, and 600,000 from second hand smoke, with smoking being linked to 71% of cases of lung cancer, and 42% of cases of COPD. It is expected that smoking related deaths will increase to 7.5 million by 2020 unless sufficient interventions are put in place (World Health Organisation, 2011, 2013).

Whilst it is evident that smoking causes individuals harm, there are also significant economic factors in play. The tobacco industry pays an estimated $300bn in taxes per annum, and makes profits estimated to be at $50bn. The societal costs are significant, with the USA estimating the annual health costs to be $130bn and the annual loss of productivity to be $150bn (Jha & Peto, 2014; U.S. Department of Health and Human Services, 2014); whilst the UK estimates the health cost at £5.2bn (Health and Social Care Information Centre Lifestyles Statistics, 2012). Extrapolated this against countries with higher smoking prevalence would result at a significant global economic implication both in the costs of healthcare and productivity loss due to illness.

Research has shown that 75% of quit attempts result in relapse, with the highest vulnerability to relapse being between four weeks and six months after the quit date. There are many contributing factors to consider that affect relapse likelihood and those who have their first cigarette within five minutes of waking, those who live with another smoker, those who smoke to cope, and those who have a low socio-economic status stand a higher chance of relapse. Predictors of success in quitting, however, are determination to succeed, and a higher socio-economic status (Ferguson, Bauld, Chesterman, & Judge, 2005; Fidler, Ferguson, Brown, Stapleton, & West, 2013). It has been shown that cravings reduce over time with only a minority experiencing strong cravings up to one year post-quit date, and after one year only mild occasional cravings are experienced (Ussher, Beard, Abikoye, Hajek, & West, 2013). Some claim that smoking calms them, although research published in the British Journal of Psychiatry suggests that abstinence from smoking reduces anxiety and unsuccessful quit attempts mildly exacerbate future anxieties (McDermott, Marteau, Hollands, Hankins, & Aveyard, 2013). Behavioural interventions, such as

exercise, have been shown to be effective in reducing cravings for tobacco (Haasova, Warren, Ussher, Janse Van Rensburg, Faulkner, et al., 2013), it has also been shown that children's engagement with physical activity acts as a preventative measure for smoking behaviours in adolescence, and thus adulthood (Audrain-McGovern, Rodriguez, Cuevas, & Sass, 2013). A concerning development is the shift towards Roll-Your-Own (RYO) cigarettes. RYO cigarettes are much cheaper than factory made cigarettes and this is possibly one of the causes for the rising prevalence of RYO, they are also becoming more fashionable. RYO smokers, however, are less likely to quit than smokers of factory made cigarettes (Young et al., 2012). Research has shown that RYO smokers tend to inhale deeper than factory made cigarette smokers, exposing themselves to more smoke per cigarette (Laugesen, Epton, Frampton, Glover, & Lea, 2009), it would also appear that the contents of RYO tobacco is more harmful than factory made cigarettes, with RYO smokers account for nine out of every 10 new cases of lung cancer in Norway (Rolke, Bakke, & Gallefoss, 2009) with RYO cigarettes containing a higher level of oxidants contributing to higher levels of oxidative stress and DNA damage than factory cigarettes (Kocyigit, Selek, Celik, & Dikilitas, 2011).

Smoking harms are largely reversible, with the damage being undone almost immediately. Within 20 minutes of the last cigarette the heart rate and blood pressure reduce, then CO2 levels within the body are normalized within 12 hours. After a few months coughing episodes and shortness of breath improve. After 10 years the risk of lung cancer falls to that of 50% of a smoker. In addition to these, the risk of asthma to children nearby is significantly reduced (World Health Organisation, 2014). People whom stop smoking before the age of forty likely to reduce smoking related harms by up to 90% (Jha & Peto, 2014).

Evidence Base

Historically the most common method for the delivery of smoking cessation interventions was through group support programmes, usually via GP referral. This has now shifted in the UK with the proliferation of the NHS Stop Smoking Services (NHS SSS) toward a more pharmacological route, with one to one support. Pharmacological interventions mostly comprise of nicotine replacement therapy (NRT), most successfully delivered if two NRT products used simultaneously, and Varenicline (Champix). Of the pharmacological methods, 60% of those on Varenicline are successful with their quit attempt, as opposed to 46% who use NRT. In 2011/12 the proportion of people setting a quit date receiving a group intervention equated to 5% (see Table 1), despite being more efficacious than One on One interventions (The Health and Social Care Information Centre, 2012). Recent findings have also concluded that group interventions should, where possible, be used due to higher success rates (Bauld, Bell, McCullough, Richardson, & Greaves, 2010; Brose, West, McDermott, Fidler, Croghan, et al., 2011).

According to Stead and Lancaster (2002), smoking cessation interventions normally include methods to facilitate smokers coping during abstinence, social skills, training, contingency management, self-control and cognitive behavioural interventions. The abstinence oriented approach sees withdrawal discomfort as remediable. Smokers' self-efficacy is built up before setting a quit day and they are empowered and supported to achieve their objective of quitting smoking during initial stage of withdrawal from nicotine.

The evidence for employing these methods was based on a report informed by the Scientific Committee on Tobacco and Health (Department of Health, 1998a). The evidence of this report was based on systematic review by (Law and Tang, 1995) by which the effectiveness of various smoking cessation interventions was evaluated. This review evaluated various interventions: 1) Advice and encouragement by doctor during consultation, with additional encouragement/support; nurses in health promotion clinics; support group sessions; in special

circumstances; men at high risk of ischemic heart disease 2) Behaviour modification therapy – non specific approaches; aversion; rapid or satiation smoking; silver acetate; sensory deprivation; hypnoses 3) Pharmacological treatments to allay withdrawal symptoms – nicotine replacement therapy; clonidine; tranquilisers and other agents 4) Miscellaneous treatments 5) Gradual reduction of nicotine intake. According to Law and Tang (1995) there is no reason to support behaviour modification therapy to assist smokers to quit. According to Law and Tang (1995) behaviour modification therapy to assist smokers to quit is not cost-effective. However, they presented no data on cost-effectiveness in spite of recommending doctor's advice based on those grounds. They made no attempt to evaluate the quality of the studies included in their review, thus included good and bad quality papers. Several of the studies included in their review used no biochemical markers. Furthermore, there was no classification of the psychological interventions; they were grouped as non-specific behavioural modification interventions led by a psychologist. The nature of the intervention may be more meaningful than the profession of the person leading the intervention. They concluded that doctors should take time to advise all their patients who smoke to quit. Those smokers should be provided with additional support and Nicotine Replacement Therapy.

Whilst the UK has extensive smoking cessation services, available free of charge on the NHS, currently only 15% of the world's population have access to some form of cessation programme (World Health Organisation, 2013). The USA states that in more than half of its states NRT is available at no cost; they also provide telephone counselling though Quitline, which enables smokers to gain social support and coping skills (Centers for Disease Control and Prevention, 2013), which follows national guidelines on effective treatment using multimodal interventions (United States Tobacco Use and Dependence Guideline Panel & Centre for Disease Control and Prevention (US), 2008). Similar to the UK, provision of CBT based interventions is not evident. Telephone counselling has been shown to be a useful adjunct to CBT interventions, although intensive CBT is superior to general telephone support (Killen et

al., 2008). The lack of provision of CBT in both of these countries could explain the scant levels of research into the efficacy of CBT for smoking cessation. Some extant studies suggest that CBT is a beneficial add-on for other types of treatment, such as pharmacological interventions (Schmitz, Stotts, Mooney, Delaune, & Moeller, 2007), although the evidence can be contradictory, where neither CBT nor pharmacotherapeutic interventions are that effective, separately nor in combination (McCarthy et al., 2008), yet in an adolescent population an NRT plus extended CBT intervention at six month follow up yielded significantly higher rates of abstinence (21%) than a non extended intervention (7%). Suggesting enhanced efficacy in extended CBT. This is echoed in a study within older adults, where an extended CBT intervention where participants received 10 sessions over the course of 10 months, with 55% maintaining abstinence over a two year follow up period. In this study the addition of NRT did not improve abstinence (Hall, Humfleet, Muñoz, Reus, Robbins, et al., 2009).

New third wave therapies, based on the CBT model, such as mindfulness, have been shown to have benefits within smoking cessation. In a comparison between traditional CBT and Acceptance and Commitment Therapy (ACT) smokers receiving the ACT intervention which focussed on enabling the participant to accept adversity, identify personal costs of actions, and classify their own values significantly outperformed the CBT intervention, with 42% of those completing the ACT intervention being abstinent at 12 months, as opposed to 17% in the traditional CBT group (Hernández-López, Luciano, Bricker, Roales-Nieto, & Montesinos, 2009). An ACT based online QuitWeb website has also been shown, in a recent pilot study, to be more efficacious than the US Government's Smokefree web intervention, 23% against 10% (Bricker, Wyszynski, Comstock, & Heffner, 2013). Mindfulness techniques, such as attentional focus using methods such as the body scan, have been shown to reduce cravings (Cropley, Ussher, & Charitou, 2007; May, Andrade, Willoughby, & Brown, 2012), although evidence currently suggests that these results are not replicable outside of the laboratory setting (Ussher, Cropley, Playle, Mohidin, & West, 2009). Mindfulness is also an intervention that is able

to deal with multiple factors at one time. In women smokers with body image concerns, mindfulness has been shown to be effective in improving body image through having a non-judgemental and accepting approach to the self, and acknowledging and letting emotions pass, reducing negative affect, the desire to smoke and thus smoking behaviours (Adams, Benitez, Kinsaul, Apperson, McVay, et al., 2013), potentially dealing with the cause of the smoking, rather than the behaviour.

Methodology

Systematic review protocol

Following Law & Tang (1995) and Pires-Yfantouda & Sykes (2010) reviews, a protocol was created (appendix 1). The aim of this protocol is to devise a framework for the systematic review.

Search strategy

Studies led by a health professional which had a cognitive and behavioural component were included in this analysis. PsychInfo, Web of Science, EMBASE, SCOPUS and Psychology & Behavioural Sciences Collection databases were searched from 2005 to 2013. Once articles were identified, they were screened for inclusion. Articles not specifically mentioning Cognitive and Behavioural interventions for smoking within the abstract were discounted.

Study selection criteria

Participants

Adults (>16 years of age) using cognitive and behavioural intervention to stop smoking.

Interventions

Psychological interventions with one or more components of cognitive and behavioural interventions which include methods to facilitate smokers to cope during abstinence, such as relaxation techniques, use of diaries, identification of triggers, visualisation, changing routines, rehearsing

strategies to cope with withdrawal, identification of thinking errors, cognitive re-framing, focusing on gains of staying abstinent, social support, social skills training, contingency management, self-control, aversion therapy, mindfulness, and acceptance and commitment therapies.

Outcomes

Cessation for at least 6 months

Study design

Randomised controlled trials

Search terms

The following search terms were employed using PsychInfo, Web of Science, EMBASE, SCOPUS and Psychology & Behavioural Sciences Collection databases.

1. relaxation
2. visuali?ation
3. imagery
4. trigger
5. positive reasons
6. self-control
7. psychological
8. behaviour therapy
9. behavior therapy
10. cognitive therapy
11. randomi?ed controlled trial
12. post-treatment follow-up
13. abstinence oriented
14. follow-up study
15. psychotherapy
16. smok* (Scopus – Smoking, Smokers, Smoke)
17. aversion Therapy
18. MBCT
19. mindfulness
20. acceptance and commitment
21. ACT

Search terms were entered as follows:

Smok*

AND

(relaxation OR visuali?ation OR imagery OR trigger OR positive reasons OR “self-control” OR psychological OR “behaviour therapy” OR “behavior therapy” OR “cognitive therapy” OR “post-treatment follow-up” OR “abstinence oriented” OR “follow-up study” OR “Psychotherapy” OR “aversion therapy” OR MBCT OR mindfulness OR “acceptance and commitment” OR ACT)

AND

“randomi?ed controlled trial”

Quality Assessment Checklist

In order to evaluate the quality of each paper, a quality assessment checklist was devised. Papers were scored based on each individual criterion whereby they were allocated 0 points if the standard was not met and 1 point if it was met. Individual scores were totalled and papers could score a minimum of 0 and a maximum of 10 points. The quality checklist was as follows:

1) Adequate randomisation (needs to be specified)
2) Adequate participants (including power analyses or over 100 participants per group in each group)
3) Biomarkers confirming self-reported abstinence in 95% of cases (CO in expired breath, saliva or urine sample)
4) Suitable comparison interventions
5) Similar groups at baseline (use of standardise scale to measure nicotine addiction, matched by age and gender)
6) No other confounding intervention

7) Acceptable drop out rate (25% or more)
8) Motivation to quit measured
9) Reliable measurement techniques (test retest/ internal consistency/split half)
10) Appropriate statistical analyses

Two researchers conducted the quality assessments independently. Each researcher had a quality assessment checklist. After both researchers have assessed all papers, scores were compared. As there was no disagreement above two scores amongst the researchers, the scores were averaged. It was agreed that the cut-off point for the inclusion of a paper was 5 as this was the median score.

Results

Two thousand five hundred and fifty three abstracts were read for inclusion. Out of those only eighteen were short-listed for inclusion. These were read and fifteen studies were excluded prior to quality assessment for the following reasons (Appendix B3-2 contains a breakdown of these papers with the individual reasons for exclusion):

Participants were diagnosed with psychoses, were pregnant, or had substance misuse problems, interventions to reduce weight, no suitable comparison group, follow-up for less than 6 months, lack of certainty over counselling intervention being delivered, and intervention not delivered by a psychologist or health professional. All of the three remaining papers scored above five in the quality assessment.

A total of three trials met the inclusion criteria for this review. One study was managed within a general practitioners' office, linked to a hospital, and facilitated by a clinical psychologist, supported by a master's level counsellor. One study appears to have taken place within a University setting, although location specifics have not been clearly stated, and administration of the CBT elements was not clearly stated, however by searching the names thanked for facilitating the intervention some were shown to be health educators working in a university setting. This

intervention had the highest cessation rate. One of the studies was managed within primary care settings by general practitioners. Two studies included group support as part of the CBT intervention.

Table B3 2 - Quality Assessments for Trials of Cognitive Behavioural Interventions for Smoking Cessation

Study	Rating
Webb, M.S., Rodriguez de Ybarra, D., Baker, E.A., Reis, I.M, Carey, M.P. (2010). Cognitive-Behavioural Therapy to Promote Smoking Cessation Among African American Smokers: A Randomized Clinical Trial. Journal of Consulting and Clinical Psychology, 78, 1, 24-33	6
Prapavessis, H., Cameron, L., Baldi, J.C., Robinson, S., Borrie, K., Harper, T., Grove, J.R. (2007). The Effects of Exercise and Nicotine Replacement Therapy on Smoking Rates in Women. Addictive Behaviors, 32, 1416-1432	5
Wittchen, H., Hoch, E., Klotsche, J., Muehlig, E. (2011). Smoking Cessation in Primary Care - A Randomized Controlled Trial of Bupropione, Nicotine Replacements, CBT and a Minimal Intervention. International Journal of Methods in Psychiatric Research, 20, 1, 28-39	7

Table B3 3 - Abstinence Rates at 6-12 Month Follow-up

Trial		Intervention Group		Control Group		
Author/Year	Quality Rating	Quiters	%	Quiters	%	Difference %
Webb et al, 2010	6	24/77	31	11/77	14	17
Prapavessis et al, 2007	5	23/53	43	18/68	26	17
Wittchen et al, 2011	7	27/129	21	13/44	30	-9

Table B3 4 - Facilitator Leading Intervention

Facilitator Author/Year	Psychologist	Doctor	Health Educator
Webb et al, 2010	✖		
Prapavessis et al, 2007			✖
Wittchen et al, 2011		✖	

✖ = selected option

Table B3 5 - Intervention Components and Methods of Interventions

Components Author/Year	Relapse Support	Coping Skills Training	Self-Help Manual	Recognising Benefits of Quitting	Recognising Risky Situations / Triggers	Identifcation of Barriers	Consider Previous Attempts /Past Successes
Webb et al, 2010	×			×		×	×
Prapavessis et al, 2007					×	×	
Wittchen et al, 2011	×		×				

Components Author/Year	Behavioural Contracting	Cognitive Reframing	Negative Affect Reduction	Mood Management Planning	Recognising Negative Beliefs and Thoughts	Diary/ Self Monitoring	Withdrawal Management	Total Number of Components
Webb et al, 2010	×	×						6
Prapavessis et al, 2007						×		3
Wittchen et al, 2011							×	3

Discussion

Similarly to the last iteration of this review (Pires-Yfantouda & Sykes, 2010), out of thousands of studies, only 3 were shortlisted and quality assessed. Having reviewed the search criteria the terms are not too specific as they are specific about randomised controlled trials, and smoking, as well as the main features and terms found within CBT based studies. Due to searching keywords many irrelevant studies with no relation to smoking were found, therefore the search strategy could be tightened further to prevent wastefully reviewing studies. The three studies used did not score very highly on the quality checklist, largely due to no participant matching and relatively high dropout, and one did not use biomarker verification of abstinence. All of the studies had multi-component based CBT interventions, one provided nicotine replacement alongside both the CBT and control interventions, another gave 50% of the CBT group a nicotine patch and similarly for the comparison group. It has been shown that multimodal interventions incorporating both CBT and NRT have increased efficacy (Reus & Smith, 2008; Richmond, Kehoe, & de Almeida Neto, 1997).

In terms of outcomes, the most successful study was conducted by Prapavessis et al. (2007), which demonstrated high cessation rates in comparison to the other studies (43%). Of particular importance, this rate was measured at 1-year follow-up. The target population of this study was females as the study in order to assess whether the perception that quitting smoking results in weight gain, and whether an exercise intervention will mitigate this weight gain as well as proving as efficacious as a CBT based intervention. For this reason the participants selected were all inactive women who were medically fit.

The second most successful intervention was a study by Webb et al. (2010). The follow-up period was 6 months, therefore shorter than the other two studies. Although, research suggests that the relapse rate after 6 months is fairly low (Ussher et al., 2013), this will have an impact on the

efficacy of the intervention compared to the other two. The target population was African Americans who were medically fit. The interventions incorporated elements of CBT such as relapse prevention strategies and focused on barriers to success, but all participants, including those in the control condition, utilized nicotine patches.

The third study was conducted by Wittchen et al. (2011) and involved participants recruited through a primary care setting in Germany. All of those delivering the CBT arm of the study were primary care physicians with no expertise in CBT. The CBT was compared to pharmacological interventions incorporated with CBT, along with a minimal intervention of a brief motivational intervention, a smoking diary and a motivational information sheet. The pharmacological interventions consisted of bupropione plus CBT or NRT plus CBT. A 12 month follow up demonstrated all three methods were more effective than CBT alone with the minimal intervention achieving an abstinence rate of 29.6%, bupropione + CBT 29% and NRT + CBT 29.6%. At three months, however, the CBT was more effective than minimal intervention. This physician led intervention is the only study of the three to be delivered one-to-one.

Both interventions by Webb et al. (2010) and Prapavessis et al. (2007) had a difference between interventions of 17%, with CBT being more efficacious. This is a marked contrast to the -9% shown in the study by Wittchen et al. (2011). This difference may highlight the importance of practitioner expertise in the delivery of CBT based interventions for smoking cessation. The evidence from Pravavessis et al. (2007) that the group support element is an important fact to consider, may explain why the participants in the Wittchen et al. (2011) study experienced poorer cessation rates.

In terms of quality assessment, the study that scored highest was that of Wittchen et al. (2011), the second highest was that of Webb et al. (2010) with 6, and the study by Pravavessis et al. (2007) just scraped in with a score of 5. Whilst the search criteria were very strict, there are very few

papers eligible for the study. Generally the quality of the studies is good, although there could be some improvements made with regard to the biomarker verification, which has been shown to improve cessation rates (Ferguson et al., 2005) and provides confirmation of cessation. There is also a very high dropout amongst many studies, and motivation to quit is not reported, or measured. Should motivation to quit be low, that could explain why the dropout rates are high amongst these studies.

As all three studies utilized multi-component CBT interventions it is not possible to pick out the most effective component. There are, however, distinct differences in the number of CBT sessions offered within each intervention. Within the Wittchen et al. (2011) study, participants were offered 4-5 sessions of CBT lasting 20-30 minutes each, given a manual, and expected to do homework in-between sessions. Webb et al. (2010) provided participants with 8 weeks of NRT, combined with 6 group sessions, 60-90 minutes long. Prapavessis et al. (2011) provided participants with 3 group sessions a week, lasting 45 minutes each, for 12 weeks – a total of 36 sessions. This vast difference in contact time could explain the higher levels of cessation than the other studies, and the cost of facilitating these sessions may not justify the difference in abstinence.

What all three studies have demonstrated is that a multimodal intervention increases the efficacy of smoking cessation interventions. NRT plus CBT increases the efficacy of the cessation treatment. Currently the NHS SSS have a 1 year abstinence rate of 14.6% (Ferguson et al., 2005), which indicates that the current stop smoking programme offered widely within the UK are less effective than CBT interventions without NRT. The statistics shown in the introduction where a large proportion of those going through NHS SSS are abstinent are misleading without a longer-term perspective being added.

The study by Prapavessis et al. (2011) demonstrated that exercise is a useful intervention, especially when combined with NRT. Encouraging regular exercise during smoking cessation could be a useful adjunct to

CBT programmes to further increase efficacy, and reduce the resistance by women to quit smoking due to the fear of gaining weight.

Conclusion

Whilst none of the studies in this review are as efficacious as studies in the previous iteration, lessons can be learned from the individual studies. A relatively brief 4 to 6 week group CBT programme, with NRT, and access to exercise, could possibly provide an additive effect to one another. Delivery of CBT interventions should be done by someone suitably qualified, rather than physicians; although, within the UK it is unlikely that physicians are likely to get involved with cessation efforts other than by making a referral to a stop smoking service.

It is evident that there is scant research on the topic of CBT for smoking cessation, especially with sufficient follow-up and delivery by suitably qualified individuals. This is possibly due to most interventions having insufficient participants to have sufficient power for quantitative analysis. Within this study we incorporated search terms to pick up interventions based on third wave, yet there were none that met the criteria.

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Appendix B3-1

Systematic review question: A systematic review of cognitive and behavioural therapy programmes for smoking cessation

Background

Historically the most common method for the delivery of smoking cessation interventions was through group support programmes, usually via GP referral. This has now shifted in the UK with the proliferation of the NHS Stop Smoking Services (NHS SSS) toward a more pharmacological route, with one to one support. Pharmacological interventions mostly comprise of nicotine replacement therapy (NRT), most successfully delivered if two NRT products used simultaneously, and Varenicline (Champix). Of the pharmacological methods, 60% of those on Varenicline are successful with their quit attempt, as opposed to 46% who use NRT. In 2011/12 the proportion of people setting a quit date receiving a group intervention equated to 5% (see Table 1), despite being more efficacious than One on One interventions (The Health and Social Care Information Centre, 2012). Recent findings have also concluded that group interventions should, where possible, be used due to higher success rates (Bauld et al., 2010; Brose et al., 2011).

According to Stead and Lancaster (2002), smoking cessation interventions normally include methods to facilitate smokers coping during abstinence, social skills, training, contingency management, self-control and cognitive behavioural interventions. The abstinence oriented approach sees withdrawal discomfort as remediable. Smokers' self-efficacy is built up before setting a quit day and they are empowered and supported to achieve their objective of quitting smoking during initial stage of withdrawal from nicotine.

The evidence for employing these methods was based on a report informed by the "Scientific Committee on Tobacco and Health" (Department of Health, 1998a). The evidence of this report was based on

systematic review by (Law and Tang, 1995) by which the effectiveness of various smoking cessation interventions was evaluated. This review evaluated various interventions: 1) Advice and encouragement by doctor during consultation, with additional encouragement/support; nurses in health promotion clinics; support group sessions; in special circumstances; men at high risk of ischemic heart disease 2) Behaviour modification therapy – non specific approaches; aversion; rapid or satiation smoking; silver acetate; sensory deprivation; hypnoses 3) Pharmacological treatments to allay withdrawal symptoms – nicotine replacement therapy; clonidine; tranquilisers and other agents 4) Miscellaneous treatments 5) Gradual reduction of nicotine intake. According to Law and Tang (1995) there is no reason to support behaviour modification therapy to assist smokers to quit. According to Law and Tang (1995) behaviour modification therapy to assist smokers to quit is not cost-effective. However, they presented no data on cost-effectiveness in spite of recommending doctor's advice based on those grounds. They made no attempt to evaluate the quality of the studies included in their review, thus included good and bad quality papers. Several of the studies included in their review used no biochemical markers. Furthermore, there was no classification of the psychological interventions; they were grouped as non-specific behavioural modification interventions led by a psychologist. The nature of the intervention may be more meaningful than the profession of the person leading the intervention. They concluded that doctors should take time to advise all their patients who smoke to quit. Those smokers should be provided with additional support and Nicotine Replacement Therapy.

Whilst the UK has extensive smoking cessation services, available free of charge on the NHS, currently only 15% of the world's population have access to some form of cessation programme (World Health Organisation, 2013). The USA states that in more than half of its states NRT is available at no cost; they also provide telephone counselling though Quitline, which enables smokers to gain social support and coping skills (Centers for Disease Control and Prevention, 2013), which follows national guidelines on effective treatment using multimodal interventions

(United States Tobacco Use and Dependence Guideline Panel & Centre for Disease Control and Prevention (US), 2008). Similar to the UK, provision of CBT based interventions is not evident. Telephone counselling has been shown to be a useful adjunct to CBT interventions, although intensive CBT is superior to general telephone support (Killen et al., 2008). The lack of provision of CBT in both of these countries could explain the scant levels of research into the efficacy of CBT for smoking cessation. Some extant studies suggest that CBT is a beneficial add-on for other types of treatment, such as pharmacological interventions (Schmitz et al., 2007), although the evidence can be contradictory, where neither CBT nor pharmacotherapeutic interventions are that effective, separately nor in combination (McCarthy et al., 2008), yet in an adolescent population an NRT plus extended CBT intervention at six month follow up yielded significantly higher rates of abstinence (21%) than a non extended intervention (7%). Suggesting enhanced efficacy in extended CBT. This is echoed in a study within older adults, where an extended CBT intervention where participants received 10 sessions over the course of 10 months, with 55% maintaining abstinence over a two year follow up period. In this study the addition of NRT did not improve abstinence (Hall et al., 2009).

New third wave therapies, based on the CBT model, such as mindfulness, have been shown to have benefits within smoking cessation. In a comparison between traditional CBT and Acceptance and Commitment Therapy (ACT) smokers receiving the ACT intervention which focussed on enabling the participant to accept adversity, identify personal costs of actions, and classify their own values significantly outperformed the CBT intervention, with 42% of those completing the ACT intervention being abstinent at 12 months, as opposed to 17% in the traditional CBT group (Hernández-López et al., 2009). An ACT based online QuitWeb website has also been shown, in a recent pilot study, to be more efficacious than the US Government's Smokefree web intervention, 23% against 10% (Bricker et al., 2013). Mindfulness techniques, such as attentional focus using methods such as the body scan, have been shown to reduce cravings (Cropley et al., 2007; May et al., 2012), although evidence

currently suggests that these results are not replicable outside of the laboratory setting (Ussher et al., 2009). Mindfulness is also an intervention that is able to deal with multiple factors at one time. In women smokers with body image concerns, mindfulness has been shown to be effective in improving body image through having a non-judgemental and accepting approach to the self, and acknowledging and letting emotions pass, reducing negative affect, the desire to smoke and thus smoking behaviours (Adams et al., 2013), potentially dealing with the cause of the smoking, rather than the behaviour.

Aims

Systematic review protocol

Following Law and Tang (1995) and Pires-Yfantouda & Sykes (2010) reviews, a protocol was created (appendix 1). The aim of this protocol is to devise a framework for the systematic review.

Search strategy

Studies led by a health professional which had a cognitive and behavioural component were included in this analysis. PsychInfo, Web of Science, EMBASE, SCOPUS and Psychology & Behavioural Sciences Collection databases were searched from 2005 to 2013. Once articles were identified, they were screened for inclusion. Articles not specifically mentioning Cognitive and Behavioural interventions for smoking within the abstract were discounted.

Study selection criteria

Participants

Adults (>16 years of age) using cognitive and behavioural intervention to stop smoking.

Interventions

Psychological interventions with one or more components of cognitive and behavioural interventions which include methods to facilitate smokers

to cope during abstinence, such as relaxation techniques, use of diaries, identification of triggers, visualisation, changing routines, rehearsing strategies to cope with withdrawal, identification of thinking errors, cognitive re-framing, focusing on gains of staying abstinent, social support, social skills training, contingency management, self-control, aversion therapy, mindfulness, and acceptance and commitment therapies.

Outcomes

Cessation for at least 6 months

Study design

Randomised controlled trials

Search terms

The following search terms were employed using PsychInfo, Web of Science, EMBASE, SCOPUS and Psychology & Behavioural Sciences Collection databases:

- relaxation
- visuali?ation
- imagery
- trigger
- positive reasons
- self-control
- psychological
- behaviour therapy
- behavior therapy
- cognitive therapy
- randomi?ed controlled trial
- post-treatment follow-up
- abstinence oriented
- follow-up study
- psychotherapy

- smok* (Scopus – Smoking, Smokers, Smoke)
- aversion Therapy
- MBCT
- mindfulness
- acceptance and commitment
- ACT

Search terms entered as:

Smok*

AND

(relaxation OR visuali?ation OR imagery OR trigger OR positive reasons OR “self-control” OR psychological OR “behaviour therapy” OR “behavior therapy” OR “cognitive therapy” OR “post-treatment follow-up” OR “abstinence oriented” OR “follow-up study” OR “Psychotherapy” OR “aversion therapy” OR MBCT OR mindfulness OR “acceptance and commitment” OR ACT)

AND

“randomi?ed controlled trial”

<u>Quality Assessment Checklist</u>

In order to evaluate the quality of each paper, a quality assessment checklist was devised. Papers were scored based on each individual criterion whereby they were allocated 0 points if the standard was not met and 1 point if it was met. Individual scores were totalled and papers could score a minimum of 0 and a maximum of 10 points. The quality checklist was as follows:

1) Adequate randomisation (needs to be specified)
2) Adequate participants (including power analyses or over 100 participants per group in each group)

3) Biomarkers confirming self-reported abstinence in 95% of cases (CO in expired breath, saliva or urine sample)
4) Suitable comparison interventions
5) Similar groups at baseline (use of standardise scale to measure nicotine addiction, matched by age and gender)
6) No other confounding intervention
7) Acceptable drop out rate (25% or more)
8) Motivation to quit measured
9) Reliable measurement techniques (test retest/ internal consistency/split half)
10) Appropriate statistical analyses

Two researchers conducted the quality assessments independently. Each researcher had a quality assessment checklist. After both researchers have assessed all papers, scores were compared. As there was no disagreement above two scores amongst the researchers, the scores were averaged. It was agreed that the cut-off point for the inclusion of a paper was 5 as this was the median score.

Data Extraction Strategy

A data extraction form will be used to obtain the necessary information from the selected studies.

Data Extraction Form For the Efficacy of Psychological Interventions to Aid Smoking Cessation

General Information

Data of extraction:

Study reference:

Author contact details:

Identification number in systematic review:

Notes:

Study characteristics

Verification of study eligibility

- Participants
- Interventions
- Outcome
- Design

Methodological Quality of Study

Study design:

Quality assessment score:

Interventions

Intervention:

Number of condition groups:

Duration of intervention:

Outcome

What was measured at baseline?

What was measured after the intervention?

Who carried out the measurement?

Analysis

Statistical analysis used:

Follow-up rates for each condition:

Results

	Condition A Mean (SD)	Condition B	Condition C	Condition D
Variable 1 Pre Post				
Variable 2 Pre Post				

Data analysis

Subsequent to the establishment of the feasibility of meta-analyses, the following options will be decided upon:

1) Comparisons to be made
2) Outcomes to be measured
3) Which effect measures will be employed to explain effectiveness

Appendix B3-2

Table 6

A table showing quality ratings, summaries, and reasons for exclusion of papers excluded from the study

Study	Rating	Summary of Paper	Reason for Exclusion
Baker, A., Richmond, R., Haile, M., Lewin, T. J., Carr, V. J., Taylor, R. L., Jansons, S., Wilhelm, K. (2006). A Randomized Controlled Trial of a Smoking Cessation Intervention Among People With a Psychotic Disorder. American Journal of Psychiatry. 163, 11, 1934-1942	7	This study demonstrated the importance of attendance at all offered sessions as from those who attended all sessions, 47% were abstinent as opposed to 21% and 11% for those who attended 5-7, or less than 5 sessions, respectively. This study's target population was adults with nonacute psychosis, followed up for 12 months. The CBT therapists were trained and the treatment consisted of a manualised CBT program, Motivational Interviewing, plus NRT. 8 x 1 hour sessions were offered, homework was given.	Too many confounding interventions to identify the benefits of CBT
Sallit, J., Ciccazzo, M. (2009). A Cognitive-Behavioural Weight Control Program Improves Eating and Smoking Behaviors in Weight-Concerned Female Smokers. Journal of the American Diabetic Association. 109, 1398-1405	5	This study's target population was weight concerned adult females and participants were offered CBT for obesity, although some of the components such as cognitive restructuring, thought modification, and stress management, are transferrable to smoking cessation. At the end of the intervention, 5 of the 70 participants had quit smoking, whilst others had reduced their cigarettes consumed. The follow up period was 9 months.	Focussed primarily on weight control
Richmond, R., Indig, D., Butler, T., Wilhelm, K., Archer, V., Wodak, A. (2012). A Randomized Controlled Trial of a Smoking Cessation Intervention Conducted Among Prisoners. Addiction. 108, 966-974	6	This study took place within a prison environment with the target population being adult prisoners. Interventions were multimodal, including 2 brief CBT sessions, nortryptaline, and a booklet to accompany the CBT techniques, plus prisoners had access to Quitline. After 12 months the study demonstrated few improvements, other than a slight reduction in cigarette smoked.	Not a naturalistic setting

Killen, J.D., Fortmann, S.P., Schatzberg, A.F., Arredondo, C., Murphy, G., Hayward, C., Celio, M., Cromp, D., Fong, D., Pandurangi, M. (2008). Extended Cognitive Behavior Therapy for Cigarette Smoking Cessation. Addiction. 103, 1381-1390	7	Adult smokers were offered open 5 x 30 minute open CBT sessions before being randomised into a telephone support group, or an extended CBT group, 12 weeks of 30 minutes. Participants were also given Bupropion and NRT. The study showed that males respond better to CBT than females, whilst females respond better to the telephone support. The study suggests that the benefits of CBT diminish over time, unless maintained. The results showed no significant difference between the two groups with the 12 month abstinence rates being 31% and 27% for CBT and the telephone support, respectively.	Confounding effect of NRT and Pharmacotherapeutic intervention
Hernandez-Lopez, M., Luciano, M.C., Roales-Nieto, J.G., Bricker, J.B., Montesinos, F. (2009). Acceptance and Commitment Therapy for Smoking Cessation: A Preliminary Study of its Effectiveness in Comparison With Cognitive Behavioural Therapy. Psychology of Addictive Behaviors. 23, 4, 723-730	4	This study investigated the difference between traditional CBT and one of the third-wave CBT interventions, Acceptance and Commitment Therapy (ACT). Both groups received 7 x 90 minute group sessions, on a weekly basis. At the end of the 12 month follow up period the ACT group's levels of abstinence were significantly higher than those of the CBT intervention, 48% against 17%.	Comparison between two CBT based therapies
El-Mohandes, A.A.E., El-Khorazaty, M.N., Kiely, A., Gantz, M.G. (2011). Smoking Cessation and Relapse Among Pregnant African-American Smokers in Washington DC. Maternal and Child Health Journal. 15, S96-S105	7	This study's target population was African American females who are pregnant. Follow up period was 6 months. Participants were offered 10 sessions of CBT, each session being 35 minutes in length. Interventions were based on the SCRIPT protocols (Smoking Cessation or Reduction in Pregnancy) and tailored to their stage of change. The sessions were run during pregnancy, as well as postpartum which was shown to reduce the risk of relapse.	Use of pregnant women so not extrapolable to the wider population
Carmody, T.P., Delucchi, K., Duncan, C.L., Banys, P., Simon, J.A., Solkowitz, S.N., Huggins, J., Lee, S.K., Hall. (2012). Intensive Intervention for Alcohol-Dependent Smokers in Early Recovery: A Randomized Trial. Drug and Alcohol Dependence. 122, 188-194	7	The target population for this study was alcohol misusers in early recovery (1 week sobriety), who are light smokers. Participants were offered 16 sessions of CBT, plus 26 weeks of NRT patches. The control was usual care. Whilst throughout the intervention cessation rates were significantly higher for the CBT group, these were not sustained over the 12 month follow up period.	Participants were in recovery from alcohol addiction

Sharifirad, G.R., Eslami, A.A., Charkazi, A., Mostafavi, F., Shahnazi, H. (2012). The Effect of Individual Counseling, Line Follow-up, and Free Nicotine Replacement Therapy on Smoking Cessation in the Samples of Iranian Smokers: Examination of Transtheoretical Model. Journal of Research in Medical Studies. 17, 15, 1128-1136	6	This study was targeting Iranian adult smokers. They were offered 5 sessions of CBT lasting 45 minutes, plus a booklet, in addition they were provided with nicotine gum for 3 months, plus telephone support. At 6 months the levels of abstinence were significantly higher than control, with 60% of the intervention group being abstinent as opposed to 13% of the control.	Core focus on the transtheroetical model rather than CBT, plus confounding effect of NRT
Khazaal, Y., Chatton, A., Zebouni, F., Edel, Y., Jacquet, J., Ruggeri, O., Burnens, E., Monney, G., Protti, A., Etter, J., Khan, R., Cornuz, J., Zullino, D. (2013). Impact of a Board-Game Approach on Current Smokers: A Randomized Controlled Trial. Substance Abuse Treatment, Prevention, and Policy. 8, 3	5	In this study adult smokers were asked to play a CBT based board game with cards providing different scenarios presenting different lapse processes and delivering relapse prevention strategies, encouraging adoption of different behaviour strategies and distraction. Comparisons were against psychoeducational groups and a waiting list group. At the 3 month follow up the board game was slightly more effective in encouraging abstinence with 15% reporting abstinence, as opposed to 12% for psychoeducation group and 3% for the waiting list group. There was also a marked reduction in cigarettes smoked in the board game group.	Too short a follow up period
Kapson, H.S., Leddy, M.A., Haaga, D.A.F. (2012). Specificity of Effects of Cognitive Behavior Therapy on Coping, Acceptance, and Distress Tolerance in a Randomized Controlled Trial for Smoking Cessation. Journal of Clinical Psychology. 68, 12, 1231-1240	3	In this intervention adult smokers were randomised into one of two arms, one for a CBT + reduction plan, and another for health education + reduction plan. Both interventions were manualised to ensure consistency. Participants were offered 8 x 90 minute group sessions over the course of 7 weeks, with 3-5 people per group. The study did not embellish upon the results of the smoking cessation efficacy and predominantly looked at the effect on coping and distress tolerance.	Focus on depression rather than abstinence
Chan, S.S.C., Leung, D.Y.P., Abdullah, A.S.M., Wong, V.T., Hedley, A.J., Lam, T. (2011). A Randomized Controlled Trial of a Smoking Reduction Plus Nicotine Replacement Therapy Intervention for Smokers Not Willing to Quit Smoking. Addiction. 106, 1155-1163	6	This study recruited Chinese adults who reported no intention to quit smoking. Participants received 15 minute face to face intervention, which was behavioural but not specifically CBT based, plus NRT. Biochemical validation confirmed no significant difference between the intervention group and the control.	Interventions not specifically CBT, plus confounding NRT use

Korhonen, T., Goodwin, A., Miesmaa, P., Dupuis, E.A., Kinnunen, T. (2010). Smoking Cessation Program with Exercise Improves Cardiovascular Disease Biomarkers in Sedentary Women. Journal of Women's Health. 20, 7, 1051-1064	5	The target population in this study was sedentary non-exercising women. Participants received an exercise prescription, NRT and brief Cognitive Behavioural Counselling, 7 x 10 minute sessions over the course of 11 weeks. At 12 week follow up 44.6% of participants reported abstinence. Those who relapsed had higher pack years.	Primary focus is weight loss and exercise behaviours
Kapson, H.S., Haaga, D.A.F. (2010). Depression Vulnerability Moderates the Effects of Cognitive Behaviour Therapy in a Randomized Controlled Trial for Smoking Cessation. Behavior Therapy, 41, 447-460	6	This study used two interventions, one CBT + reduction, the other health education + reduction. Participants were recruited through advertisements asking for people who wanted to quit and were willing to be involved in group sessions. 8 x 90 minute sessions were provided in the psychotherapy training unit at American University. Some participants had used NRT and this adjunct to treatment improved efficacy of the interventions. No details of abstinence per condition were given due to the study's primary objective being the study of depression proneness.	Primary focus is depression
Whiteley, J.A., Williams, D.M., Dunsiger, S., Jennings, E.G., Ciccolo, J.T., Bock, B.C., Albrecht, A., Parisi, A., Linke, S.E., Marcus, B.H. (2012). YMCA Commit to Quit: Randomized Trial Outcomes. American Journal of Preventative Medicine, 43, 3, 256-262	3	The target population was underactive women smokers who were relatively healthy. Participants were offered 12 weeks of CBT, 60 minute group sessions, plus either a 12 month gym membership and personal training, or contact control. Those who engaged with the CBT plus personal training achieved abstinence of 9%, whereas those in the CBT plus contact control group was 5% after a 12 month follow up period.	Primary focus on the additive effect of exercise
Ward, K.D., Asfar, T., Ali, R.A., Rastam, S., Vander Weg, M.W., Eissenberg, T., Maziak, W. (2012). Randomized Trial of the Effectiveness of Combined Behavioural/Pharmacological Smoking Cessation Treatment in Syrian Primary Care Clinics. Addiction. 108, 394-403	7	Adult smokers were randomised into groups, with the intervention group consisting of NRT and behavioural support. No CBT was defined. At 6 month follow up the placebo condition was more effective than the NRT intervention, although this was reversed at 12 months with the brief counselling plus NRT condition 7 day point prevalence being 20% as opposed to 15% for the placebo.	CBT was not stipulated within the intervention, plus confounding effect of NRT

Section C: Professional Practice (Case Studies)

Area of Competence: Teaching and Training 1

Solution-Focused Therapy: In-House Staff Workshop

Setting

[redacted]

Target Group

[redacted] staff team and volunteers

Description of Training

Practicable Solution-Focused skills for use with substance misuse clients

Planning and Designing Training Programmes That Enable Students To Learn About Psychological Knowledge, Skills, and Practices

[redacted] host a monthly team development session to allow the staff and volunteers to develop skills, knowledge, and enhance understanding of referral pathways for clients. As I had knowledge and experience of using a solution-focused approach with my clients I offered to deliver this training, and the management team accepted the offer.

A training needs assessment questionnaire was designed and distributed to all staff and volunteers via email to identify extant knowledge of solution-focussed approaches; confidence in the use of solution-focussed techniques; preferred training style; and, any specific areas that attendees would like covered by the training. The initial questionnaire only generated one response, potentially due to the busy schedule of all staff and volunteers. In light of this I developed a survey on SurveyMonkey with the aforementioned components. When a respondent stated they have no experience of solution-focussed approaches they would be diverted away from questions regarding confidence and use in clinical work. Twelve people responded to the SurveyMonkey questionnaire (see appendix 3 for summarised results), where 42% had no awareness of solution-focussed approaches. With 75% stating they prefer a mixed training

style, and with only having one-hour to deliver the training I developed a training plan (Appendix 1) that would gradually build solution-focussed skills, providing a brief introduction to the solution-focussed approach.

The aims of the workshop were briefly mentioned in the hand-out (appendix 2). The workshop and teaching materials were developed based on relevant training that I have attended, personal experience, and Bill O'Connell's book (O'Connell, 2012).

Delivering the Training Programme

Prior to delivering this workshop I had experienced delivering training to external groups (through drug and alcohol awareness courses delivered to organisations), designing and delivering workshops to client groups, and to the staff and volunteers. In addition I attended a DPsych workshop on teaching and training. I took on board feedback and implemented changes as required, considering the specific needs of the audience. Past experience demonstrated this particular audience do not enjoy didactic presentations, which was reinforced through the training needs assessment. For this reason, the workshop was predominantly practice based with three group exercises. References were provided for those who wanted an evidence-base for using the methods being taught.

On 5th June 2014 the workshop was delivered to 13 staff and volunteers. The training plan was adhered to in terms of content, although following the first exercise it was apparent the time allowed for the following exercise was insufficient and was therefore increased to allow proper exploration of the techniques. This did not impact the rest of the timings and the workshop ran to time.

Attendees were encouraged to ask for clarification on the group exercise, and were given an opportunity at the end to ask questions. Following each group exercise, attendees were encouraged to feedback their thoughts and experiences to the group.

Planning and Implementing Assessment Procedures for the Training Programme

The learning objectives were assessed throughout the workshop through listening into each small group during the group exercises to ensure the methods were being utilised correctly. In one instance one attendee was not following the method so I reiterated the use of eliciting solutions from the "client", which led to him correcting his technique during the exercise. Furthermore, understanding was assessed when individual members were feeding back to the group following the exercises.

Evaluating the Training Programme

Due to the success collecting responses to the training needs evaluation, I designed an evaluation form on SurveyMonkey and disseminated it to all attendees, along with an electronic copy of the training materials. Responses were reviewed and collated (Appendix 4). The evaluation highlighted that most learners found the training highly effective and particularly appreciated the opportunity to trial the techniques discussed during the exercises. The majority of respondents rated the workshop as highly motivational, stating the most beneficial aspects were "Tim's subject material was pitched at just the right level. It was well researched and his facilitation style was very engaging" and "Empowering the clients by exploring what worked for them in the past". It was apparent that one attendee did not appreciate the training, stating that "it could have been explained better" and that a negative of the training was "the role plays as it was not made clear what to do", and another stated that it would have been better to have more time to practice the skills.

Feedback on my skills as a trainer were largely positive, although one respondent reported my skills not showing any confidence or enthusiasm, not checking understanding, nor including everyone. The summary data was sent to the Chief Executive for his information.

Summary and Reflection

Overall the feedback from the workshop was positive and staff and volunteers found the training motivational and educational. A deficit in the evaluation form resulted in the inability to compare increase in confidence and on reflection this

should have been included. Past training experiences have demonstrated the need to target the delivery correctly to the audience, with the right balance of information giving, and skills building. In this instance the workshop was short, with the objective of providing a brief introduction to solution-focussed approaches, with some practicable new clinical skills. I purposely jumped into the workshop with an exercise, partially due to time restraints, and to break the ice. Whilst I am happy with this approach, on reflection I could have included a clearer verbalisation of the aims and objectives of the workshop following the brief icebreaker exercise.

Reflecting upon the individual who gave very negative feedback, I tried to ensure that the workshop was targeted at all practitioners. That individual is a former service user who is now staff, and therefore has a different background to the other attendees. As I was aware of his position, I could have given this greater consideration, checking in with him during practice sessions providing him more opportunities to ask questions and gain a better understanding of the techniques.

This training has helped me acknowledge I am more comfortable with interactive training, rather than using overtly didactic methods, and attendees engage better with my training when they can interact through exercises.

References

O'Connell, B. (2012). *Solution-Focused Therapy* (3rd ed.). London: Sage Publications Limited.

Appendix 1: An introduction to solution-focused therapy – Training Plan

Aims

The aim of this brief workshop is to introduce you to using a solution-focused approach within your clinical practice.

Activity 1

(check total number of attendees) in pairs, spend 5 minutes talking about a problem you're currently having. (2.5 minutes each). One person sits and listens for 2.5 minutes, and I'll tell you when to swap over. The other can acknowledge listening through nods and utterances, but try to resist a conversation as much as possible.

Discussion – Now, without having to reveal your problem, how did that feel? Did it make you feel better? Worse? How was it to listen to? To talk? How helpful was it in finding a solution to your problem? Are you closer to sorting it out?

Introduction

A solution-focused approach is a way of helping clients to identify goals, which will lead to their future recovery. By guiding clients away from storytelling and focusing on problems we can allow clients to be the expert in the room: we become facilitators of change. The client is the expert in their own life; and, despite often not realising it, have had experiences in their past of success in either reducing or abstaining from their substance or substances of choice. By assisting clients to identify these past successes we can help them construct future goals and the methods by which they will achieve them.

Solution focused approaches can be very brief and delivered in one or only a few sessions if needed. They can be delivered within minutes and are therefore useful within the context of drop-in sessions as well as during keyworking and counselling sessions.

Substance misuse is maintained through routine. Clients often report daily routines revolving around their substance misuse. By encouraging clients to

consider solutions to create new routines disrupts this old pattern and strives to create more variety and less routine; therefore, facilitating recovery.

When using a solution-focused approach it is important to be agnostic towards the clients' routes to recovery. Clinicians should make no assumption of what a healthy or unhealthy resolution to the problem is – the process is client led.

Questions in a solution focused approach

- Tell me, what are your hopes for this session?
- What would you like to get out of the session?

These questions open the door to clinicians using solution-focused approach. It is possible that the client's first reaction will be "I don't know". This is not a sign for us to give up using this approach; alternatively we can use other questions to elicit more detail from the client. We may simply ask, "What do you think?" To try and encourage clients to think more about the question rather than dismissing it out of hand, or we can rephrase the question to something like "what needs to happen here today to make you think this meeting was worthwhile?" Or "what makes you think that now is a good time to make some changes?"

If the client remains vague with responses like "I suppose it will be useful", continue with curiosity "in what way do you hope it will be useful?" If they respond with a statement like "it might help me stop drinking" you can respond with a reflective question similar to "so if this meeting helps you to stop drinking it will have been worth your while?".

This approach prevents clients wasting session time by recounting stories and assigning blame for the problems that they experience in their lives. It may seem alien at first, but focusing on future orientated goals can allow the client to start gravitating towards goal achievement.

Exercise 2 – now, in your same pairs, be more engaging with your client. Forgetting the story telling about the problem, and start off with a solution focused approach. Again, spending 5 minutes (2.5 per person) doing this.

Discussion – how was this different to merely recounting your problem?

Often clients break routine just to attend our sessions, yet they don't recognise this as any form of success. They can also experience increased motivation to reduce just by knowing that they have a weekly session to attend, or that they are on the waiting list to attend a weekly session with a substance misuse worker. It is therefore important that we acknowledge, and allow them to acknowledge, this change, however small it may be.

- What's changed since you started coming here?
- What's changed since I last saw you?

Allowing clients to recall small changes can enhance their self-efficacy and boost their chances of recovery.

When a client recalls delaying using their substance of choice for any period of time, ask them how they did that or how they decided to do that. Again, if they respond with "I don't know", give them a few minutes to think back to the situation and recall what was going through their mind at the time, whether they were thinking something or doing something that allowed them the ability to abstain. This allows the client to learn that some activities allow them to delay their substance use and formulate methods to increase this delay and increase abstinence in the future.

The client is at the centre of this method. The client knows best how they live their lives, and what works and does not work for them. The clinician is there to facilitate the clients learning about their own experiences and give them the space, time, and opportunity to explore their own path to recovery using resources that they already have. Asking clients about situations where they have abstained, for any amount of time, promotes their learning and questions

like "what have you learned from this?" And "what do you now know works or does not work for you?".

If the client is struggling to think of a recent event where they had success encourage them to cast their minds back to success in the past. The curious practitioner enquiring how they managed to do that, finding out what they found helpful and unhelpful, and maybe finding out what the client knows about themselves that could reassure them that they can deal with their situations.

Similarly to motivational interviewing, solution focused approaches can incorporate scaling questions. Question such as "how confident are you in your recovery on a scale of 1 to 10, where 10 is the most confident you can be?" Can allow exploration and understanding of the current situation. If a client responds with 2, ask them how they would increase that to a 3 or 4. With a question along the lines of "what would you have to do to help you do that?".

Exercise 3 – Now, again in your same pairs, continue your solution focused approach, but building on it by drawing on events from the past in which they have achieved a goal, using scaling questions to understand and enhance their confidence. You have 5 minutes each to do this.

Discussion – how has your confidence improved in dealing with your problem? Have you found the methods effective?

As a substance misuse service the main goal for any client that we sit opposite will be a reduction in use of their substance, or abstinence from use. Sometimes to get to this point we may need to help clients achieve other goals to increase their confidence in reducing their substance use. If a client uses problem-focused statements, a skilled practitioner can flip these into an outcome and therefore maintaining a solution-focused approach.

Throughout a solution focused approach the clinician should have confidence in the methods being used. As with any treatment method one component is a placebo; therefore, creating a positive expectancy of success within the client

increases chances of client recovery. It is therefore important to try and steer away from negative language throughout the session. If the client does stray into storytelling this can result in wasted time and return the focus back onto the problem. It may be necessary to interrupt the client and refocus them, acknowledging that what they said is useful but asking them a question to bring them back on track.

Throughout the session the clinician should be listening for possible solutions: evidence of strengths, qualities, and past successes stated by the client. These may be very subtle. The use of “how” questions is very important. If a client has stated certain skills, talents, or experiences from the past that they do not associate with their current problem or therefore the solution, highlight what skills are transferable to enable them to achieve their goals. If they've had success in the past, even in totally different areas of their life, acknowledge these and ask them how they did it.

Some novel ways of using solution-focused methods in session

Drawing

Using drawing in session can take various forms. The use of visual methods with some clients can allow them to relate to their solutions in a way they understand better.

Drawing can be something simple, such as drawing their current positions with scaling question responses, to more complex diagrams of their idealized future, achieving a goal, or a comic strip of them going through the process of goal achievement. Or can be something like a “problem island” and “solution island”.

Letter writing/Journal/Diary keeping

For some clients, writing or diary keeping can be a powerful part of their recovery.

It could be valuable for clients to note down successes between sessions – times they resisted that extra drink, or that first drink. They can also note down lapses, the thoughts and feelings, the circumstances surrounding the lapse. This can benefit both the client, and the practitioner, by boosting confidence in

the successes, and gaining understanding in what they stopped doing when they lapsed.

The above are merely examples of what you could do to incorporate solution-focused approaches into your clinical practice. You can use your imagination, and your knowledge of your client, to develop something specific to their needs.

Do solution-focused approaches work?

There is evidence that they do. In one study, of 72 outpatients with problem drinking behaviours, 81% reported goal maintenance at 4 year follow-up (de Shazer & Isebaert, 2003). The Bruges Model (de Shazer, 2004) has also been used in Germany and has been found to be popular with clients due to the transparent method of treatment; the clients found it helpful; and, would recommend it to others (Nelle, 2005).

Q&A – Closing Discussion

Further reading

Solution-Focused Therapy by Bill O'Connell

Bibliography

De Shazer, S. (2004). The Bruges Model. *Journal of Family Psychotherapy*, *14*, 43–52.

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Nelle, A.-C. (2005). Solution and Resource-Oriented Addiction Treatment with the Choices of Abstinence or Controlled Drinking. *Journal of Family Psychotherapy*, *16*(3), 57–68. doi:10.1300/J085v16n03_05

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An introduction to solution-focused therapy

Aims

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Solution focused approaches can be very brief and delivered in one or only a few sessions if needed. They can be delivered within minutes and are therefore useful within the context of drop-in sessions as well as during keyworking and counselling sessions.

Substance misuse is maintained through routine. Clients often report daily routines revolving around their substance misuse. By encouraging clients to consider solutions to create new routines disrupts this old pattern and strives to create more variety and less routine; therefore, facilitating recovery.

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The above are merely examples of what you could do to incorporate solution-focused approaches into your clinical practice. You can use your imagination, and your knowledge of your client, to develop something specific to their needs.

Do solution-focused approaches work?

There is evidence that they do. In one study, of 72 outpatients with problem drinking behaviours, 81% reported goal maintenance at 4 year follow-up (de Shazer & Isebaert, 2003). The Bruges Model (de Shazer, 2004) has also been used in Germany and has been found to be popular with clients due to the transparent method of treatment; the clients found it helpful; and, would recommend it to others (Nelle, 2005).

Q&A – Closing Discussion

Further reading

Solution-Focused Therapy by Bill O'Connell

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Breaking Routine

Using the sheet below, consider your current substance use patterns, and how you might be able to change one thing to change the pattern in the next 48 hours.

When do you start using?

_____
_____
_____
_____
_____

Where do you start using?

_____
_____
_____
_____
_____

What triggers off your using?

_____
_____
_____
_____
_____

Who is around when you use?

_____
_____
_____
_____
_____

Now, choosing one of the above, what can you do differently this week? And how will you do this?

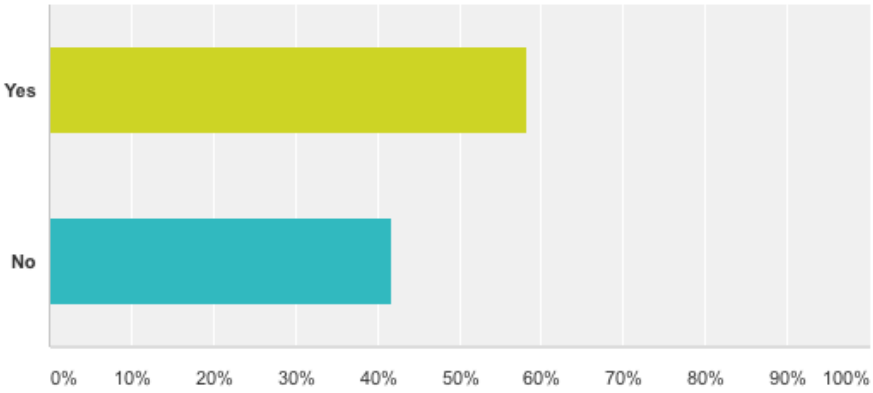
_____
_____
_____
_____
_____

Q1

Customize Export

Are you currently aware of solution focussed therapy?

Answered: 12 Skipped: 0



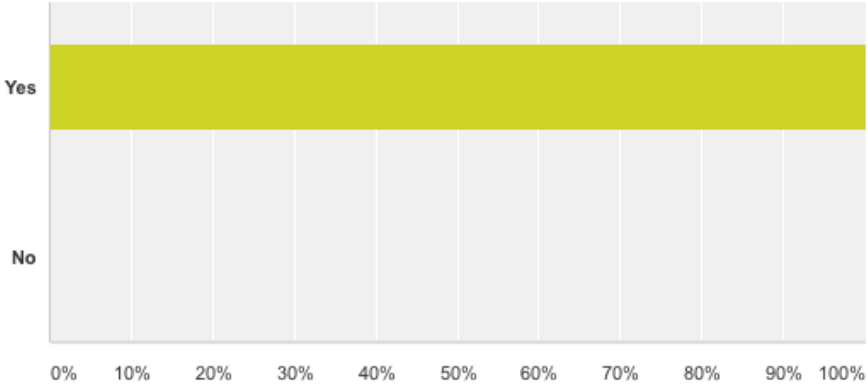
Answer Choices	Responses	
Yes	58.33%	7
No	41.67%	5
Total		12

Q2

Customize Export

Have you ever used a solution focussed approach in your clinical practice?

Answered: 6 Skipped: 6

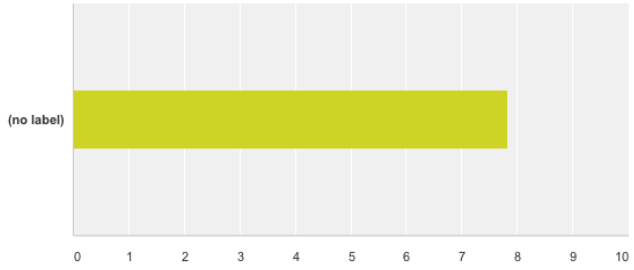


Answer Choices	Responses	
Yes	100.00%	6
No	0.00%	0
Total		6

Q3 Customize Export

How confident are you in using a solution focussed approach?

Answered: 6 Skipped: 6

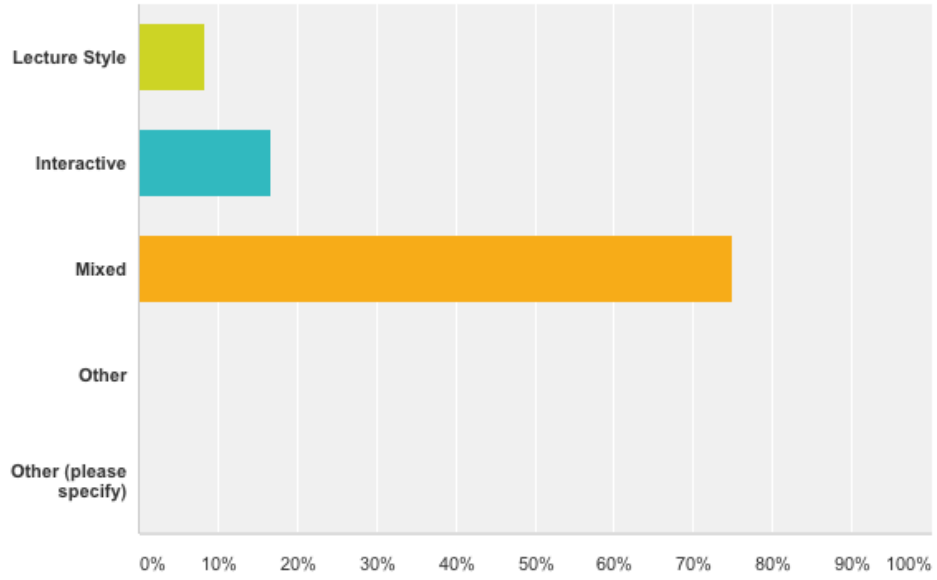


	No Knowledge	(no label)	(no label)	(no label)	(no label)	(no label)	(no label)	(no label)	(no label)	Experienced	Total	Weighted Average
(no label)	0.00% 0	0.00% 0	0.00% 0	0.00% 0	0.00% 0	16.67% 1	16.67% 1	50.00% 3	0.00% 0	16.67% 1	6	7.83

Q4 Customize Export

What is your preferred method of learning?

Answered: 12 Skipped: 0



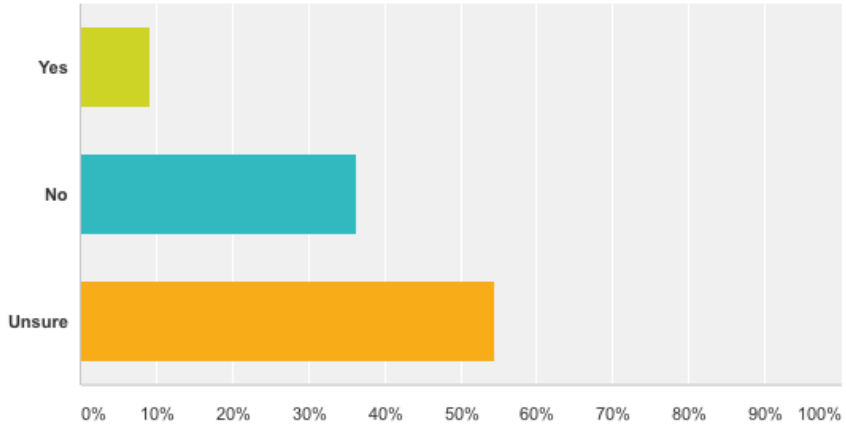
Answer Choices		Responses	
Lecture Style		8.33%	1
Interactive		16.67%	2
Mixed		75.00%	9
Other		0.00%	0
Other (please specify)	Responses	0.00%	0
Total			12

Q5

Customize | Export

Is there any specific area of solution focussed therapy that you would like clarification on?

Answered: 11 Skipped: 1



Answer Choices	Responses	
Yes	9.09%	1
No	36.36%	4
Unsure	54.55%	6
Total		11

Comments (1)

Q6

Export

What would you like from this training?

Answered: 9 Skipped: 3

Responses (9) | Text Analysis | My Categories

Categorize as... | Filter by Category | Search responses

Showing 9 responses

Knowledge refreshment
6/4/2014 4:28 PM View respondent's answers

nothing in particular
6/2/2014 11:28 AM View respondent's answers

Feel more confident and natural when using this approach
5/30/2014 3:23 PM View respondent's answers

I understand the principle of it but have no understanding of how it would work in practice working with clients
5/30/2014 1:21 PM View respondent's answers

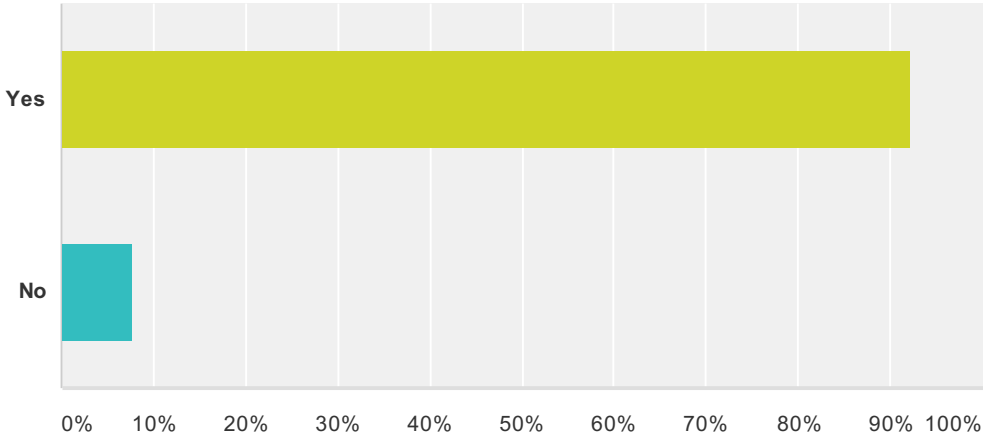
To know more about solution focussed therapy
5/30/2014 1:06 PM View respondent's answers

To learn in more detail about solution focussed therapy. I have heard of it, but would like to better learn what it is and how I could use it at work.
5/30/2014 12:24 PM View respondent's answers

knowledge on brief solution focus methods

Q1 Were the objectives of the training made clear?

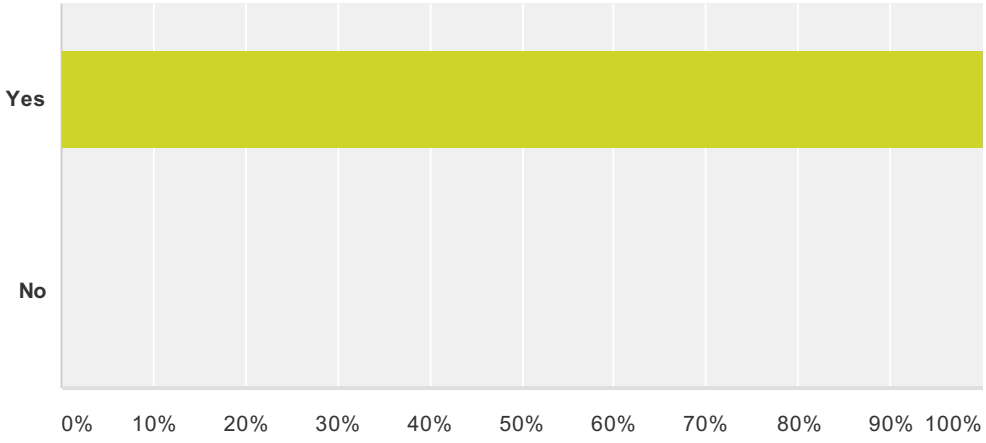
Answered: 13 Skipped: 0



Answer Choices	Responses	
Yes	**92.31%**	12
No	**7.69%**	1
Total		**13**

Q2 Do you feel the training met its objectives/goals?

Answered: 13 Skipped: 0

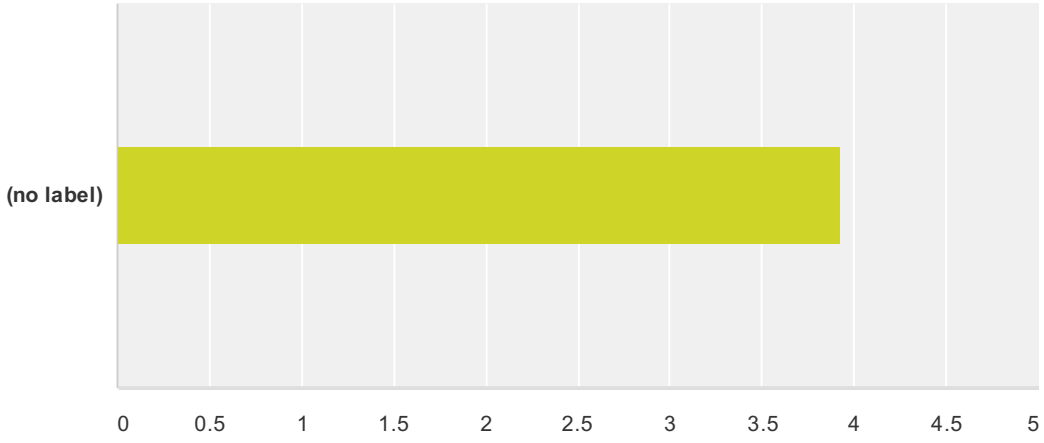


Answer Choices	Responses	
Yes	**100.00%**	13
No	**0.00%**	0
Total		**13**

#	If not, why?	Date
	There are no responses.	

Q3 To what extent did you find the training session motivational?

Answered: 13 Skipped: 0



	Not at all	Somewhat	Fairly	Very	Completely	Total	Average Rating
(no label)	**0.00%** 0	**15.38%** 2	**0.00%** 0	**61.54%** 8	**23.08%** 3	13	3.92

Q4 In your opinion, what was the most beneficial section/element of the course, and why?

Answered: 11 Skipped: 2

#	Responses	Date
1	Tim's subject material was pitched at just the right level. It was well researched and his facilitation style was very engaging	6/18/2014 9:34 AM
2	time to actively use the techniques discussed, practical application	6/18/2014 3:59 AM
3	All of it	6/17/2014 1:11 AM
4	it was ok. Could have been explained better	6/16/2014 10:57 PM
5	Empowering the clients by exploring what worked for them in the past-	6/16/2014 6:22 AM
6	all of it	6/16/2014 5:08 AM
7	working in pairs	6/12/2014 3:49 AM
8	Getting a better understanding of what the practicalities of solution focused therapy are.	6/6/2014 5:35 AM
9	Your instruction	6/5/2014 4:06 AM
10	teaching us to encourage clients to use previous achievements of theirs/ times when they overcome problems to demonstrate that they can put these skills to use in overcoming problems current/ future issues	6/5/2014 3:45 AM
11	putting discussion into practice	6/5/2014 3:27 AM

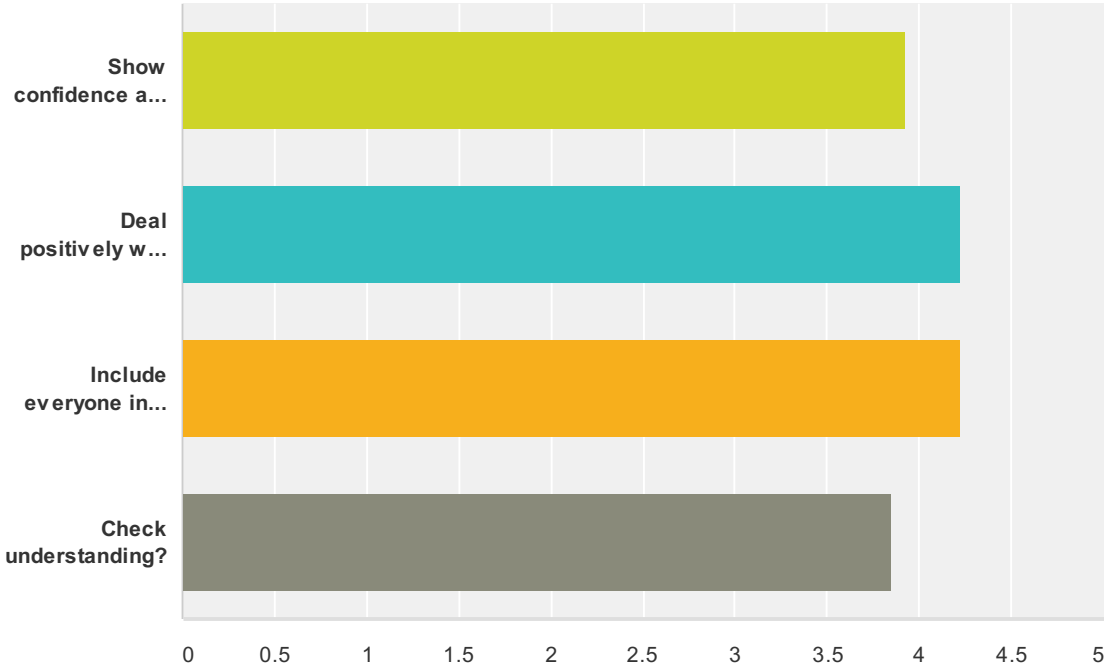
Q5 In your opinion, what was the least beneficial section/element of the training, and why?

Answered: 11 Skipped: 2

#	Responses	Date
1	Cannot think of anything that wasn't beneficial	6/18/2014 9:34 AM
2	none	6/18/2014 3:59 AM
3	nothing	6/17/2014 1:11 AM
4	the role plays as it was not made clear what to do	6/16/2014 10:57 PM
5	The training was perhaps bit short	6/16/2014 6:22 AM
6	none	6/16/2014 5:08 AM
7	no	6/12/2014 3:49 AM
8	Not having enough time to get a more comprehensive understanding of SFT and using most of the time in group work.	6/6/2014 5:35 AM
9	none	6/5/2014 4:06 AM
10	none	6/5/2014 3:45 AM
11	nothing	6/5/2014 3:27 AM

Q6 To what extent did the trainer:

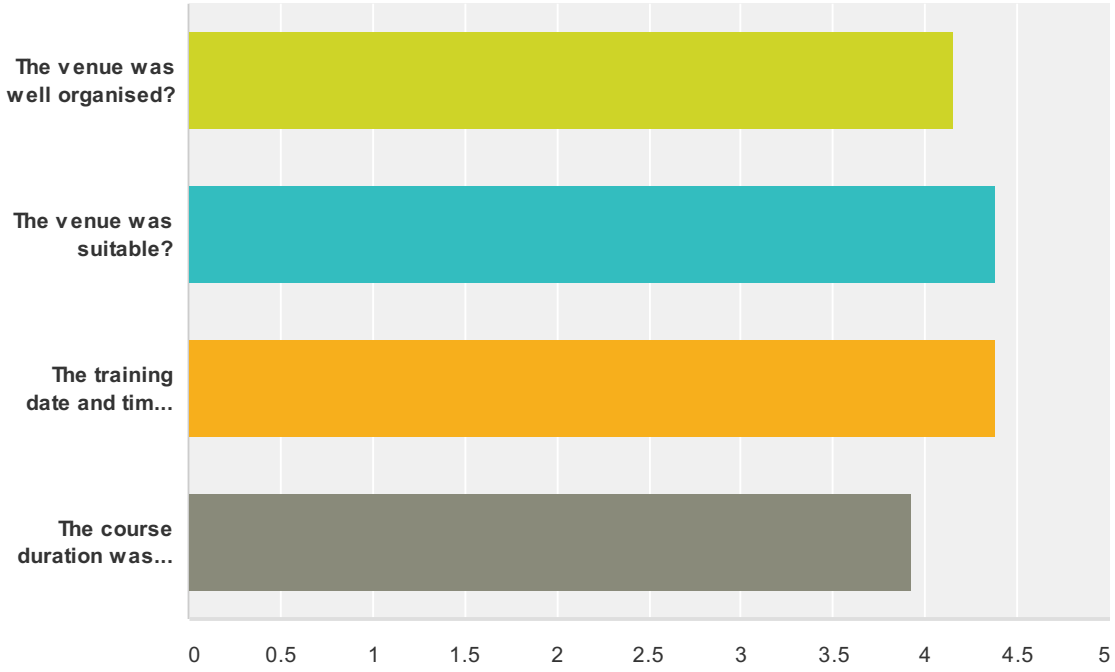
Answered: 13 Skipped: 0



	Not at all	Somewhat	Fairly	Very	Completely	Total	Average Rating
Show confidence and enthusiasm?	**7.69%** 1	**7.69%** 1	**7.69%** 1	**38.46%** 5	**38.46%** 5	13	3.92
Deal positively with questions?	**0.00%** 0	**7.69%** 1	**7.69%** 1	**38.46%** 5	**46.15%** 6	13	4.23
Include everyone in discussion/activity?	**7.69%** 1	**0.00%** 0	**7.69%** 1	**30.77%** 4	**53.85%** 7	13	4.23
Check understanding?	**7.69%** 1	**0.00%** 0	**23.08%** 3	**38.46%** 5	**30.77%** 4	13	3.85

Q7 Training practicalities

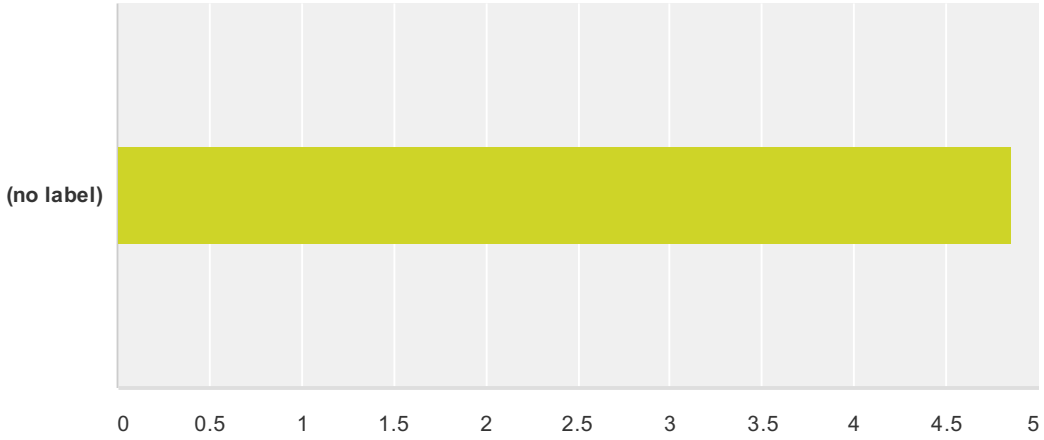
Answered: 13 Skipped: 0



	Not at all	Somewhat	Fairly	Very	Completely	Total	Average Rating
The venue was well organised?	**0.00%** 0	**0.00%** 0	**23.08%** 3	**38.46%** 5	**38.46%** 5	13	4.15
The venue was suitable?	**0.00%** 0	**0.00%** 0	**7.69%** 1	**46.15%** 6	**46.15%** 6	13	4.38
The training date and time was convenient?	**0.00%** 0	**0.00%** 0	**15.38%** 2	**30.77%** 4	**53.85%** 7	13	4.38
The course duration was appropriate?	**7.69%** 1	**0.00%** 0	**23.08%** 3	**30.77%** 4	**38.46%** 5	13	3.92

Q8 Please rate the overall effectiveness of the training in terms of what you have gained.

Answered: 13 Skipped: 0



	Poor level of effectiveness	(no label)	(no label)	(no label)	(no label)	Highest level of effectiveness	Total	Average Rating
(no label)	**0.00%** 0	**15.38%** 2	**0.00%** 0	**0.00%** 0	**53.85%** 7	**30.77%** 4	13	4.85

Q9 Any other comments regarding the training?

Answered: 5 Skipped: 8

#	Responses	Date
1	very informative	6/16/2014 5:08 AM
2	Very useful	6/12/2014 3:49 AM
3	A few minutes more on introduction before staring the paired work could have set the scene, otherwise inclusive, very helpful and good pace	6/5/2014 4:06 AM
4	very informative and engaging	6/5/2014 3:45 AM
5	A big topic and a very good introduction!	6/5/2014 3:27 AM

CITY UNIVERSITY LONDON

Department of Psychology
City University
Northampton Square
London
EC1V 0HB

Stage 2 Training in Health Psychology/ Doctorate of Psychology

Teaching and Training Observation Report

Trainee Details

Name: Timothy Mahy
Chartered Health Psychologist Supervisor: Dr Clare Eldred
Audience: Staff and volunteers employed by [redacted]

Please circle the appropriate response and make comments

Appropriate resources and material were used YES

Delivery of material: Good

Responded effectively to problems, queries and issues during the training YES

Supported students through the learning programme YES

Provided encouragement and accurate feedback to learners during training YES

Appropriate evaluation methods were used YES

Comments

The training session, on Solution Focused approaches, was well prepared and presented in an informal manner that was appropriate setting. The training content was developed based on prior assessment of attendees' skills and knowledge in this area. The aim of the training was provide practical techniques that those attending could apply in their work role. This was achieved by the use of regular short practice sessions throughout the training with opportunities for discussion and feedback in between with new skills being introduced gradually. Attendees were supported well throughout the training and questions answered appropriately. Feedback at the end of the session indicated that the training aims had been met attendees had developed new, applicable skills.

Declaration

I am of the opinion that the above named trainee has completed the teaching and training competence to a high professional standard and is able to act autonomously in this competence.

Signature: Date: 03/07/2014

Area of Competence: Teaching and Training 2

A Brief Series of Workshops on Stress, Wellbeing, and Happiness

Setting

[redacted]

Target Group

[redacted] Service Users

Description of Training

A brief series of educational workshops to promote the adoption of behaviours that reduce stress and enhance wellbeing

Planning and Designing Training Programmes That Enable Students To Learn About Psychological Knowledge, Skills, and Practices

[redacted] was planning a new day programme, requiring the designing and planning of new groups that would appeal to the service users. As I am a trainee health psychologist; and, have an interest in positive psychology and stress reduction techniques I was asked to design and implement a new psycho-educational relaxation group.

A training needs evaluation form (appendix 1) was distributed through the staff and volunteers to assess components that they believe their clients would benefit from; and, the suggested optimal mode of delivery. The responses from three of the staff and volunteer group indicated that all of the proposed topics – diet; exercise; mindfulness; relaxation; stress; sleep hygiene; and meditation – were deemed to be quite to very important. One of the three was uncertain of the meaning of sleep hygiene so after being given an explanation, they agreed this would be of benefit to their clients. It was identified that service users tend to prefer group discussion based training, although it was also noted that practical elements would also be useful with some didactic training in the case

of dietary training. Based on this feedback, plus experience of delivering training courses to service users, I developed a training plan to deliver an 8 week psycho-educational group, incorporating relaxation training each week, plus a health related topic.

The plan to deliver the 8-week programme had to be reconsidered due to poor attendance and the nature of the referrals into the group. The relaxation training sessions did continue, although the highest attendance was 2 and both attendees were intoxicated at the time. I was asked to provide holiday cover for Project Aspire by the project co-ordinator. Project Aspire is a workshop-based group promoting the benefits of volunteering and providing skills to cope in stressful situations. After discussing my proposed workshop with the facilitator, and proposing that I return at a later date to deliver another session, I adapted my training to fit into the 2-hour workshop format. I had regularly co-facilitated Project Aspire in the past and was therefore experienced delivering training to this group. Some of the initially planned components of the training were abandoned due to their being incorporated into other groups that HAGAM were planning, such as nutrition and exercise groups. My final plan was a 2-session programme, with the first workshop introducing the affect of stress on the body, based on “Why Zebras don’t have Ulcers” (Sapolsky, 2004). Stress was chosen as a key topic to cover as stress is acknowledged to be a significant contributor to the risk of relapse (Sinha, 2007), in addition to the myriad of other health risks associated with stress, such as cardiovascular disease and a reduced immune response (Sapolsky, 2004); with the second workshop promoting positive psychology, based on “Action for Happiness” (Action for Happiness, 2014a). Whilst there has not been much research into the efficacy of positive psychology based interventions within the field of addiction (Krentzman, 2013), there is potential for interventions to reduce alcohol dependence and drug use, plus improve happiness (Akhtar & Boniwell, 2010). Positive psychology interventions can be helpful in improving overall subjective wellbeing and psychological health (Bolier et al., 2013).

Training plans were devised:

Workshop 1 (appendix 2) Using skills and knowledge of psychoneuroimmunology developed over the course of stage one training; the ideomotor response learnt during a recent BPS approved course in hypnotherapy; and, the knowledge developed through reading "Why Zebras Don't Have Ulcers" (Sapolsky, 2004) a training plan was developed using exercises to demonstrate the impact of thoughts on our physiology – primarily the "bucket and balloon" test, plus a dowsing exercise. In addition to this, a stress bucket exercise was used (appendix 4). The stress bucket is an exercise I discovered on a recent [redacted] MIND course on mental health that encourages the individual to consider the stressors in their life, how those stressors affect behaviour and life, and coping mechanisms to 'empty the bucket'. The remainder of the workshop was didactic. Due to the nature of the audience, there would be opportunities to discuss the content as we ran through it to maintain engagement with the content.

Workshop 2 (appendix 5) – Based on knowledge from "Action for Happiness"; a recent lecture on the science of happiness (Ben-Shahar, 2014); and, previous experience of research into the psychology of wellbeing and quality of life, I devised a training plan. The core of the workshop revolved around the 10 ways to wellbeing (Action for Happiness, 2014b). PowerPoint slides were designed to be simple in nature and included a prompt for discussion on each of the 10 ways to wellbeing (Appendix 7). One task was designed whereby attendees would write down three strengths of another person in the room (Appendix 8).

Delivering the Training Programme

Historically, I was co-facilitator of Project Aspire and assisted with the delivery of workshops, as well as delivering workshops when providing cover for the main facilitator. Past experience of this client group allowed me to understand the importance of group involvement in the training to maintain engagement throughout the two-hour workshops, which include 30 minutes of tea break and checking-in time.

The first workshop was delivered on 11th July 2014 to 2 Project Aspire service users. One volunteer also attended the session as she had an interest in Health Psychology. The hand-out (appendix 3) and equipment were prepared prior to the session to ensure it ran smoothly and to time. It was apparent that the focus required for one of the exercises was not present; therefore the exercise was cut short. This helped with the timing of the workshop, as the 2 service users were 30 minutes late. To ensure that the workshop ran to time, I had to cut the cigarette and coffee break short by 5 minutes. As there were only 2 attendees the discussions were much more brief than planned for, therefore the workshop ran to time. Some of the material presented was complex, although delivered through metaphor to enhance understanding. Understanding was checked throughout and any uncertainties clarified.

The second workshop was delivered on 22nd August 2014 to 5 Project Aspire service users. The facilitator of Project Aspire also attended and observed this workshop. For this workshop I included a PowerPoint presentation of the Action for Happiness flyers denoting each of the topics being covered. It was intended to project the PowerPoint slides onto the wall. Unfortunately the projector was not working with the laptop provided so a large computer monitor was removed from the office and setup to enable attendees to view the slides during the discussion, as a visual aid. Initially the service users were quiet due to not being used to the presence of technology in workshops, but once they realised that the workshop was still very participatory and not a didactic lecture they relaxed and all contributed to the group discussions. The training plan was adhered to fully and finished exactly with a few minutes to spare for completion of the feedback forms. Throughout the workshop service users engaged well with the content delivered. One service user was new to the group, and had moderate learning difficulties. Throughout the workshop I checked his understanding and ensured he was included within the group discussions and the group activity.

Planning and Implementing Assessment Procedures for the Training Programme

Due to the nature of the group, there were no formal assessment procedures for either of the workshops. The learning objectives were assessed throughout

the workshops by checking understanding and monitoring attendee's engagement based on the questions being posed, and comments being made. The groups were small and situated around one boardroom style table. All of the attendees participated in all of the group discussions, interpreting the content and relating it to their own experiences.

Evaluating the Training Programme

The feedback from both workshops was very positive overall.

Workshop 1 (Appendix 9) – All three attendees completed evaluation forms and stated that the objectives of the workshop were made clear, and were met. All attendees also rated the exercises and content as excellent; one attendee rated my checking of their understanding as 4/5, although this was the volunteer who was sitting in to gain a better understanding of Health Psychology so was not my main focus. One comment on the most beneficial part of the workshop was "reminding myself how to deal with self". Other than a comment about insufficient cups of tea being available, there were no negative comments. All three attendees rated the workshop as having improved their understanding of how to manage stress.

Workshop 2 (Appendix 9) – All five attendees completed evaluation forms and stated that the objectives were made clear and were met. All attendees rated the workshop as excellent, with the majority finding it extremely useful. Overall scores for my workshop facilitation skills were excellent. Two attendees stated that the most beneficial aspect of the workshops was the group discussions, with only two negatives being reported: 1) Cold tea 2) not enough time. Overall, all attendees reported that their understanding of how to improve their wellbeing and levels of happiness had increased by attending the workshop.

The Project Aspire co-ordinator provided feedback on the workshop, stating that clients found the workshop useful and seemed to enjoy it. Also stating that the workshop was well delivered, taking the different abilities and learning styles into consideration by using visual examples, brainstorming, and discussion (Appendix 10).

Summary and Reflection

My initial plans for this series of workshops would have been my preferable mode of delivering this competence. Within the field of addiction attendance rates are known to be fairly poor (Lefforge, Donohue, & Strada, 2007), and within [redacted] group attendance rates really fluctuate. Some groups have 0 to 1 people some weeks, and 14+ another. Due to this, I created a poster to attract people into the group workshops (appendix 11). Clinicians referred people, yet nobody turned up. Throughout the past few months that the group has been running the highest number of attendees was two. These two attendees were not in the right place within their recovery to engage with the content – the group became of a therapeutic nature as opposed to an educational relaxation workshop. Due to these issues, when the opportunity arose to deliver the training within Project Aspire I decided the initial 8-week programme would continue, delivering a more flexible relaxation session. Having co-facilitated Project Aspire in the past I knew that attendance was fairly consistent, the structure of the workshops would be suitable for this specific client group, and the attendees particularly enjoy engaging discussions.

I wanted to demonstrate various skillsets; therefore with the first workshop being didactic in nature I was taking a bit of a risk with the level of engagement. I was pleased that the attendees engaged well, although the bucket and balloon exercise did not work. I have used this demonstration with friends and family to great effect in the past so I am not certain where it went wrong. It is generally an exercise that benefits from less explanation at the outset – it is possible that neither of the attendees were very suggestible.

During the second workshop there were two challenges that I was aware of. Firstly, there was one instance where an attendee went off-piste with a monologue on their past. We were discussing the importance of goals. She discussed a goal she achieved, of writing a novel, before wandering into her experiences of rejection from publishers; the experience of racism from specific communities in South London; and an instance of rape. As this was not a therapeutic group I noted an opportune time to bring the discussion back to the topic of goals. This may have seemed briefly abrupt, but the discussion corrected its path and she discussed solutions to her publishing dilemma.

Secondly, with having an individual with learning difficulties present, I had to ensure that he was included within the group discussions and group activities. The reassuring aspect was that when prompted he responded appropriately. On a couple of occasions, as he relaxed, he contributed to the group discussion without prompt. The other group members were also very supportive and engaged well, ensuring he was included.

Other than comments regarding the refreshments, there were no really negative comments. Whilst this can be seen as a great thing, it also does not give me much opportunity for development. I was well acquainted with the majority of the attendees through other groups that I have run, plus my past facilitation and co-facilitation of Project Aspire: it is possible that those attending may have had more constructive feedback had I not been so well-known to them. From my perspective, I liked the interactive components of this training but in future I would consider having a more flexible format: allowing me to include detailed information if the attendees wanted it, and providing more engaging activities to get the ideas across to those who cannot fully comprehend the detailed information.

This training identified that the more I teach and present to a particular group of people, within a certain environment, the more relaxed I am in my preparation, and delivery. I feel that is also evident to my attendees. I know the content, I know the audience, and deliver the training confidently – this means that the attendees have a greater level of confidence in me too.

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Appendix 1 – Needs Assessment and Responses

Training Needs Questionnaire
Stress Management and Relaxation Skills & Health Workshops – 6 Week Course

Proposed Outcomes for Attendees:
Improve understanding of how stress affects the body, learn skills to relax, improve sleep patterns, and improve knowledge on what a healthy life consists of.

Topics	Importance				Comments
	Not very	Indifferent	Quite	Very	
Diet			YEs		
Exercise			YES		
Mindfulness			YES		
Relaxation				Yes	
Stress				YES	
Sleep Hygiene				YES	
Meditations				YES	

What other topics do you feel are important to be covered within these sessions?
The ones I have put yes by are absolutely a must and need to be addressed at the out set. The others under ' quite' are things that will follow naturally at the client's own pace once the other 4 are in place and the benefits being seen. Clients once they see an improvement will naturally progress through.

The best learning styles for this group? (please tick all that apply)
Didactic
Practical
Group Discussions
Other (please describe *A mixture of all, some structure followed by group discussions is a winning theme. However it is always necessary to allow for the unexpected as this is life!*

Attendees will be asked to give some feedback on the sessions delivered so we can evaluate the efficacy of the group and make amendments to ensure a positive learning experience.

Proposed format:
Check-in (15 mins)
Relaxation Session (10-30 mins)
Discussion/Learning (35-55 mins)
Sign-Out (10 mins)

Training Needs Questionnaire
Stress Management and Relaxation Skills & Health Workshops – 6 Week Course

Proposed Outcomes for Attendees:
Improve understanding of how stress affects the body, learn skills to relax, improve sleep patterns, and improve knowledge on what a healthy life consists of.

Topics	Importance				Comments
	Not very	Indifferent	Quite	Very	
Diet				x	
Exercise				x	
Mindfulness				x	
Relaxation				x	
Stress				x	
Sleep Hygiene				x	
Meditations				x	

What other topics do you feel are important to be covered within these sessions?

_____

_____

_____

_____

The best learning styles for this group? (please tick all that apply)

Didactic
Practical x
Group Discussions x
Other (please describe)_____

Attendees will be asked to give some feedback on the sessions delivered so we can evaluate the efficacy of the group and make amendments to ensure a positive learning experience.

Proposed format:
Check-in (15 mins)
Relaxation Session (10-30 mins)
Discussion/Learning (35-55 mins)
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Training Needs Questionnaire
Stress Management and Relaxation Skills & Health Workshops – 6 Week Course

Proposed Outcomes for Attendees:
Improve understanding of how stress affects the body, learn skills to relax, improve sleep patterns, and improve knowledge on what a healthy life consists of.

Topics	Importance				Comments
	Not very	Indifferent	Quite	Very	
Diet			x		
Exercise			x		
Mindfulness			x		
Relaxation			x		
Stress			x		
Sleep Hygiene					Not sure what this is Tim
Meditations			x		

What other topics do you feel are important to be covered within these sessions?

___I think that some people would enjoy this type of session and that the content above would be interesting and potentially useful

The best learning styles for this group? (please tick all that apply)

Didactic – dietary discussion tends to be didactic but a coaching approach is probably a good idea (I think you would call this motivational interviewing ☺)
Practical – experiential relaxation would probably be a good idea
Group Discussions
Other (please describe)_____

Attendees will be asked to give some feedback on the sessions delivered so we can evaluate the efficacy of the group and make amendments to ensure a positive learning experience.

Proposed format:
Check-in (15 mins)
Relaxation Session (10-30 mins)
Discussion/Learning (35-55 mins)
Sign-Out (10 mins)

Appendix 2 – Understanding and Managing Stress Teaching Plan

Understanding & Managing Stress Workshop

Intoduction

- Include ground rules re confidentiality, respecting others' experiences and behaving in a non-judgemental way to ourselves and others in the group.
- Purpose of the workshop
  - Gain a better understanding of stress
  - Gain an understanding of how our mind affects our physiology
  - Understand the impact of stress
  - Understand some techniques to manage stress

Practical Demonstrations - How thoughts affect body

1 – Deep Breathing exercise (5 minutes)

Sit up straight, eyes closed, with a hand on your belly. Slowly inhale through your nose, feeling the breath start in your abdomen and work its way to the top of your head. Reverse the process as you exhale through your mouth. Notice how the breath feels different on the in-breath to the out-breath.

Notice any thoughts that come into your mind, acknowledge them, and then return your focus to the breathing.

Discussion: on how this brief exercise made people feel and how this can be applied in daily life (5-10 minutes).

2 – Balloon and bucket demonstration (5-10 minutes).

Get the group members to stand up with their arms out. Get them to close their eyes and imagine in their left hand is a bucket full of sand. The right hand has a helium balloon tied around the wrist.

Suggested script: The bucket is red and cast iron, you can feel the weight of the bucket tiring your arm and as you hold the bucket longer the arm feels heavier and heavier. The right arm is feeling lighter and lighter as the helium balloon is lifting the arm up. Now imagine the helium balloon growing and pulling the arm up, making it feel lighter and lighter, whilst the left arm gets

heavier and heavier. Feel the bucket of sand making the left arm heavier and heavier, arms getting more and more tired. Another balloon has been tied to the right arm so it feels even lighter and you can feel it rising up – your right arm is very light and feeling supported.

Repeat suggestions of weight for the left arm and lightness for the right arm, observing the effect. Don't do this for too long as the right arm will start to get tired and the effect will be lost.

Following this, get them to open their eyes, see what affect it has had on the arms and sit down and discuss this.

3- Pendulum demonstration (5-15 minutes)

Best done sat around a table, but is not essential.

Hand out the pendulums – there should be 7 available.

Pass around the pendulum sheets. Ask the group to hold their pendulum as if they are using it for divination and give a demonstration (see image). Now ask the group to think about the pendulum moving in a clockwise direction. Give them a few minutes and observe whether it's working for everyone. Then suggest that they think about it stopping and then imagine it going in an anticlockwise direction. Then suggest they think of up and downward swinging movement being a yes, and sideways swing being a no. Give them a few minutes to try different things. Then give the suggestion that whenever they try to make it go clockwise, it will go anticlockwise instead. Again, give some time for them to play with this.

Discussion: Get a discussion going on their findings; what they think might be causing this reaction in the pendulum, plus their reaction to the bucket and balloon exercise.

Discuss how the micro-muscles within the body are controlled by our thought patterns, how when we think about the pendulum moving our brain instructs tiny motor muscles within the body to move without being obvious to the human eye.

These muscles are what move the pendulum.

Now consider, if we can control little muscles like this and move a pendulum with our thoughts, what effect on the body do other thoughts have?

Learning Discussion - Why Zebras Don't Have Ulcers?

Starting discussion

What does stress feel like? How do you know when you are stressed?

Exercise: Stress Bucket (handout)

Main discussion

Stress can affect every aspect of your life, every cell in your body, and can make you sick.

Two people with the same illness will not be affected the same way, differences will have an impact on how we are all affected by illness – one of the biggest contributors is how we react to stressors.

Brief discussion: Imagine yourself as a zebra:

What would be a stressor for a zebra, and how might you react if you were a zebra?

Humans are very skilled at generating stressful events in the mind, whereas animals, such as the zebra, react to acute physical crises (such as seeing a lion wanting you for lunch).

Does stress have a purpose?

For much of the animal kingdom a stress reaction is a life saving response. A zebra's stress response system functions to allow it the chance to escape from the hungry lion.

Humans, however, have developed in a slightly different way. We can sit around and dwell on "issues", and can suffer chronic-stress, which can then lead to a stress-induced illness.

The body has a stress-response. The theory is that stress responses are the body's ways of restoring balance. A stressor throws your body out of sync, a stress reaction is then employed. This can work in different ways – the body is a great adapter! Just like it reacts in different ways in different extreme temperatures (sweating or shivering).

What is the stress response though?

The stress-response is where energy is rapidly mobilised from storage sites (i.e. fats) to the muscles.

Sugars released from your fat stores get quickly transported around your body – this means your body has to increase its heart rate, blood pressure, and breathing rate, to facilitate this.

The body needs a lot of energy in a time of perceived crisis. It therefore becomes very efficient and reduces the power to unnecessary processes.

In an emergency, who needs to be wasting energy digesting food? There are more important things to do. Similar with other unessential processes, such as sexual function, growth and tissue repair, immune function, and pain perception. Whilst the brain sharpens up to allow you to escape through a well-known route to safety.

The body can also lighten itself to make escape easier and faster – by empting the bowels or the stomach.

This is the fight or flight mechanism in action.

This is brilliant if you are in imminent danger! (i.e. a zebra being chased by a lion).

Not so brilliant if the danger is perceived and the stress becomes chronic, as this is when you become affected by stress-related disease.

Constantly mobilising energy depletes energy stores, leading to increased risk of:

- Fatigue
- High Blood Pressure
- Increased brain age (memory issues)
- Sexual dysfunction
- Slower healing
- Stomach Ulcers
- Dwarfism (in children)

One of the main risks is cardiovascular disease (heart attack, stroke, angina).
As we mentioned earlier, the stress reaction increases the heart rate and blood pressure so the blood is shot around the body at high speed. When it returns to the heart, it hits the heart wall with considerable force. This causes the heart wall to thicken and the heart becomes lopsided (left ventricular hypertrophy), increasing risk of irregular heartbeat.

This lopsided heart is a major predictor of cardiac risk!

With the blood rushing around the body quickly over a prolonged period of time (hypertension) your vessels have to adapt and vessel walls thicken to cope, increasing blood pressure. Where vessels (arteries) branch off, damage can occur, causing inflammation and small craters. These craters can become home for fatty cells, blood cells, sugar, fat, and bad cholesterol (HDL) – this buildup is known as atherosclerotic plaque.

This plaque is a predictor and cause of heart attack, stroke, and angina.

How?

Plaque can break free and get stuck in a smaller vessel.

If this vessel is in the heart, it is a heart attack (myocardial infarct)

If this vessel is in the brain, it is a stroke (brain infarct)

If this is a vessel feeding the heart, it is angina.

Closing Discussion: How can we manage stress?

- Repackage the anxiety
- Stop denying the truth, but focus on some good moments
- Better differentiate threatening from neutral interactions
- Exert some control over social conflicts
- Differentiate good news from bad
- Displace Frustration (into an inanimate object, or into an activity)
- Improve social connections
- Increase control of your life
- Exercise
- Meditate
- Understand how you cope
- Understand that sometimes stress is useful (i.e. exams)
- Just do it – stop putting things off.
- Reframe stress – think of it as something that is there to help you cope with current events, thus reversing the negative health impacts of stress.

Check out and Questions (15 mins)

Completion of feedback forms

Understanding & Managing Stress Workshop

Purpose of this workshop:

- Understand how stress affects the body
- Understand the impact of stress
- Understand how to manage stress

Exercises

1 – Deep Breathing/Stomach Breathing

Place your hand on your tummy, inhale slowly through your nose, feeling your breath moving from your nose, down your neck, and down to your tummy, feeling the tummy rising. If you're breathing shallowly (into the chest), breath deeper until your tummy rises. Exhale and notice your breath moving up through your body and out of your head.

Notice how your breath feels different when you breathe in and out.

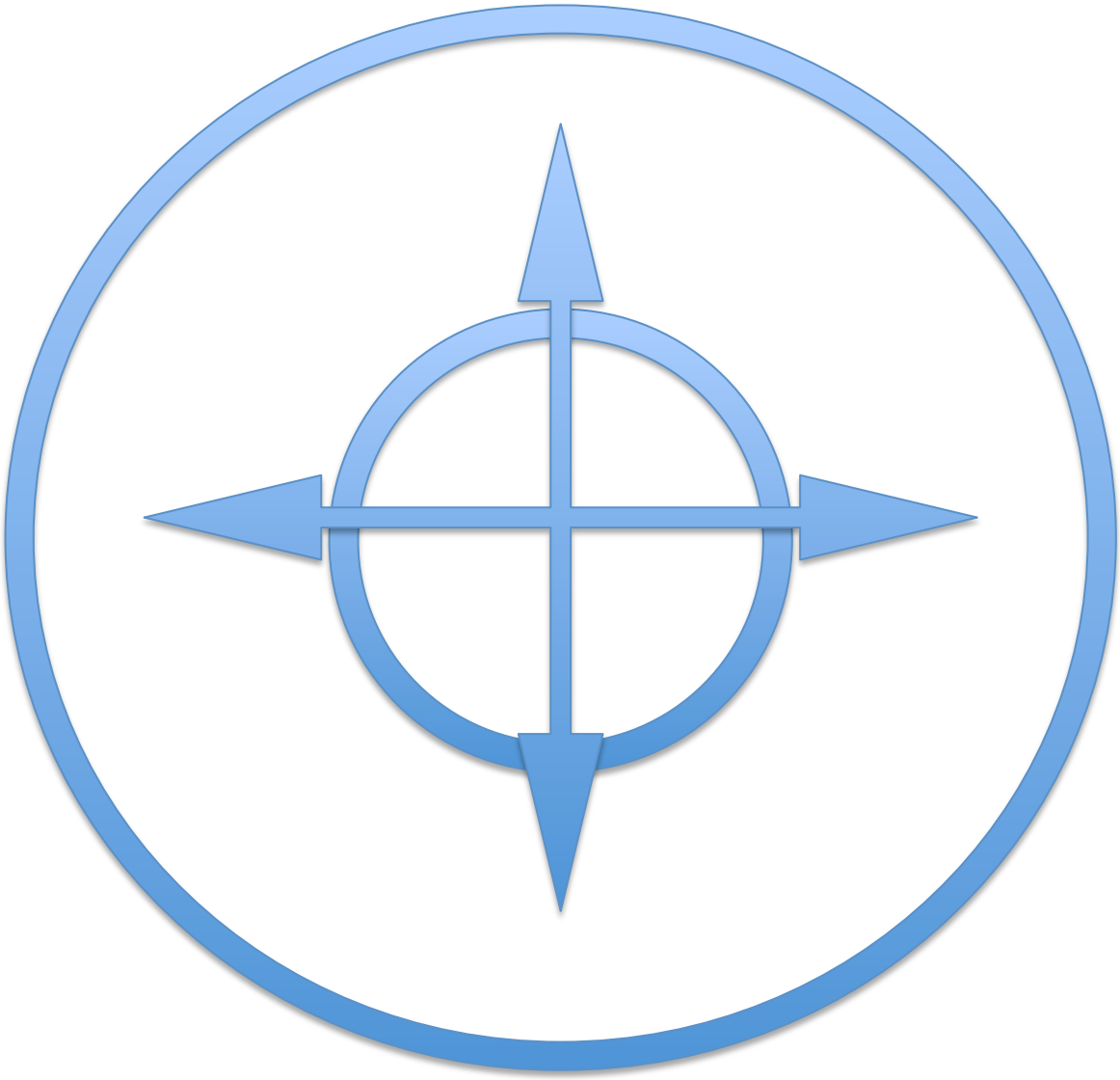
Notice any thoughts that arise during this exercise, acknowledge them, and let them go returning to focusing on the breath.

What were your thoughts on this exercise?

2 – Bucket and Balloon Exercise

What are your thoughts on this exercise?

3 – Pendulum Exercise



What are your thoughts on this exercise, and how does it relate to stress?

4 - Stress Bucket

What are your stresses? What do you do when stressed? How do you relieve your stresses?

Once you've completed the stress bucket handout, note what you thought of the stress bucket.

Understanding Stress

Imagine yourself as a zebra

What would be a stressor for a zebra, and how might you react if you were a zebra?

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Does stress have a purpose?

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Humans, however, have developed in a slightly different way. We can sit around and dwell on "issues", and can suffer chronic-stress, which can then lead to a stress-induced illness.

The body has a stress-response. The theory is that stress responses are the body's ways of restoring balance. A stressor throws your body out of sync, a stress reaction is then employed. This can work in different ways – the body is a great adapter! Just like it reacts in different ways in different extreme temperatures (sweating or shivering).

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The stress-response is where energy is rapidly mobilised from storage sites (i.e. fats) to the muscles.

Sugars released from your fat stores get quickly transported around your body – this means your body has to increase its heart rate, blood pressure, and breathing rate, to facilitate this.

The body needs a lot of energy in a time of perceived crisis. It therefore becomes very efficient and reduces the power to unnecessary processes.

In an emergency, who needs to be wasting energy digesting food? There are more important things to do. Similar with other unessential processes, such as sexual function, growth and tissue repair, immune function, and pain perception. Whilst the brain sharpens up to allow you to escape through a well-known route to safety.

The body can also lighten itself to make escape easier and faster – by empting the bowels or the stomach.

This is the fight or flight mechanism in action.

This is brilliant if you are in imminent danger! (i.e. a zebra being chased by a lion). Not so brilliant if the danger is perceived and the stress becomes chronic, as this is when you become affected by stress-related disease.

Constantly mobilising energy depletes energy stores, leading to increased risk of:

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- High Blood Pressure
- Increased brain age (memory issues)
- Sexual dysfunction
- Slower healing
- Stomach Ulcers
- Dwarfism (in children)

One of the main risks is cardiovascular disease (heart attack, stroke, angina).
As we mentioned earlier, the stress reaction increases the heart rate and blood pressure so the blood is shot around the body at high speed. When it returns to the heart, it hits the heart wall with considerable force. This causes the heart wall to thicken and the heart becomes lopsided (left ventricular hypertrophy), increasing risk of irregular heartbeat.

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This plaque is a predictor and cause of heart attack, stroke, and angina.

How?

Plaque can break free and get stuck in a smaller vessel.

- If this vessel is in the heart, it is a heart attack (myocardial infarct)
- If this vessel is in the brain, it is a stroke (brain infarct)
- If this is a vessel feeding the heart, it is angina.

How to manage stress?

What methods did you include in your stress management techniques in the stress bucket exercise?

What other methods have others mentioned that you think might work for you?

Some suggestions

- Repackage the anxiety
- Stop denying the truth, but focus on some good moments
- Better differentiate threatening from neutral interactions
- Exert some control over social conflicts
- Differentiate good news from bad
- Displace Frustration (into an inanimate object, or into an activity)
- Improve social connections
- Increase control of your life
- Exercise
- Meditate
- Understand how you cope
- Understand that sometimes stress is useful (i.e. exams)
- Just do it – stop putting things off.
- Reframe stress – think of it as something that is there to help you cope with current events, potentially reversing the negative health impacts of stress.

Feedback Form – Understanding and Managing Stress

About the workshop:

Were the objectives of the workshop made clear?

Yes / No

Did the workshop meet its objectives?

Yes / No

How interesting was the content?

Not at all 1 2 3 4 5 Extremely

How useful was the content?

Not at all 1 2 3 4 5 Extremely

How useful were the exercises?

Not at all 1 2 3 4 5 Extremely

What is your overall rating of the workshop?

Did not enjoy it 1 2 3 4 5 Excellent

About the facilitator:

Did the facilitator seem confident and enthusiastic?

Not at all 1 2 3 4 5 Extremely

Did the facilitator deal well with questions?

Not at all 1 2 3 4 5 Extremely

Did the facilitator include everyone in the discussion and activities?

Not at all 1 2 3 4 5 Extremely

Did the facilitator check you understood the content?

Not at all 1 2 3 4 5 Extremely

What was the most beneficial part of the workshop?

What was the least beneficial part of the workshop?

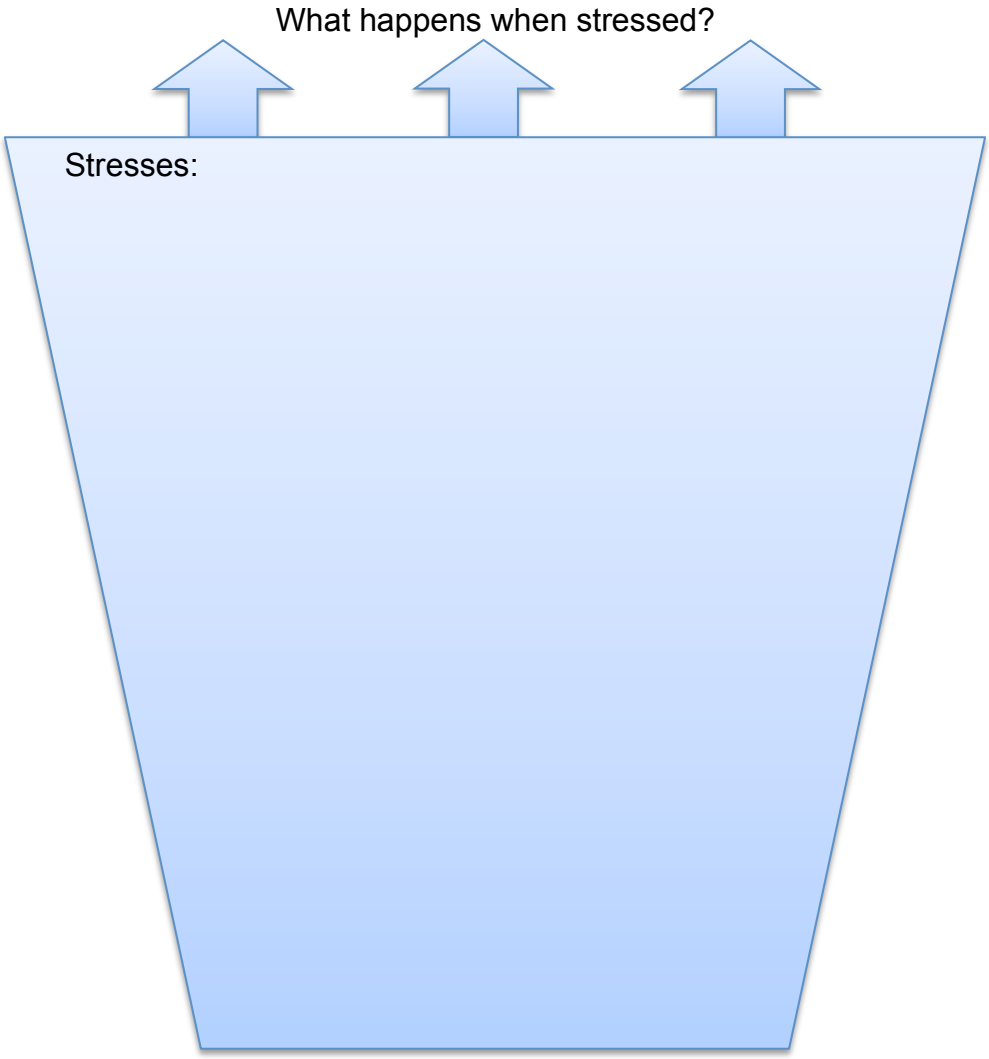
Has your understanding of stress and how to manage it improved due to attending this workshop?

Yes / No

Any Other Comments:

Appendix 4 – Stress Bucket

Stress Bucket



Tools to empty the bucket:

Appendix 5 – Happiness and Wellbeing Teaching Plan

Teaching commences – 10am to 12 noon (2 hours)

Materials needed:
Worksheets
PowerPoint Presentation
Laptop
Projector

Tea/Coffee and check-in – 15 minutes

Commence teaching of GREAT – 8 minutes per letter (40 minutes)

Tea/Coffee/Cigarette Break – 15 minutes

Commence teaching of DREAM (50 minutes)

D – 5 minutes, plus 5 minutes for group discussion of goals
R, E – 8 minutes each (25 minutes)
A – include activity whereby each member of the group is given a name of another group member, and they write 3 positive traits of that group member on the paper, returning to the pot for dissemination to the named – 10 minutes.
M – 5 minutes

Closing discussion, time to complete feedback questionnaire

Appendix 6 – Happiness and Wellbeing Hand-out

Achieving Happiness & Wellbeing

Purpose of this workshop:

- Understand the benefits of being happy
- Understand the factors that improve happiness & wellbeing

What are the benefits of happiness?

- **Happy people are healthier people**
- **Happy people have better relationships**
- **Happy people are more productive and can earn more when working**
- **Happy people are more generous**
- **Happy people cope better with stress**
- **Happy people are more creative**
- **Happy people are happy – they feel good!**

GREAT DREAM

Giving

Giving either your time or money to someone or something else can improve your happiness longer than buying something nice for yourself. Sometimes a simple act of kindness can improve your day, and the recipient of your kind act.

How do you, or how could you give?

_____

_____

_____

_____

Relating

If you have strong relationships with people, close friends and/or who you can confide in, you can feel love, meaning, and happier. Being part of a bigger social network can give a sense of belonging.

Have you made new friends or connections lately? Where are there opportunities to make some more?

Exercise

Activity makes us happier, and healthier. Exercise can be a good antidepressant, instantly lifting mood. Exercise can involve intensive activities such as running, but short walks can be advantageous too!

Consider some activities you could do to increase your exercise levels (get off the bus one stop earlier, use the stairs, take a stroll in the park etc).

Appreciating

How often do you just stop and take in your surroundings?

Take a few moments to notice your environment. Notice any sounds, smells, and sights around you. Don't speak, just notice. Don't think, just notice.

What is your experience of mindfulness? And what benefits do you think it can bring to you?

How could you integrate mindfulness into a daily activity?

Trying Out

Learning new things make us feel more confident of our own abilities, and make us feel a sense of satisfaction. Learning does not have to be just about education. It can be a skill, an instrument, a new game, a new receipe, or maybe even local history.

What have you learnt recently?

Is there anything new you've wanted to try, but have put off? If so, what is it and what's stopping you from trying it?

Direction

Why are goals important?

Name one of your goals, and one thing you can do today to take a step closer to achieving that goal.

Discuss your goals with the people next to you, why it is important to you, and listen to their goals.

Resilience

Stress, loss, troubles… they affect all of our lives. The way we respond to these events have a serious affect on our wellbeing.

It may not feel like it sometimes, but we can learn better ways to cope. It may not be easy though!

Consider how in the past you might have bounced back after a difficult time. What helped you to bounce back?

Emotion

This whole workshop is about living with a positive outlook, but why? Having a positive outlook improves our resilience, physical health, and makes us feel good! Reflect on the positives- forget the negatives.

Name three positives from your week:

Acceptance

You're perfect! Perfectly flawed, just like everyone else. Some people may appear to have perfect lives, perfect families, and are perfect people. These people can make you feel like you're really flawed. Fortunately nobody is perfect. Learning to accept who you are, rather than dwelling on your "flaws", accepting sometimes things go wrong, and being more kind and compassionate to yourself can improve your life, wellbeing, and resilience. It can also make you see others in a different light.

What are your greatest strengths and talents (even if they're hidden!)?

Meaning

A sense of purpose can come from having a job you love, giving back to society through volunteering for a cause you love, through being part of a community or family – it makes us feel connected to something bigger than ourselves. This can make us happier; less stressed; and, can reduce anxiety and depression.

Consider something you've done that gave your life a sense of meaning:

Feedback Form – Achieving Happiness & Wellbeing

About the workshop:

Were the objectives of the workshop made clear?

Yes / No

Did the workshop meet its objectives?

Yes / No

How interesting was the content?

Not at all 1 2 3 4 5 Extremely

How useful was the content?

Not at all 1 2 3 4 5 Extremely

What is your overall rating of the workshop?

Did not enjoy it 1 2 3 4 5 Excellent

About the facilitator:

Did the facilitator seem confident and enthusiastic?

Not at all 1 2 3 4 5 Extremely

Did the facilitator deal well with questions?

Not at all 1 2 3 4 5 Extremely

Did the facilitator include everyone in the discussion and activities?

Not at all 1 2 3 4 5 Extremely

Did the facilitator check you understood the content?

Not at all 1 2 3 4 5 Extremely

What was the most beneficial part of the workshop?

What was the least beneficial part of the workshop?

Has your understanding of stress and how to manage it improved due to attending this workshop?

Yes / No

Any Other Comments:

Appendix 8 – Personal Strengths Task

Name_____

Strengths
1 –
2 –
3 –

Name_____

Strengths
1 –
2 –
3 –

Name_____

Strengths
1 –
2 –
3 –

Name_____

Strengths
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Name_____

Strengths
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Name_____

Strengths
1 –
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Name_____

Strengths
1 –
2 –
3 –

Name_____

Strengths
1 –
2 –
3 –

Appendix 9 – Evaluation of Wellbeing Workshops

Summary of Scores for Wellbeing Workshops

	Understanding Stress n = 3	**Happiness & Wellbeing n = 5**
Were Attendee Objectives Met?	3x Yes - 100%	3 x yes - 100%
Were Workshop Objectives Met?	3 x Yes - 100%	3 x yes – 100%
How Interesting was the Content (1-5)	15/15 – 100%	24/25 – 96%
How useful was the content? (1-5)	15/15 - 100%	22/25 – 88%
How useful were the exercises? (1-5)	15/15 – 100%	N/A
Overall rating of the workshop (1-5)	15/15 – 100%	24/25 – 96%
Did the facilitator seem confident? (1-5)	15/15 – 100%	25/25 – 100%
Did the facilitator deal well with questions? (1-5)	15/15 – 100%	24/25 – 100%
Did the facilitator include everyone in the discussion (1-5)	15/15) – 100%	25/25 - 100%
Did the facilitator check you understood the content? (1-5)	14/15 – 93.3%	24/25 – 100%
Most Beneficial part?	• Reminding myself how to deal with self • All of it • Pendulum exercise	• Discussing A-Z • The facilitator was good • Great discussions about subject • Covering all aspects of the topics • It made me see different views and a better understanding of people
Least Beneficial part?	• Not enuff [sic] tea • N/A	• More time • Cold tea • None
Has your understanding of stress and how to manage improved due to attending this?	3 x yes – 100%	5 x yes - 100%
Other comments	• It reminds you that you can deal with it well and to my benefit • Bisquits, lovely • Great surprising facts about stress	• Being aware is always beneficial • Ongoing support • Well done! • I enjoyed attending the workshop. It was very relaxing and fun.

Appendix 10 – Project Aspire Facilitator Feedback on Happiness Workshop

From: **Tim Mahy** [redacted]
Subject: FW: Workshop
Date: 28 August 2014 11:57
To: Mahy, Timothy [redacted]

From: [redacted]
Sent: Thursday, August 28, 2014 11:17 AM
To: Tim Mahy
Subject: RE: Workshop

Hi Tim,

Sorry that it took me a while to do this!

Content/Subject matter: The content of the workshop was varied and well thought of. I think that all the clients could relate to everything that was discussed and found the tips and solutions extremely useful.

Appropriateness: In my view the workshop was very appropriate for the client group and the clients found it very useful for the challenges that they are facing. All the clients stated that they found the workshop useful and seemed to really enjoy it!

Delivery to attendees: The workshop was well delivered and the facilitator took the variety of abilities and learning styles into consideration. There was a great balance between visual examples, learning, brainstorming and discussion that was skilfully handled by the facilitator.

Interaction with attendees: The facilitator interacted very well with all the attendees and ensured that everybody had the chance to participate equally. He especially made sure that one of the attendees, who has learning difficulties, followed what was discussed, took part in discussions and received extra support with areas that he struggled with.

Hope that helps!

Going to miss you ☹

From: Tim Mahy
Sent: Tuesday, August 26, 2014 9:43 AM
To: Miriam Jassey
Subject: Workshop

Hi [redacted]

I was wondering whether you'd have time to give some feedback on my workshop so I can put it into my portfolio? Something along the lines of your thoughts on content, appropriateness of subject matter, delivery to attendees. Interaction with attendees. Any areas for development or anything I did particularly well.

Many thanks!
Tim

Area of Competence: Consultancy

A Systematic Review of the Evidence of the Efficacy of Group Based Motivational Interviewing in the Treatment of Alcohol Misuse

Setting

[redacted]

Client

Chief Executive Officer

Aims of Consultancy:

- To provide consultancy services to evaluate the efficacy of group based motivational interviewing for substance misusers.
- To design and implement a waiting-list group based on the findings of the evaluation.
- To evaluate the waiting-list group's efficacy.

Assessing Request for Consultancy

In January 2013 the Chief Executive of [redacted] contacted me, in my role as a Trainee Health Psychologist within [redacted], to enquire whether I could look into methods of reducing relapse rates within their client base (appendix 1).

As relapse reduction is a broad topic area, I had a discussion with the Chief Executive to narrow-down the scope. It was agreed that a systematic review on the use of group motivational interviewing would be the first part of the consultancy request, using the information found to develop a waiting-list treatment group as a separate component (appendix 2). The Chief Executive proposed the group format as a way of cutting down costs of treatment provision. Group therapeutic interventions have been shown to be as effective as individually delivered interventions (Weiss, Jaffee, de Menil, & Cogley, 2004). As a consultant, who is trained in motivational interviewing, I proposed

investigating the efficacy of a group motivational interviewing intervention. Motivational interviewing has been shown to be effective in the short-term for reducing substance misuse (Smedslund et al., 2011) and could therefore compliment the additional services offered by [redacted] such as skills training, volunteering opportunities, and one-to-one interventions such as keyworking and counselling.

It was agreed with the client that I would allocate, initially, one day per week to the consultancy. I had a full diary, therefore reviewed which of my planned tasks would have the least impact on clients should I cancel them. Weighing up all the options, I proposed to my line-manager (also my clinical supervisor at the time) that I use Tuesdays, then made arrangements for cover to be found for any tasks I was involved in on a Tuesday.

It was agreed that I would work on the consultancy project, initially for a period of three-months, followed by a further nine-months to develop and pilot the waiting-list group. This case study will focus predominantly on the first component – the systematic review.

The client expected an executive summary of the systematic review, along with the development of a waiting-list group, and evaluation of the efficacy of the waiting-list group. As a consultant, I was trusted to complete the project with minimal input from the client due to his time-pressures.

The contract was formally agreed, with the work to be completed free-of-charge as I was already a voluntary worker within the organisation. The terms of the consultancy were noted within a consultancy contract (appendix 3).

Reflection

Having worked with the Chief Executive for six-months prior to receiving his consultancy request, I already had a good working relationship with him. The aims of the consultancy were simple and achievable. I have missed out on some of the opportunities an external consultancy project may have afforded me: development and exhibiting new skills, such as a more rigorous contract

and fees negotiation; experience in another organisation; and, developing a new relationship for the purpose of the consultancy project.

Planning Consultancy

Before commencing the systematic review of the literature, a search was undertaken to assess whether there were any extant systematic reviews on the efficacy of group motivational interviewing with alcohol misusers. Google Scholar and the Cochrane databases were reviewed. As there were no extant reviews and no authors had lodged a protocol to indicate any were in progress, it was deemed reasonable to perform a systematic review without any date constraints. The second component would be planned at a later date, based on the outcome of the systematic review.

The expert model of consultancy was adopted for the first component of this consultancy project. The expert model can take two forms, the purchase of expertise model, or the doctor/patient model. The purchase of expertise model is where a consultant is hired to use their specific skillset to solve a known problem, or use their extant knowledge, or skills in eliciting appropriate knowledge, to solve a known problem. The client is then free to use the information gathered however they choose, if at all. The doctor/patient relationship is different, insofar as the client gives the consultant more control over the process, delegating the diagnosis of the exact problem and awaiting a prescribed fix (Schein, 1978). In this project the client was aware that the problem facing all services in the local area was the high dropout rate, and relapse rates. As such, the requirements for using the purchase of expertise model, being: The client had correctly diagnosed the problem; the client had correctly identified that I have experience in doing systematic reviews, and knowledge of motivational interviewing as a modality; the client effectively communicated the problem; and, the client was aware of any consequences of the consultancy, which in this case were minimal. The client also had very little time for involvement in the project, making this model the most suitable.

Reflection

The expert model, using the purchase of expertise, was the most suitable model for this consultation, albeit with no monetary exchange. The process was straightforward and made me consider various aspects of how I work – checking whether my work was novel, and considering the implications should I discover it was not. As I highlighted in my earlier reflection, I would have had significantly different experiences with the consultancy planning process should I have had a client who wanted to be more hands-on. As it was a very pure elicitation of expertise I had free-reign over all decisions made.

Developing, Monitoring, and Maintaining Working Relationships with Client

Contact between the client and I took various forms, and whilst there were very few discussions on the topic of the consultancy project. Other than the initial meeting to discuss the consultancy, other communications were brief informal updates. I was kept updated about events within the organisation that affected my consultancy project through the attendance at staff meetings, and through informal discussions. Being in the office resulted in my being kept in the loop with the rapidly changing service and the changing requirements of the organisation.

Reflection

Throughout the entire project, excepting at the initial stages of requesting the review, the client took a backseat and left me to run with the project. This gives me some sense that they trust and respect the work that I am doing, and have sufficient confidence in me to not micro-manage.

Conducting the Consultancy

The project began on 15 January 2013 and ran most Tuesdays over a period totalling 83 weeks. Not all of these 83 weeks were spent on the consultancy project.

Firstly a protocol was developed, detailing the aims of the systematic review; the extant research on the topic area justifying the need for the review; the databases that were to be searched; the keywords that would be used; inclusion and exclusion criteria; and, the quality criteria that each journal article would need to meet in order to be considered for inclusion. The systematic review forms a component of the research competence within this thesis and the full review can be found in Section B.

Once the systematic review was complete, my DPsych supervisor reviewed it and an Executive Summary drafted for the client (appendix 4). The client at this point in time was under a great deal of pressure due to the imminent commencement of a new tendering process, therefore wanted as much information in as few words as possible.

The systematic review suggested that much of the research into group motivational interviewing interventions is of low methodological quality and there is a high level of heterogeneity amongst the studies with regard to outcome measures, components of motivational interviewing used, and competence of those delivering the interventions. There was evidence to suggest that group motivational interviewing interventions can be effective for problem alcohol users. It was concluded, however, that further research is required with non-student populations to give further validity to the current findings.

Due to some changes within the organisation, and within the consultancy, an additional piece of work was completed and incorporated within the Executive Summary. As the results of the systematic review demonstrated that group motivational interviewing can be effective, it was decided to draft a flyer for the clients who have a fear of groups, espousing some of the benefits of group attendance, such as altruism; learning from others; being able to teach others; universality; and, group cohesiveness (Yalom & Leszcz, 2005).

Reflection

Throughout the process some spanners were thrown into the works, slowing it down. Primarily, I made the mistake that many DPsych students report, expecting to be able to do a systematic review quickly. My initial three-month expectations were naïve, and having already completed a systematic review not long prior to commencing this one, I was aware that systematic reviews are a time consuming piece of work. Secondly, there were needs within the organisation for me to put the systematic review on hold in order to assist with trying to reduce the rapidly expanding waiting list, by taking on keyworking clients on a Tuesday. This arrangement lasted for two months. Furthermore, as the rest of the week was very busy, when I was requested to do other tasks, such as run training workshops for clients or staff, I used Tuesdays as my only available day in order to prepare, as necessary. The Chief Executive was happy with this arrangement, and was not chasing me for the review. I was very fortunate, however, that my second reviewer for the quality scoring was very efficient with returning the reviewed articles and accompanying score sheets.

Aside from the issues of timings, I found the process very draining. Looking at a computer screen, reviewing 539 article titles fatigued my eyes considerably. Having only a small amount of useful vision (due to being registered blind) I have to consider more rest breaks in the future for intensive computer work.

I was fortunate to have completed a systematic review prior to commencing this consultancy, although I feel that gave me false confidence that I could complete this faster than was reasonable given the time available. Having attended the DPsych workshop on systematic reviews, and sought advice from the subject librarian, my confidence was reignited and I learnt how to search more effectively than I had initially planned. Throughout the process I improved my ability to complete a review, and have learnt that in future I need to consider more than just my academic ability when estimating the time it may take to conduct a piece of work; and, to take note of other considerations in order to maintain my own good health.

Monitor the Process

During the consultancy process there were significant organizational changes that resulted in amendments to the project. [redacted] waiting list increased exponentially, meaning clients had at least a two to three month wait until they were able to be allocated a worker. In light of this, the organisation implemented a new waiting list psycho-educational "recovery training" group, facilitated by one of the staff counsellors. Furthermore, there were added pressures on the organisation due to the uncertainty of when the contract tendering process was due to commence. Due to the imminent re-tendering for the organisation's contract the management team opted to implement a group-based service, where one-to-one interventions were used as an adjunct to groups as and when required, rather than the opposite. Meaning a more cost-effective service where the client can access services much quicker. It was acknowledged that many new groups are being developed, and the organisation would have to justify its existence to the commissioners in the near future. It was agreed that the consultancy would still furnish the client with valuable information through the delivery of understanding of the efficacy of using motivational interviewing as a framework for groups – the "recovery training" incorporates elements of motivational interviewing.

During staff meetings, and during client assessments, as well as with my clinical experience, I was aware of apparent resistance from many clients toward group-based treatments. As the organisation is now predominantly group-based, it is vital to mitigate the resistance to joining groups, which research has shown is often linked to social inhibition (MacNair-Semands, 2002). As such I included an evidence-based flyer proposal within the report to the client, as mentioned above in the "conducting the consultancy" section.

The second component of the consultancy became unnecessary once the "recovery training" had commenced.

Once this was completed the final report was emailed to the client for his perusal and feedback.

Reflection

Throughout the process I have had to be observant of the needs of the organisation, listening and acknowledging its changing needs through attending staff meetings, through office-based discussions, and through email notifications from the management of [redacted] I took a pragmatic approach and made the amendments as necessary. Due to the organization going through a competitive tendering process I was reluctant to interrupt the client. He had expressly advised me at the outset that as I had experience with systematic reviews and had trained in motivational interviewing that he would trust my decisions during this consultancy project. The organizational changes had happened, and are continuing to happen; therefore aspects of my initial plan had become unnecessary. In hindsight I would have requested more than one day a week to focus on the systematic review in order to complete it within the planned 3-month timescale. Had this happened the second component of the consultancy would have been deliverable and filled a need within the service.

Whilst using my own initiative to this extent would not be ideal in many instances during a consultancy project, I feel that in this instance it was fully justified. Whilst the second component of the consultancy became redundant, there were new opportunities for a more immediate impact.

With the systematic review demonstrating that groups are effective, I recognised that there was another need within the organisation that could be fulfilled with this consultancy. As such, I was able to read up on some group psychotherapy theory and utilise some of the health communications skills developed during Stage 2 training in the creation of a flyer to promote the benefits of groups. In hindsight, if the client had been consulted about this development, we could have agreed an evaluation period to assess the efficacy of the flyer in increasing group attendance and breaking down resistance.

Impact Evaluation

With the core component of this consultancy being a systematic review, there are no formal methods of evaluation that can be used.

In order to evaluate the client's satisfaction of the consultancy, I emailed a pdf-formatted report (appendix 4). As requested, the document was very brief with a two-page document summarising the systematic review: the key findings were bullet-pointed for ease of reading. Included on the two-pages was a "Don't do groups?" flyer, along with justification for its design.

Once the client had reviewed the report we had a brief meeting (see appendix 5) where he stated that he found the report very useful, remarking that it was very unusual, and pleasing, to have such valuable information delivered in such a brief and understandable form. Furthermore he stated that the concept of a flyer to increase confidence in attending groups was a "great idea" and that excepting one word that he wanted amending, was very well worded and designed. Once the one word amendment is made the flyer will be included in the welcome packs handed out during the assessment process.

Reflection

There was a great deal of satisfaction completing the consultancy project for the client, and the feedback was encouraging. I felt throughout the process that I lacked some confidence in my "expertise", but have learned that I am knowledgeable on this topic, have the skills to produce a systematic review, and can do write a succinct summary that disseminates the knowledge and findings to someone who can use it for future decision-making.

Had I considered the need for the flyer at the outset, I would have included that within the proposal and planned a proper evaluation. That would have taken the form of assessing how many assessments were completed within a set time-frame (3 months) prior to the flyer being implemented, and attendance at the recovery training, and other relative [redacted] groups, comparing it to the group attendance 3 months post-implementation. Had I completed this process

earlier in my placement I would have had time to incorporate this additional evaluation.

Summary

Throughout this process my confidence has grown, in both the many aspects of consultancy and also in completing systematic reviews. I stuck to the expert model, donating my expertise to a charitable organisation, and feel that in this instance it was the right thing to do. On reflection, I may have developed more had I taken an opportunity advertised for an external consultancy project, but that would have involved taking a long break from my placement at [redacted] As I had committed to dedicate two years to them, I felt it would have been unfair. There are still some areas I feel would benefit from developing further, such as contract negotiation with some monetary components, in addition to managing the client's expectations regarding feasible timescales, and my own time-estimates.

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Appendix 3 – Consultancy Contract

Consultancy Agreement

between

Timothy Mahy – Trainee Health Psychologist

And

[redacted]

This agreement is made the 13 January 2013 between:

1) Tim Mahy (TM) (the consultant)
2) [redacted]

Contents:

1. Introduction
2. Aims and Objectives
3. Duration
4. Terms and Conditions
5. Key Performance Indicators
6. Budget
7. Reporting and Dissemination
8. Key Responsibilities and Project Team
9. Evaluation

1 - Introduction

With the upcoming changes to funding for drug and alcohol services within the UK it is becoming increasingly important to ensure that the services delivering treatment solutions are running as efficaciously as possible, that relapse rates are low to maximise income post payment-by-result, and that when services are retendered that there is sufficient differentiation to ensure continued funding from the Borough.

Alcohol misuse is a pertinent issue within the UK at present; highlighted by the numerous efforts to curb alcohol use through minimum pricing, and per Professor David Nutt et al's 2010 research into drug harms, the most harmful drug to the user and also damaging to society. [redacted] statistics demonstrate less than favourable relapse and drop-out rates, therefore an investigation into new methods of improving client engagement and reducing relapse are desirable.

The plan to deliver change will involve a two phase approach:

Phase 1 – Systematic Review of the Literature on the efficacy of Group Motivational Interviewing in the treatment of alcohol misuse.

Phase 2 – Design, Implement, and Evaluate a Pre-Treatment Group Intervention to Enhance Engagement and Prevent Relapse.

The success will be evaluated using Key Performance Indicators.

2 - Measurable Aims & Objectives (SMART)

Phase 1

- To perform a systematic review of the literature on group motivational interviewing for alcohol misuse clients in order to assess the efficacy of group motivational interviewing.
- Report the findings to Chief Executive of [redacted]

Phase 2

Based on Phase 1:

- Design a group pre-treatment intervention to increase engagement with counselling and/or keyworking treatment provided by [redacted]
- Market Intervention to [redacted] staff and provide clients with option of attending pre-treatment intervention.
- Implement intervention with alcohol misuse clients.
- Evaluate Intervention.
- Report the findings to Chief Executive of [redacted]

Key Objectives:

- Develop an intervention that increases engagement with structured treatment and reduces relapse.
- Deliver a value for money intervention.

3 – Duration

Phase 1 to be completed and reported by 31 March 2013

Phase 2 to commence after completion of Phase 1 with an indicative implementation date of late June, completion by 31 December 2013.

4 – Terms and Conditions

A) All work will be performed pro-bono by the consultant
B) Resources for phase 1 will be provided to [redacted] at no cost to the charity

5 – Key Performance Indicators (KPIs)

Performance of Phase 2 will be assessed by the following means:

- Units of alcohol consumed prior to commencing treatment and post-treatment
- Engagement with structured treatment
- Drop-out rates
- Relapse rate following successful completion of treatment programme (1, 3 and 6 month intervals)

- Quality of Life scores before commencing Intervention, after intervention, and after treatment (using WHOQOL-BREF).

6 – Budget/Resources

This consultancy will be completed on a voluntary basis, at no cost to the client.

Phase 1

Time – minimum of one day per week, to be assessed as the project develops.

Resources – stationary and IT supplies to be supplied by TM at no cost to [redacted]

Phase 2

Time – minimum of one day per week, to be assessed as the project develops.

Resources – stationary and IT supplies to be confirmed once further information regarding the nature of phase 2 is known. Once developed, a room shall be required to run the group intervention with possible funding for tea and biscuits.

7 - Reporting and Dissemination

Phase 1

An Executive Report of the Systematic Review will be disseminated to the Chief Executive of [redacted] summarising the findings and providing a contextual description of the findings in relation to Phase 2.

The consultant will submit copies of documents as evidence of the consultation process to City University, London for assessment. The systematic review may also be re-written for dissemination through an appropriate peer-reviewed journal.

Phase 2

The Chief Executive will be kept apprised of the progress of the intervention as it is being designed, implemented, and evaluated; followed by a formal report on the success of the intervention with appropriate KPIs.

Depending on the level of success, the intervention may be reported through a peer-reviewed journal, and/or through an appropriate conference or other academic channels.

8 - Key Responsibilities and Project Team

The consultant shall be solely responsible for the systematic review; as well as the design and implementation of the intervention. Other members of staff (counsellors and keyworkers) may be required to collect KPI information on clients who have engaged with the intervention.

9 – Evaluation

The success of the consultancy will be based on two main features:

The success of the intervention

The [redacted]hief Executive's satisfaction with the consultancy process

Agreed by:

[redacted]

Timothy Mahy
Consultant
Trainee Health Psychologist

[redacted]

For and on behalf of
[redacted]

A Systematic Review – Executive Summary

Tim Mahy

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Executive Summary

Background

There are an estimated 7,000 deaths per year in the England due to alcohol misuse, with the cost of alcohol-related harm on the NHS amounting to £2.7bn a year. Of that £2.7bn, only 2% is allocated to the provision of specialist treatment services. The majority of the 7,000 deaths were attributable to alcohol liver disease. In addition to alcohol liver disease, alcohol is wholly attributable to another 12 medical conditions, and linked to another 34. Due to this impact on health, hospital admissions linked to alcohol related illness or injuries exceed 1.2million per annum.

In 2011/12 the number of people in the UK presenting for alcohol misuse treatment reduced, although it is acknowledged that presentations do not account for the full picture within the country. It is important to utilize methods that are able to engage people in a service, and provide a cost-effective service at the same time. With the advent of payment by results, and the tendering of substance misuse services within London, it is vital to provide a service which is both effective and value for money.

Motivational interviewing was initially designed for increasing motivation and tackling ambivalence with alcohol misusers. It has grown in importance and is now one of the UK government's recommended psychosocial interventions.

The purpose of this review is to assess the current evidence of how effective motivational interviewing is when used within group alcohol treatment. By delivering interventions within a group format, it is possible to deliver interventions to more people in a shorter period of time, thus having the potential to make significant time and cost savings.

Results

After reviewing 539 titles and abstracts, 14 papers were selected for quality assessment. Following quality assessment by two researchers, 6 papers were included.

Findings

- Motivational Interviewing based groups facilitated by qualified/skilled and experienced alcohol workers are more effective than those run by peer or inexperienced facilitators.

- Group visits to after-care groups significantly increases attendance at after-care groups post-discharge compared to those who attended individual counselling.

- Multiple-session Motivational Interviewing groups tend to be more effective than single-session Motivational Interviewing groups.
- The adjunctive use of normative feedback can enhance the effects of a Motivational Interviewing group.

Conclusion

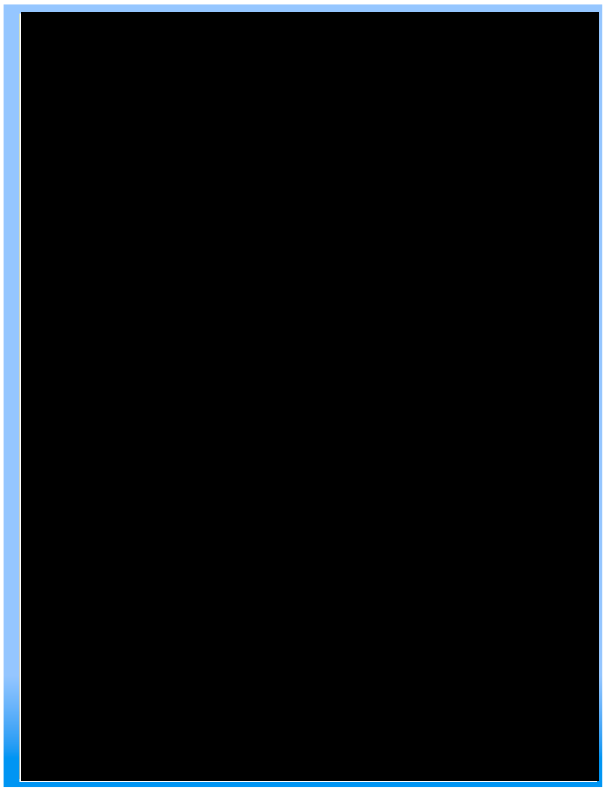
Group Motivational Interviewing can be more effective than individual Motivational Interviewing for the treatment of alcohol misuse, when skilled and experienced workers facilitate groups. Using a group Motivational Interviewing framework with psycho-educational groups and therapeutic groups can be an effective intervention with problem alcohol users.

Next Steps

[redacted] has recently implemented a group-based treatment programme in order to deliver a more effective and competitive service in light of the upcoming tendering process. Whilst it is acknowledged that there are many benefits of group treatment, the client base can be resistant. As [redacted] now offer groups as the primary method of treatment delivery, with individual counselling being offered as an adjunctive treatment as and when required, it is vital to begin socialising new clients to the concept of group treatments from the outset. Whilst this is currently done verbally during the assessment process, a simple flyer that can be discussed during the assessment process, incorporated within the welcome pack, may be beneficial.

“Don’t do groups?” Flyer

The flyer below was designed to be eye-catching, and uses simple language to convey some of the benefits of group therapy, such as the ability to learn from peers’ experiences, and to teach peers with experiences; the concept of universality; altruism; and group cohesiveness (Yalom & Leszcz, 2005).



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Appendix 1 – 4-Week Mindfulness Based Relapse Prevention Programme

Week 1 – Automatic Pilot & Relapse

Materials Required

- Folder to store hand-outs
- Body scan CD
- 4 hand-outs
    - Overview of sessions
    - Definition of Mindfulness
    - Daily Practice Tracking Sheet

Session Goal

- Introduce the concept of automatic pilot and bringing awareness to our lack of awareness
- Introduce the foundations and practice of mindfulness based relapse prevention
- Introduce mindfulness as a way of becoming aware of the patterns of the mind
- Introduce the body scan

Session Outline

- Introduction
- Format of the programme
- Automatic Pilot & Relapse
- What is mindfulness?
- Body Scan Meditation
- Home Practice
- Close

Home Practice

- Body Scan 6 or 7 days
- Mindfulness of a daily activity
- Daily Practice Tracking Sheet

Introduction

A brief introduction – clinician explains the experiential nature of the programme.

Key features to mention:

- 4 week programme
- Beneficial if engage with the homework
- Honesty is key as struggles to practice can be explored in session
- Each week is a 50 minute session

Ask the client to reflect upon what is really important in their life – i.e. "If treatment could really help have the life you want, what would change?"

Keep the introduction brief as the programme could become time-pressured if too much time is spent on each section.

What is Mindfulness?

Elicit from the client, based on the raisin experiment and other experiences, to describe what mindfulness is.

Expect the following responses:

- Quality of awareness
- Being in the moment
- Feeling connected
- Ability to stop habitual processes

Hand-out 1.2 – Jon Kabat-Zinn description of mindfulness – "mindfulness means paying attention in a particular way: on purpose, in the present moment and non-judgementally".

Key points to consider in the discussion:

- Gentleness and Kindness to the present experience
- Compassion
- Non-judgemental
- Encourage clients to be gentle with themselves
- Curious awareness of all experiences (pleasant/unpleasant).

Practice 1 – Body Scan Meditation

The body scan allows us to expand the awareness of the body and is one of the foundations of mindfulness. It is vital to stress that during this exercise the client remains curious and open about their experience, and removes expectations of what one should and should not experience.

This exercise is about learning to pay attention to the experience, whatever it may be.

How this is useful for preventing relapse? When in automatic pilot we don't pay attention to the processes happening within our body and mind. By paying attention to our body's processes we become more aware of our experiences and this can be the first step toward controlling urges in the future.

Script:

Allowing your eyes to close gently, take a few moments to get in touch with the movement of your breath.
<pause a moment>

When you are ready, bring your attention to the physical sensations of your body, noticing where your body is touching the chair. On each outbreath, allow yourself to let go and sink a little more into the chair.

The intention of this practice is not to change anything or to feel different, relaxed, or calm. This may happen, but it may not. Instead, the intention of this practice is, as best you can, to bring awareness to any sensations you feel as you focus attention on each part of the body. If you find your mind wandering, just bring it back to the awareness of your body.

Now bringing your awareness to your abdomen, become aware of the sensations there as you breathe in; and, as you breathe out. Take a few moments to feel the changing sensations. How the in breath feels different to the outbreath.

<pause briefly>

Having connected to the sensations in the abdomen, move your focus down to your big toe on your left foot. Notice all the sensations in that toe. Then allow your focus to move to each of the toes on your left foot, bringing a gentle curiosity to the quality of sensations you find, perhaps noticing the sense of contact between the toes, a sense of tingling, warmth, or no particular sensation. If there are areas you cannot feel, just keeping your focus there, noticing whatever you can about that area.

When you are ready, feeling or imagining the breath entering the lungs, and then going all the way down through the body, down to the left foot and the toes, then imagining the breath coming from the tips of the toes, through the body, and out of the nose. Continue this for a few breaths – you may find this strange, or challenging, but practice it as best you can.

<wait for the client to do a few breaths before continuing>

Now, letting go of the awareness of the toes, bring the awareness of the sensations on the bottom of your left foot, bringing a gentle, curious awareness to the sole of the foot, feeling all the sensations there. Now bring your attention to the top of the foot, then to the ankle. Noticing all the muscles, bones and tendons in the ankle. Now moving the attention up to the calf and shin, feel your clothing touching the skin, any sensations in the muscles. Now upto the knee – detect as best you can the sensations in the knee, sending your breath to each area as you move up the leg.

You might think of your awareness as a spotlight, moving slowly through the body bringing into focus any sensations in that area. If there are areas where it is difficult to feel sensations, that is okay. Just notice what you can.

Now, bringing your attention to the left thigh, noticing the sensations there. Maybe you feel the pressure of your leg against the chair.

Throughout this exercise the mind will wander away from the breath and the body that is okay. It is entirely normal. When you notice it happening, acknowledge it and gently return your attention to the part of the body. If you

find yourself thinking about the body, acknowledge this and return to just noticing with a curiosity, and not thoughts.

Now, sending your attention down the right leg, through the right foot, and into the right toes. Again, picture the breath going right down into the toes and then coming back up through the body and out of the nose. Continue bringing awareness and gentle curiosity to the physical sensations, allowing whatever sensations are in the toes to just be here as they are.

Notice now what you feel in the bottom of your right foot, and in the top of the right foot, and the ankle. Bringing the awareness up the leg to the calf and shin and noticing any sensations there. Now moving up to the knee.

If you feel any pain or discomfort in any of these areas, just be aware of it and practice sending breath there, as best you can, letting the sensations be as they are.

Now, gently moving your awareness up to the right thigh, noticing any sensations here, before moving up to your hips and waist.
Notice your weight on the chair.

Moving your attention up to your abdomen, feeling it rise and fall with each breath. Now moving your awareness to your ribcage – just notice all the sensations that you can. Move your attention to your back, the lower back, and the upper back. Feel where the back touches the chair, and any areas of tension or discomfort.

Now move the attention into your shoulders and chest.

When you become aware of any tension or other intense sensations, you might try breathing into them as best you can. Using that breath to bring the awareness right to the sensations. Then on the outbreath, letting go.

It is okay to notice your thoughts wandering, or if you become distracted or restless, just notice that and then gently guide your attention back to the body.

Guiding your attention down your left arm and into your fingertips, noticing all sensations in each finger. Moving up into the wrist and forearm, noticing all sensations here, before moving up to the elbow, the upper arm, and the shoulder. Notice any tension or tightness.

Now moving your attention across the body to the right side and guide the attention to the fingertips of the right arm. Feeling each finger separately. Notice any tingling or urges to move them. Notice if there's any fingers that you cannot feel as well as others. Now guide your attention into the palm of the hand, up through the wrist and forearm, to the elbow, then the upper arm and shoulder.

Now, let your attention come to your neck – feel where there is tightness or tension. Be aware of areas where it is harder to detect sensation. Now, bringing the attention to the back of the head. See if you can feel the hair on your head. Bringing the awareness to just above the left ear, now above the right ear and then to the forehead.

Exploring now the sensations in the face, your eyes, cheeks and nose. See if you can notice the temperature of the breath, feeling whether it changes as you breath in and out. Feeling any sensation in your lips, chin, and jaw.
Now, bring awareness to the very top of your head.

Now, after you have scanned the whole body in this way, spend a few moments being aware of the body as a whole and the breath flowing freely in and out.

Very slowly and gently, whilst still maintaining awareness of your body, start moving the body a little, wiggle the toes and fingers maybe, allowing your eyes to open and bringing your awareness to include the room around you.

Proceeding Discussion

Use a few minutes to explore the client's experience of the body scan, any difficulties experienced, anything that was good or not so good. Should they feedback issues concentrating, mind wandering etc then provide reassurances

that this is normal. Use your own experience of mindful meditation if appropriate.

Affirm that there is no right or wrong way to do mindful meditation – just try to remain curious and non-judgemental.

Home Practice

Introduce the home practice which, for this week, is to complete the daily tracking sheet. Analogy to describe how practice makes it easier.

Tasks: Body Scan (CD) & Mindfulness in a Daily Activity

Week 2 – Triggers & Craving

Materials Required

- 4 hand-outs
    - Common Challenges in Meditation Practice (and in our daily lives)
    - Noticing Triggers
    - Daily Practice Tracking Sheet

Session Goal

- Increase awareness of body sensations
- Practice awareness of physical, emotional, and cognitive reactions to triggers
- Introduce mindfulness as a way to create a pause in this typically automatic process.

Session Outline

- Check-in
- Urge Surfing Exercise
- Home Practice
- Close

Home Practice

- Body Scan 6 or 7 days
- Mindfulness of a daily activity
- Daily Practice Tracking Sheet
- Noticing Triggers Worksheet

Check-in & Home Practice Review

- Review how client is doing.
- Review home practice tracking sheet and discuss any challenges experienced within the first week of practice. Challenges are very common when commencing a relaxation programme and it is therefore important to acknowledge and recognise these. Some of the most common issues are restlessness, drowsiness, falling asleep, self-judgement, and expectation of peace and relaxation.
    - Five typical challenges for mindfulness meditation practitioners:
        - Aversion – could include fear, anger, irritation, resentment
        - Craving/ Desire – or the experience of wanting, maybe the subtlety of wanting to relax, or the intensity of a desire to use a substance
        - Restlessness/ Agitation – the desire to move, or mental agitation.
        - Sloth and Torpor – Sleepiness, drowsiness, mental sluggishness
        - Doubt – personal doubt, or doubt about the practice.
- Recognise these can be a part of meditation; observe them as you would with bodily sensations, with a sense of curiosity, rather than trying to eradicate them.

Practice 1 - Urge Surfing

Introduction

This exercise is designed to change the relationship with the experience of urges and cravings to use substances, from the feeling of fear or resistance, to one of curiosity and "being with" the craving. It encourages us to explore cravings in a different way, observing the physical sensations at the start of the craving, along with the accompanying thoughts and urges, allowing the craving to be dismantled and viewed from a different perspective from the overwhelmingly reactive, sense of defeat, and attempting to control the process. Practicing a curious and compassionate look behind the craving allows us to recognise what you may truly need, yet be replacing it with a substance. Substance misuse is often a deceptive refuge.

Exercise - Script

Now we are going to do an exercise that may be quite intense. I'm going to ask you to picture a situation that you might find challenging in your present life, one in which you are triggered in some way, maybe a situation in which you might be tempted to use alcohol (or drugs) or engage in another behaviour that is

problematic for you. Ensure you take care of yourself by choosing a behaviour that is challenging but not overwhelming.

As you picture this, I am going to ask you to imaging that you are not going to engage with the reactive behaviour, whether it is substance use, getting into a fight, or whatever it might be for you.

I encourage you to stay with whatever comes up as best you can with a sense of gentleness and curiosity. If the scenario you pick feels overwhelming or like something ou do not want to do or are ready to do, respect that and imagine a less intense situation. Do you have something in mind? If at any time this becomes overwhelming, you can always just open your eyes, move your body a little, and reground yourself in the present.

Now I am going to ask you to close your eyes again, if that feels comfortable. You may also leave them open if you choose, maintaining a soft focus a few feet in front of you and letting your eyes rest there.

Begin by feeling your body here in the chair. Noticing the sensations. Letting the breath flow easily in and out. Now bringing this scenario you've chosen to mind. A situation that might or has in the past caused craving or urges to act in a reactive manner, in a way that is not in line with how you want to be in your life. Maybe you are with a certain person, or in a certain location. Maybe it's something that has happened in the past that you can recall, or a situation that you imagine would be challenging for you. Remember that in this scenario you are going to make the choice not to drink or to engage in whatever reactive behaviour this scenario triggers for you.

Now taking a few moments to really picture yourself in that place or situation or with that person. Imagining the events or situation that lead up to this reactivity, and bringing yourself to that point where you feel triggered, as though you might behave reactively. And we're just going to pause here for a moment. We often tend to either fall into a craving, or fight to resist it. Here, we are going to explore our experience a little, finding a balance, just staying with and observing the experience without "automatically" reacting.

So you might begin by noticing any emotions that are arising. Noticing what thoughts might be going through your mind. What physical sensations you are experiencing in this situation? What does this feel like in your body? Noticing, too, what it is about this experience that feels intolerable. Can you stay with it, and be gentle with yourself? If you begin to feel overwhelmed at any point, you can back off a bit by allowing your eyes to open or letting your attention come back to observing your breathing. Remember that we are practicing staying with this experience in a kind, curious way. We are making the choice to not act on any urges or cravings that are arising… Just staying with them and observing, as best you can, what is happening in your body and mind, what a craving or an urge feels like. See if you can feel what's here without tightening around it or resisting it.

Feeling what it is like not to engage in the behaviour, discovering what happens when you stay with this experience and explore it a little: What is it you are truly needing? Is there a longing for something? Maybe there is fear, anger, loneliness. Maybe relief, or freedom. What is it you really need right now? Just staying with this discomfort and unfamiliarity. Observing with a very gently curiosity.

If a craving or urge becomes increasingly intense, you might imagine it is like an ocean wave. Imagine that you are riding that wave, using your breath as a surfboard to stay steady… Your job is to ride the wave of desire from its beginning, as it grows, staying right with it, through the peak of its intensity, keeping your balance whilst the wave rises, and staying ontop of it until it naturally begins to subside. You are riding this wave rather than succumbing to the urge and being wiped out by it. Just watching the pattern as the urge or craving rises and then falls, and trusting that without any action on your part, all the waves of desire, like waves on the ocean, arise and fall, and eventually fade away.

Noticing how you can simply stay present with this wave instead of immediately reacting to it. Accepting the craving and staying with it, without giving into the urge, without acting on it, without having to make it go away.

Now, taking the time you need, gently letting go of the scenario you've imagined, and slowly and gently bring your attention back into the room. Taking a deep breath if you'd like to. Maybe moving the body a little if that feels right.

Week 3 – Acceptance & SOBER Breathing Space

Materials Required

- 2 hand-outs
  - SOBER Breathing Space Worksheet
  - Daily Practice Tracking Sheet

Session Goal

- Discuss role of acceptance to create a different relationship with uncomfortable situations and challenges.

Session Outline

- Check-in
- Acceptance
- Use of SOBER breathing space
- Home Practice
- Close

Home Practice

- Body Scan 6 or 7 days
- Mindfulness of a daily activity
- Daily Practice Tracking Sheet

Check-in & Home Practice Review

- Review how client is doing.
- Review home practice tracking sheet and discuss any challenges experienced within the first week of practice. Challenges are very common when commencing a relaxation programme and it is therefore important to acknowledge and recognise these. Some of the most common issues are restlessness, drowsiness, falling asleep, self-judgement, and expectation of peace and relaxation.
    - Five typical challenges for mindfulness meditation practitioners:
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        - Sloth and Torpor – Sleepiness, drowsiness, mental sluggishness
        - Doubt – personal doubt, or doubt about the practice.
- Recognise these can be a part of meditation; observe them as you would with bodily sensations, with a sense of curiosity, rather than trying to eradicate them.
- Review thoughts on Urge Surfing exercise.

Practice 1 – SOBER Breathing Space

Stop or Slow down

Observe what is happening right now

Breath focus – centring attention on the breath

Expanding awareness to include a sense of the body as a whole

Responding with full awareness, asking yourself what is needed

We're going to stop, now, right here in this moment. Now observe, and become aware of what is going on right now. What situations are in the body? What feelings or emotions are present? What thoughts are going through your mind? Just noting the whole experience, without judging it or needing to change anything.

Now, gathering awareness by focusing on the breath. By bringing attention to the movements of the rise and fall of the abdomen, to the sensations of the breath moving in and out, and just staying with that for a few breaths.

And now allowing your awareness to expand, to include a sense of the body as a whole, all the sensations that are here. Also an awareness of any feelings or emotions. And checking in, too, on the mind – the quality of the mind and any thoughts that are here.

And then finally, from this place of greater awareness, notice that you can make any one of a series of choices in how to respond. Maybe reflecting briefly before opening your eyes and bringing your awareness back into the room

Now, allowing your awareness to expand, bring yourself back into the room.

Week 4 – Relapse Cycle, Awareness, and Recap

Materials Required

- 2 hand-outs
  - SOBER Breathing Space Worksheet
  - Daily Practice Tracking Sheet
  - Relapse Cycle

Session Goal

- Furthering the recognition of thoughts being only thoughts, and the role of thoughts and beliefs in relapse.

Session Outline

- Check-in
- Relapse Cycle – Observing and labelling thoughts.
- Recap of the three sessions
- Home Practice
- Close

Home Practice

- Continue use of Body Scan
- Mindfulness of a daily activity
- Daily Practice Tracking Sheet

Check-in & Home Practice Review

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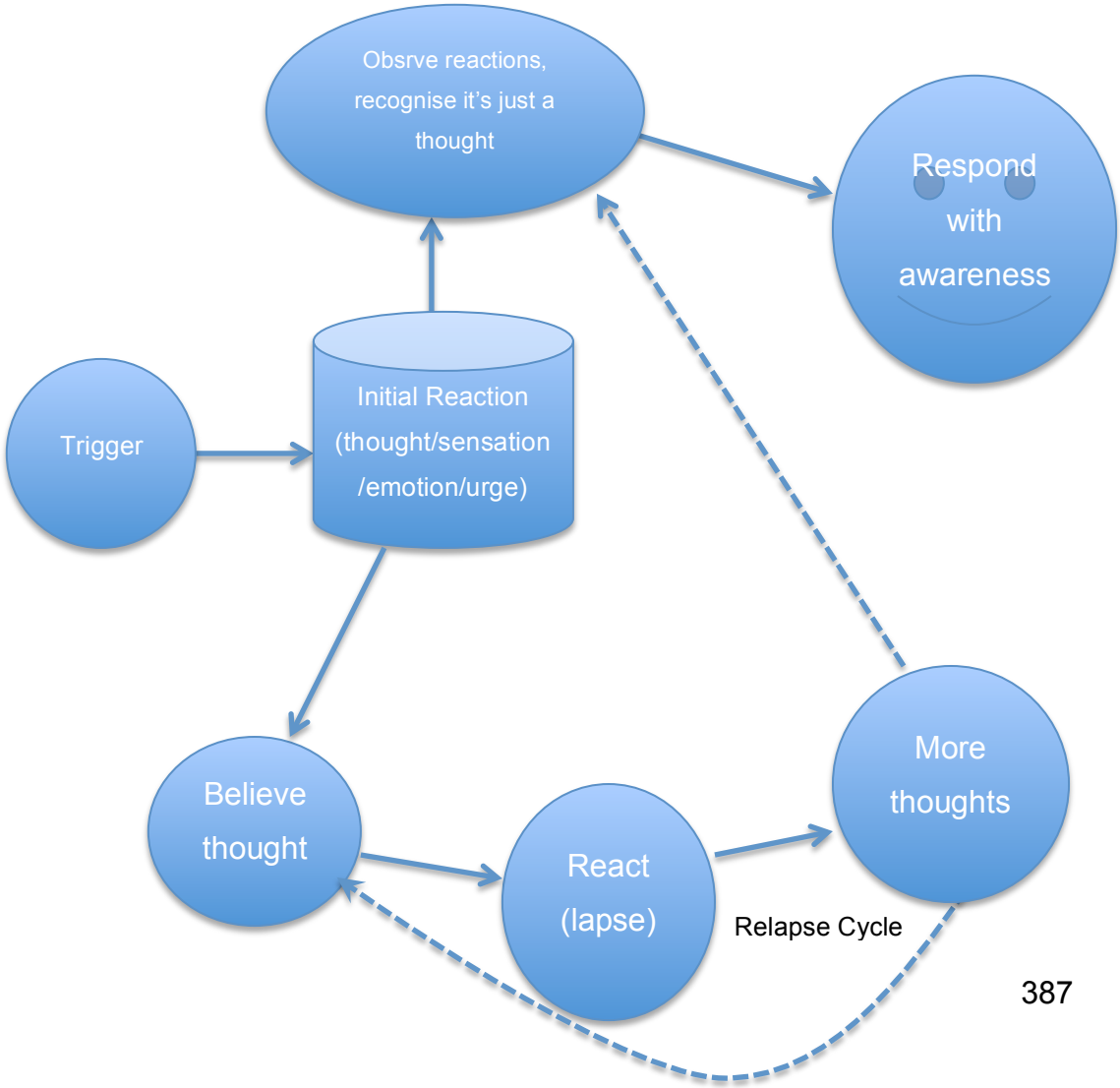


Handout 1.1
Overview of Sessions

Session 1 – Automatic Pilot & Relapse

In this session we discuss "automatic pilot", or the tendency to behave without full awareness of what we are doing. In specific, the automatic use of drugs or alcohol (acting upon cravings and urges "automatically" without awareness). We begin this exploration with an exercise called the body scan to practice bringing attention to the body.

Session 2 – Awareness of Triggers and Craving

This session focuses on building skills to experience cravings, triggers and thoughts to use without automatically reacting. We look at recognizing triggers and what the reaction feels like in the body, specifically the sensations, thoughts, and emotions that often accompany craving. We begin to use mindfulness to bring greater awareness to this typically automatic process, learning to experience cravings and urges in a way that we can avoid the automatic process and respond in a different way.

Session 3 – Acceptance and Risk

Although it can feel paradoxical to accept unwanted thoughts, feelings, and sensations, it can be the first step toward change. Acceptance of the present experience is an important foundation for taking care of oneself and seeing clearly the best course of action to take. We practice techniques such as the breathing space and focus on using these in challenging situations. This session moves

from noticing warning signs and learning to pause to taking skillful action in both high-risk situations and in daily life.

We learn the “SOBER” space as a way to expand the quality of mindfulness from formal sitting or lying down practice to situations encountered in daily life. This may help us learn to “be with” various physical sensations and emotions that arise, including those associated with cravings and urges, without reacting in a harmful way. We will also look at the formal sitting meditation.

Session 4 – Seeing Thoughts as Thoughts and Continuing Practice

We explore further the awareness of and relationship to thinking, with a focus on experiencing thoughts as merely thoughts (even when they feel like the truth). We look at what role thoughts play in the relapse cycle, specific thoughts that seem particularly problematic, and ways to work more skillfully with these.

In this final session we review the skills and practices learned in this course. We discuss the importance of building a support system and reflect upon what has been learned. We discuss how mindfulness practice can be continued in daily life.

Handout 1.2
Definition of Mindfulness

Mindfulness means paying attention

In a particular way:

On purpose,

In the present moment

And non-judgementally.

Jon Kabat-Zinn

Handout 1.3
Session 1 Theme & Home Practice: Automatic Pilot & Relapse

Theme:

Automatic Pilot describes our tendency to react without awareness. When we experience cravings and urges to use alcohol or other drugs, we often go into automatic pilot; that is, we act upon them without full awareness of what is happening and of what the consequences will be. Mindfulness can help us to step out of this automatic pilot mode, helping us to raise our awareness and make more conscious choices in how we respond rather than reacting in habitual and self-defeating ways.

Home Practice:

1 – **Body Scan** – do your best to practice the body scan on 6 or 7 days between now and next time we meet. There's no "right" way to do this, nor is there anything particular you "should" experience. Just notice whatever is arising in the present moment.

2 – **Mindfulness of a Daily Activity** – Choose an activity you do daily (i.e. ironing, washing dishes etc), and (as best you can) bring your full attention to the task in the same way you did when experiencing the raisin. You may notice qualities of the object or activity as well as sensations, thoughts, and/or feelings that may arise.

3 – **Complete Daily Practice Tracking Sheet** – Fill this out each day to record your mindfulness practice (both body scan & daily activity). Please be honest with your tracking! You will not be judged on how often you practiced over the week. You will benefit most from the programme if you practice daily. Note any comments, experiences, or things that get in the way of practicing.

Handout 1.4
Daily Practice Tracking Sheet

Instructions – Each day, record your practice. Please note any barriers to practice, any observations, and/or comments.

Day/Date	Formal Practice with CD: How Long?	Mindfulness of Daily Activities	Observations/comments
	_____ minutes	What activities?	
	_____ minutes	What activities?	
	_____ minutes	What activities?	
	_____ minutes	What activities?	
	_____ minutes	What activities?	
	_____ minutes	What activities?	
	_____ minutes	What activities?	

Handout 2.2
Noticing Triggers Worksheet

Pay attention this week to what triggers you to crave alcohol. Use the following questions to bring awareness to the details of the experience as it is happening.

Day/Date	Situation/Trigger	What sensations did you experience?	What moods, feelings, or emotions?	What were your thoughts?	What did you do?
Friday 13/6	*Example: had argument with friend*	*Tightness in chest, cold, clammy palms, heart racing*	*Anxiety, craving*	*I need something to get me through this. How much cash do I have?*	*Took a walk, later talked with friend about what upset me.*

Handout 2.1

Common Challenges in Meditation Practice

There are some challenges that arise commonly during meditation practice – this list of challenges has remained stable for thousands of years. These experiences are neither bad, nor wrong; they are simply part of meditation practice. They do not mean you are doing it incorrectly, or that your practice is not working. They can be tricky because when they arise, they can become extremely distracting, and people can feel defeated by them. Learning to recognize these experiences as they arise and knowing they are simply part of the experience of meditation practice can be helpful. It's not just you!

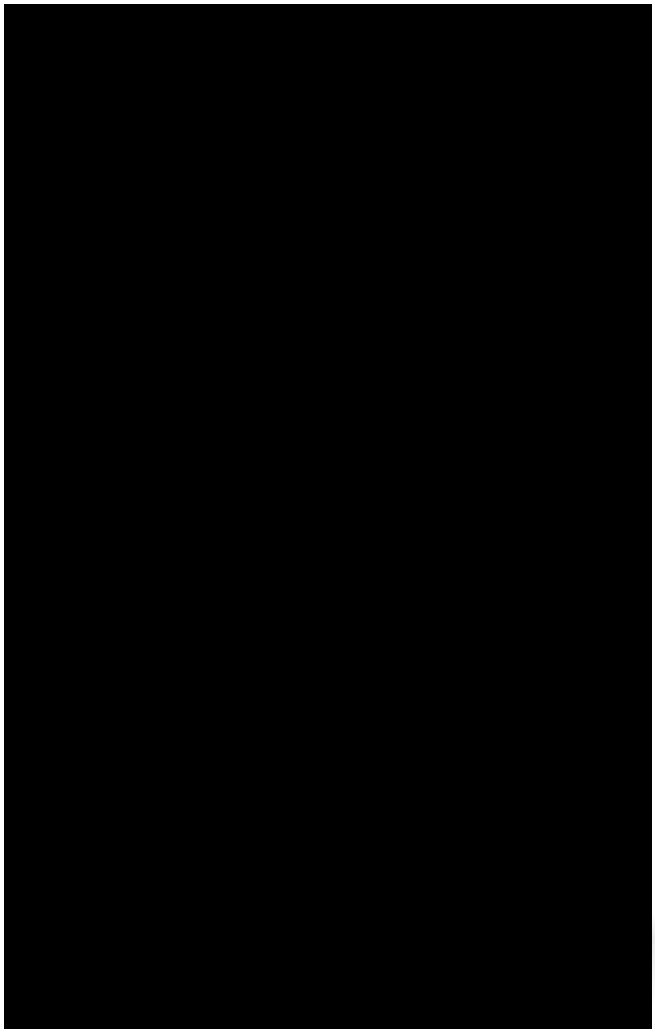
Handout 3.1
Using the SOBER Breathing Space in Challenging Situations

Instructions: In the left column, list any situations (people, locations, relationships, emotions, events) that happen this week that feel challenging, triggering, or like high-risk situations. In the next column, write what you notice about your reactions, especially sensations, thoughts or emotions that might be cues for you in the future to take a SOBER space. In the third column, note whether you were able to take a SOBER breathing space, and in the final column, write your response to this situation.

High-risk situations or triggers (People, locations, emotions, events)	**Reactions (sensations, thoughts, feelings that might be cues for taking a SOBER space)**	**SOBER Space? (Yes/No)**	**How did you respond?**

Notice that the reactions you listed in the second column can be cues for you to **STOP** and take a breathing space. See if you can recognize these reactions and begin to use them as a reminder to step out of an automatic, reactive mode and **observe** your experience.

Handout 3.1
Using the SOBER Breathing Space in Challenging Situations



Stop or Slow down

Observe what is happening right now

Breath focus – centering attention on the breath

Expanding awareness to include a sense of the body as a whole

Responding with full awareness, asking yourself what is needed

Professional Autonomy and Accountability

Practise Within Legal and Ethical Boundaries

The first workshop I attended for the DPsych at City University concerned ethics. In preparation for the workshop I read the ethical codes of both the HCPC and the BPS. Throughout my two years working on placement, I kept my ethical obligations at the forefront of my mind. When I commenced the placement I had very little practical experience of working in the field of psychology. I used the time to acquaint myself with the client base, read around the topic, and ensure that I was competent enough to deliver interventions to substance misuse clients. My role at [redacted] entailed group facilitation, drop-in facilitation, keyworking, and assessments. Notes are recorded onto a secure database after each session. During the assessment process new clients are asked to sign a consent form, whereby they provide details of individuals with whom [redacted] were allowed to share treatment information with. In addition to this consent, clients were asked to sign a driving declaration form. Prior to signing the driving declaration form, clients are advised that should anyone within [redacted] discover or suspect that they are driving under the influence of drugs and/or alcohol then a report will be sent to their General Practitioner (GP). On one occasion, during a drop-in session with a current client (of one of my colleagues), the client accidentally advised me that he had been driving under the influence of alcohol. I informed him that I would have to report this fact to his GP. As this was breaching confidentiality I escalated a query to the management team to verify my actions. This caused debate within the office, particularly within the counselling team. Some team members believed the client should have time to report himself to the police. This breach of confidentiality was acceptable as, per section 1.2 (vi) of the BPS Ethical Principles, breaches of confidentiality should be restricted to occasions where there appears to be sufficient evidence to raise concerns about the client's safety; the safety of others potentially endangered by the client's behaviour; and

the health, welfare and safety of children or vulnerable adults. In this particular instance, anyone nearby the client's vehicle would be at significant risk.

For my research I used SurveyMonkey, ensuring identifying information was not collected. Demographic data consisted of age and country of residence. During the ethics application process the ethics committee enquired about the collection of IP addresses. Initially this was something that had not crossed my mind. I looked into the options available on SurveyMonkey and discovered an option to not collect IP addresses. The IP address enables someone to discover where the survey was completed and therefore could identify one of the participants. My smaller study on the lived experience of guide dog ownership involved meeting the participants face to face. I ensured that the consent forms for this were scanned onto my personal computer and stored in a password-protected file to ensure privacy and confidentiality. During the analysis process I deemed it important to consider any information that may be identifying and my options for mitigating that risk without compromising the results. Any identifying information was therefore anonymised.

During my time at [redacted] I dealt with individuals from all backgrounds, sexualities, ethnicities and religions. Many of my clients had some criminal background. When sat face to face with individuals, they are all there for the same reason – they are seeking your help and support. As a practitioner I was sat opposite the individual and worked with the individual, rather than their ethnicity, sexuality, religion, or crime. Sometimes this took some cognitive effort to bracket personal feelings, such as when one individual attended drop-in having recently been released on bail for sexual offenses against a child. As a clinician in a charity setting we are there to help everyone who walks through the door. As the client had not been charged, it was my obligation to "avoid practices that are unfair or prejudiced". This client was at risk of self-harm due to their level of shame; therefore I fast-tracked him into support through a project dealing with individuals within the criminal justice system.

Practise as an Autonomous Professional

In my role at [redacted] I had a clinical caseload, to which I delivered interventions under the appropriate clinical supervision. During this process my knowledge and competence grew as I became more experienced in the workplace. There were occasions when I deemed it essential to make external referrals. Often clients would bring many issues that are interrelated to their substance use such as housing issues and legal issues. On occasion I would deal with some of the issues during the session. As I did not live in the borough I had less experience with some housing issues than others so would refer clients to one of my colleagues who had the requisite knowledge. Similarly with legal issues, I would often signpost clients in the first instance to Citizens Advice Bureau, or to the local Law Centre that provided free legal advice on some matters. With one particular client, both my colleagues and I had concerns over his mental health. He was a cannabis user so I was aware, having had dealings with the consultant psychiatrist in the neighbouring NHS service, that a cannabis user should be abstinent from cannabis for a month prior to a mental health assessment. My client was displaying extreme paranoia during our weekly sessions. I checked in with him for his progress during our sessions and was very pleased the week he threw his cannabis grinder into the River Thames. The client was then referred to see the psychiatrist, where he was diagnosed with early signs of schizophrenia and prescribed an anti-psychotic. The client refused medication. I continued discussing the client with my supervisor and the consultant psychiatrist, and continued working to support him. Eventually the client discharged himself as he had a new job and reported being much happier, and not misusing alcohol or cannabis. Within a couple of weeks I had a report from the psychiatrist advising me that my former client had a psychotic break and had been sectioned. This was in some ways a relief insofar as I knew he was now getting the medication he needed, but a disappointment as it may have been avoidable had he agreed to take the medication. Six-months later I received a further report to advise that my former client had been found "underneath a train". Initially this was a shock. I sat down with my workplace supervisor, who is a BACP registered counsellor, and discussed the matter. [redacted] offered me further counselling should I require it, and the Chief Executive offered personal support.

Engagement in Continuing Professional Development

When I commenced my DPsych placement I was aware that my clinical skills would benefit from some solid foundations. To ensure I was fully prepared to deal with a clinical caseload I enrolled in numerous courses: a foundation in counselling skills; motivational interviewing; brief solution focused therapy; and, positive therapy. These courses provided me with a solid underpinning of knowledge and helped me grow. Upon further discussions with my placement supervisor I identified some further benefits of a more substantial motivational interviewing course. I researched the options and found that Central and North West London NHS Trust ran a 13-week course. I discussed this with my line manager and Chief Executive and signed up for the course. This course acted as a catalyst to my seeing individual clients for keyworking and was instrumental in my professional development. I noted that many of my clients were struggling with more than one addiction at a time. Many of my clients were smokers. Whilst it was not within the remit of my role to address the smoking, I completed the NCSCT online courses to become a smoking cessation practitioner. Whilst I did not officially practice as a smoking cessation practitioner, it added an understanding of the impact of stopping smoking on psychiatric medications for consideration when talking to my clients. In order to stay abreast of current events within the addictions field I subscribed to DrugScope Daily email bulletin, reading the email and any links that I found interesting before starting my day.

As someone who is striving to work in a small community, with a wide repertoire of skills, I wanted to ensure I had many practicable skills. Through discussions with my academic supervisor, I became aware that hypnotherapy was a recognized adjunctive treatment within Health Psychology. I researched the available courses and signed up for a BPS approved foundation certificate in evidence-based hypnotherapy. This course reinforced my extant knowledge of psychoneuroimmunology and the mind-body links, and furnished me with some tools to induce a deep relaxation, and guide clients towards their goal behaviours. Upon further research I discovered that hypnotherapy is a NICE

recommended treatment for irritable bowel syndrome, and is occasionally used for pain management and dental treatment. This course left me inspired and I went on to do further additive courses on the use of hypnotherapy for weight loss and smoking cessation, which incorporate other components of behaviour change techniques. Whilst I have not had the opportunity to practice the hypnotherapy skills, I have been able to use some of the relaxation techniques with clients to demonstrate how they are able to relax.

Further to these external courses, I have attended the requisite CPD workshops held by City University for the DPsych. One I particularly enjoyed focused on cognitive behavioural therapy (CBT). I have many books on CBT, and it was my intention to attend an introductory course but did not have the available funds to do so. This is something I plan to invest in once I have completed my doctorate as I feel that as part of a mix of methodologies, CBT would be extremely beneficial for future clients. I was fortunate to have the ability to attend a live demonstration of CBT by Windy Dryden – this sparked my interest further having seen it being demonstrated. I also attended [redacted] in-house CPD sessions. Many were very specific to the role, such as care planning. One on risk, run by a consultant psychiatrist, was very interesting. The key take-away message for me was that those who tell you they are going to commit suicide are not the ones you really have to be concerned about. It's often the ones that do not tell you, that actually do it. This message turned out to be true in one of my former clients.

Throughout the DPsych I perused the online access to The British Journal of Health Psychology, and Health Psychology, in addition to other relevant journals. These are often interesting, but my placement work was quite specific with working with addictions, so many of the topics were not relevant to my current workload. I occasionally read through Addiction journal, ensuring I was up-to-date with best practice. Having worked with person-centred counsellors for a while, I became aware that I worked differently. I would challenge my clients' behaviours, in a professional and therapeutic manner, to promote behaviour change. I would acknowledge that I am having thoughts and feelings when sat opposite a client. Speaking to some pure person-centred counsellors you should bracket all of your own content and be in the room for your client. I

then read two books of case studies: Momma and the meaning of life: Tales of Psychotherapy (Yalom, 2006); and, Love's Executioner and Other Tales of Psychotherapy (Yalom, 1991). From reading these two books, and speaking to my workplace supervisor, I came to accept that my method of working was acceptable. If someone as eminent as Irvin Yalom has thoughts that he would not share with a client during a session, and sometimes questions himself, then it is okay for others to do the same. This boosted my confidence in my own ability. On one occasion a client complained to a colleague that I had bullied him during the session. The feedback was shocking to me, so I explored with my colleague exactly what was said, and took the matter to supervision. I also raised this with my client at our next session. He continued coming and was eventually discharged successfully as abstinent, having failed to achieve this with numerous workers in the past. His complaint was due to his behaviour being questioned during our sessions. I directly challenged his beliefs and his motives for some of his actions, such as hiding alcohol where he knows his partner will look, which he found uncomfortable. Ultimately, this discomfort facilitated significant changes and the client thanked me for the work we did together.

Professional Skills

Communicating Effectively

Whilst on placement at [redacted] I ensured that I used appropriate methods to communicate the impact and harms of alcohol and substance misuse to clients. Often in the case of alcohol misuse clients would remark about other health concerns, such as weight. In order to elicit a greater impetus for change I provided clients with a unit wheel that visually demonstrated the number of units in each drink, in addition to the calorie content. Often the clients were aware of the units, but the calories can be the shocking component.

Largely, I have a relaxed demeanour. Clients have commented that they often come into our sessions feeling tense, but are much more relaxed when they leave. This relaxed environment allows clients to feel comfortable from the outset, facilitating a better level of engagement. I like to work with the client to develop interventions that are practicable and ensure that I do not dictate to

them. With endings, I started off referring many of my clients onward to counselling with a colleague. As my confidence and skills grew, fewer of my clients required counselling and often we would discuss the point at which they would be happy to be discharged, set a date, and should they maintain their goals the agreed discharge would occur.

Providing Appropriate Advice & Guidance

In my role as a projects volunteer I would meet individuals needing advice and support on a daily basis. Running regular drop-in sessions enabled me to provide brief interventions prior to new client entering the service. Advice was largely based on harm-reduction, but varied depending on what the individual required at that moment in time. I often adapted my approach to the client's needs, incorporating motivational interviewing and a solution-focused approach predominantly. On one occasion a new client presented to the drop-in service. It was her first time in a substance misuse service and she was concerned about her alcohol consumption. We explored her current use and had a discussion about this, how it all started, and her goals. From this one session she took on-board some harm minimization advice I had given. When she presented for assessment a colleague provided me with feedback advising that she had used our discussion as a catalyst to change, reducing her alcohol consumption significantly.

As an example of adaptation, I am interested in positive psychology and often encourage optimism and walks in leafy, green areas. One client who was stressed within the workplace went home and drank after each shift. He was not keen on walking so we explored alternatives. He ended up joining a gym, would work out his work stresses, and became abstinent from alcohol much sooner than originally anticipated. Often with clients I would use the analogies from Why Zebras Don't Get Ulcers (Sapolsky, 2004) to explain the effect of stress on the body. Ensuring that they are comfortable enough to ask questions if they do not understand my story.

Building Alliances & Engagement in Collaborative Working

Throughout my placement I was a member of a small projects team. Further to that, I was also a member of the organization as a whole. I actively engaged in the weekly meetings that all were able to attend, where there were different topics each week. The first week of the month was the main meeting, where organizational developments were discussed, in addition to health and safety concerns. The second and fourth weeks (and any possible fifth week) were case discussion meetings where practitioners had the opportunity to discuss challenging clients and gain advice and support for how to move forward with that client; alternatively, if someone had been very successful with a client they could discuss that during this session. The third week was a development meeting, where brief training could be delivered, or outside organisations could come and discuss the service they deliver, enabling clinicians to make better referrals.

I met with my workplace supervisor on a monthly basis, discussing my client progress and my methodologies for working with my clients. My supervisor changed partway through my placement, and my supervision changed focus. Whilst we still focused on the client, we also focused on my personal and emotional growth more. Considering how I felt during the sessions, and working through any issues that arose.

One of my roles within [redacted] was to be the facilitator of the service user involvement group. Part of the role was to arrange for the service users to meet with the management of the services within the borough to provide feedback, in addition to surveying the client base annually, feeding back that information to the management of the services to enable them to make improvements.

Leading Groups Effectively

During my time at [redacted] I was a co-facilitator of various groups and projects, facilitator of some projects and groups, and at times I had at my disposal undergraduate students to assist in some projects. I was aware that undergraduate students were not competent enough to perform some roles

without supervision, such as drop-in. Although, I provided some brief training to one particular student to enable them to make telephone calls to dropped-out clients in an attempt to reengage them and offer them support if required. The aforementioned service user involvement group was one of my main weekly duties, and required a diplomatic approach in managing them. The group was independent, but facilitated by both a social worker from the NHS and myself. The purpose of the group was to organize the quarterly publication of newsletter advising service users of events in the borough, new groups and services. In addition, they group provided feedback to management of the local services, and a Christmas and summer party for service users to encourage socialization. Whilst all members of the group were service users, they often only understand their drug of choice. As such, I organized for them to receive substance misuse training. The group as a whole was disjointed and often strayed from the topic of discussion onto politics – the group required significant management in order to achieve the deadlines for submission of articles for the newsletter. To achieve this I set regular goals for the production of articles and reminded the members of outstanding work on a regular basis, offering support should it be required. I implemented an online calendar through Google apps, which held details of article deadlines, meeting times and dates, and the deadline for publishing the newsletter, and made this available to all group members.

Reflection

When I look back on where I was as a practitioner two years ago, I have grown considerably. My confidence has soared, where I can stand in front of a group of people who I have never met and present without being obviously nervous. And I can enjoy it. My confidence in my ability to help people have significantly improved, and it would appear that the greater my confidence in myself, the more efficacious my interventions are. I have learnt through various CPD sessions to never judge, and this act of being non-judgmental is apparent to clients and is vital to being comfortable with me in a room. I recall a story from Irvin Yalom where he met an obese woman and judged her – she disgusted him – but he thought she was unaware. At the end of treatment, it turned out that she was highly aware of his feelings, but was so used to being judged that she ignored them (Yalom, 1991).

My awareness of the importance of health psychology interventions, using an evidence-base, and reflecting upon the health psychology models will equip me well for my future career in health psychology.

Two years ago I was a trainee health psychologist, academically. Now I feel I can practice competently in a clinical setting. I am looking forward to adding to my toolbox of skills to ensure I provide future clients with the best service possible as part of the on-going CPD requirement as a Chartered Psychologist and Health Psychologist.

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Group Motivational Interviewing for Alcohol Misusers

Area of Competence

Systematic Review

Motivational Interviewing for Alcohol Misusers

1 - Background

1.1 Prevalence and Costs

The highly profitable alcohol industry affects the employment of 1.1million people, makes up 2% of the total tax rake, at £10bn, has a turnover of £38.1bn and contributes £6.4bn to the export market. Yet the economic costs are also massive. It is estimated that the total economic cost, including health, crime, and lost productivity exceeds £20bn, with some estimates as high as £55bn (Institute of Alcohol Studies, 2013).

Currently approximately 3.3 million deaths per year are linked to the harmful use of alcohol that equates to 5.9% of annual global deaths, with approximately 7 thousand deaths per year in England. Within England the estimated cost of alcohol-related harm to the NHS is £2.7bn a year, with only 2% of that allocated to specialise alcohol treatment services (National Institute for Health and Care Excellence, 2011b). Currently the maximum daily recommended alcohol consumption 3-4 units for males and 2-3 units for females. Should drinking exceed these levels, it is recommended to give the body a 48-hour rest to allow the tissues to recover. With the affordability of alcohol increasing significantly since 1980, by 61%, more people are able to indulge. There is, however, a positive correlation between heavy regular drinking and a higher income. In England men are more likely to be heavier drinkers, with 33% engaging in hazardous drinking, as opposed to 16% of females. As of 2009, it was estimated that 9.3% of males were alcohol dependent, with 3.6% of females being dependent. Alcohol has a significant impact on physical health.

The majority of England's 7 thousand deaths were due to alcohol liver disease, and alcohol is wholly attributable to 13 medical conditions and linked to another 34. Due to this, hospital admissions due to alcohol related illness or injury exceed 1.2 million per year (Health and Social Care Information Centre Lifestyles Statistics, 2013). This puts significant financial and time pressures on an already stretched health service.

1.2 Motivational Interviewing

Motivational Interviewing (MI) is an evolution of a Rogerian counselling style, whereby a skilled practitioner uses core skills, such as open-ended questioning, simple and complex reflections, affirmations and summarising statements to elicit the client to state their reasons for changing their behaviour, using the principle that when an individual hears themselves coming up with reasons to change, they are more compelling (Miller & Rollnick, 2013; Miller, 1983; Rollnick & Miller, 1995). MI is deemed to be an effective treatment in alcohol misuse, and is recommended by the National Institute of Health and Clinical Excellence as part of the treatment pathway (National Institute for Health and Care Excellence, 2010, 2011a). Past reviews have shown MI helps increase engagement in alcohol treatment (Dunn, Deroo, & Rivara, 2001), and is therefore a useful modality when individuals first access treatment. Whilst it is less effective for dependent drinkers than hazardous drinkers (Vasilaki, Hosier, & Cox, 2006) it has been shown to be more effective than advice alone with helping reduce alcohol misuse (Rubak, Sandbaek, Lauritzen, & Christensen, 2005). When MI was developing as intervention approach the Transtheoretical Model (TTM) was also gaining attention (Miller & Rollnick, 2013). One component of the TTM was the stages of change, whereby it was proposed that people cycle through various stages on the road to behaviour change. Those stages start with precontemplation, whereby the individual is not currently aware that they want to make a change. Next is contemplation, whereby the individual is aware that they should make a change, but is not quite ready to do anything about it. When the individual is ready, they start to prepare before putting a change plan into action. The final stage is maintenance (Norcross, Krebs, & Prochaska, 2011; Prochaska & DiClemente, 1982; Prochaska &

DiClimente, 1983). MI is a good fit with the TTM as whilst therapists are often action orientated, supplementing their skills with MI can help therapists deal with ambivalent clients, or clients who are not ready to make any changes (Hettema, Steele, & Miller, 2005).

1.3 Rationale

Whilst there have been less people in the UK presenting for alcohol misuse treatment in 2011/12, there is an acknowledgement that the presentations do not make up the full picture of the problem with alcohol abuse within the country (National Treatment Agency for Substance Misuse, 2013). In the advent of payment by results (PBR), it is important to ensure that the services being offered are effective and impact on recovery rates to ensure that treatment providers receive payment for their services and that service users receive the best chances of recovery.

Motivational Interviewing (MI) was originally designed as a method of increasing motivation and tackling the ambivalence of problem alcohol users using the client's own words to boost self-efficacy. This is a shift away from treatment aimed at the action stage and targets those in a precontemplative or contemplative state (Miller, 1983). MI has grown in importance as a tool for increasing motivation and engagement with treatment, and is a recommended psychosocial intervention for treating substance misusers (Department of Health (England) and the devolved administrations, 2007; World Health Organisation, 2013). Recent reviews on the efficacy of MI for substance misusers have not been conclusive due to the low quality research in the field, although there are indications that MI can be effective in reducing drinking in the short-term (Klimas, Field, Cullen, O'Gorman, Glynn, et al., 2012; Smedslund, Berg, Hammerstrøm, Steiro, Leiknes, et al., 2011). Some differences are likely due to the emphasis of the method on interactions between practitioner and client, which play a significant role in MI (Miller & Rollnick, 2002), similarly to other therapeutic methodologies which rely on a strong therapeutic alliance (Meier, Barrowclough, & Donmall, 2005).

With the looming PBR it is becoming more important to find value for money solutions to treating service users. There is some evidence that Group MI interventions are as efficacious as individual sessions (Nyamathi et al., 2010) and there are suggestions that group therapy can be more effective than individual treatments (U.S. Department of Health and Human Services, 2005).

Having reviewed the literature, to our knowledge, this is the first examination of GMI interventions (GMII) for alcohol misusers. To ensure that GMIIs are to be seriously considered for providing a cost-effective and valid treatment to service users then the evidence base needs to be clearly demonstrated.

2 Methodology

A protocol was created to devise a framework for the systematic review.

2.1 Search strategy

Studies led by someone trained in motivational interviewing, incorporating a group motivational interviewing intervention were included in this analysis. EBSCOhost (incorporating Psychology And Behavioural Sciences Collection, PsychArticles, PsychINFO, and MEDLINE); SCOPEUS; Web of Science; and EMBASE were searched from start date to 2014. Once articles were identified, there was screened for inclusion. Articles not specifically mentioning group motivational interviewing within the abstract were discounted.

2.1.1 Study selection criteria

2.1.1.1 Participants

Alcohol misusers (where alcohol is the sole addiction) who are 18 years or older.

2.1.1.2 Intervention

Psychological interventions delivered in a group setting using motivational interviewing to facilitate a reduction in alcohol misuse.

2.1.1.3 Outcomes

A measurement of change in alcohol consumption. Studies may also include impact on engagement, maintenance of new behaviours, and quality-of-life improvements.

2.1.1.4 Study design

Randomised controlled trials

Randomised clinical trials

Cluster randomised trials

Randomised trials

Data must be quantitative.

2.1.1.5 Search terms

The following search terms were employed using EBSCOhost (incorporating Psychology and Behavioural Sciences Collection, PsychArticles, PsychInfo, and MEDLINE); SCOPUS; Web of Science; and EMBASE:

((“motivational interviewing” OR “motivational enhancement”) AND Group)

AND

(alcohol* OR dipsomani* OR crapulence OR methomania OR “problem drinking”)

NOT

Drug

2.1.1.6 Quality assessment checklist

In order to evaluate the quality of each paper, a quality assessment checklist was devised. Papers were scored based on the criterion in the checklist and allocated 0 points if this criterion was not met and one point if it was. Papers could score a minimum of 0 and a maximum of 10. The criteria used were as follows:

1 – Suitable statistical analysis

1 = yes

0 = no

2 – Suitable comparison group (i.e. waiting list, individual MI, other therapeutic modality)

1 = yes

0 = no

3 – Less than 100 participants, or sufficient power established by power analysis

1 = yes

0 = no

4 – Adequate method of randomisation

1 = yes

0 = no/insufficient description

5 – Minimum of 6-month follow-up

1 = yes

0 = no

6 – Real-world/Non-college/university based cohort

1 = yes

0 = no

7 – Detailed information on MI components used and incorporated into the study

1 = yes

2 = no/insufficient description

8 – Problem alcohol user population

1 = yes

0 = no

9 – Biomarker verification of alcohol use

1 = yes

0 = no

10 – MI delivered by suitably trained; and supervised practitioners

½ = yes (trained)

½ = yes (supervised)

0 = no/inadequate description

Two researchers conducted the quality assessment independently. Each researcher has a quality assessment checklist. After both researchers had assessed all papers scores were compared. Where there were disagreements between two scores amongst the researchers the scores were averaged. It was agreed that the cut-off point for inclusion of a paper was 5, being the median score. A list of the

Data were extracted using the data extraction form designed for this review (see Appendix D1).

3 Results

A total of 539 papers were found during the search, the titles and abstracts were reviewed and 525 papers were excluded from the review. The studies were excluded for a variety of reasons; for example, did not include a group motivational interviewing approach, or no comparison group used. Conference proceedings were also excluded.

The 14 selected papers were then read in detail and assessed for quality by the author and another researcher, independently. Inter-rater reliability was high, with no score being different by more than 1. Papers scoring below 5 were excluded from the study. Table D1 provides an overview of the scores assigned. Following the quality assessment, 6 papers were included in the review. The remaining 8 were excluded for the following reasons: scored below 5; on further reading included individuals under the age of 18; or did not have a group intervention (see appendix D2 for table of excluded papers). Of the 6 papers included, only one scored highly, with the remaining 80% achieving a medium quality rating.

Table D 1 - Quality Assessment Outcomes

Study Title	Author	Quality Assessment Score	Quality Rating
Feedback-based alcohol interventions for mandates students: an effectiveness study of three modalities	Alfonso et al, 2013	6/5	Medium
Assessing the effectiveness of peer-facilitated interventions addressing high-risk drinking among judicially mandated college students	Cimini et al, 2009	6/6	Medium
Motivational Intervention: An individual counselling approach vs a group treatment approach for alcohol dependent in-patients	John et al, 2003	7.5/8.5	High
What makes group MET work? A randomized controlled trial of college student drinkers in mandated alcohol diversion	LaChance et al, 2009	7.5/6.5	Medium
Effect of motivational interviewing on reduction of alcohol use	Nyamathi et al, 2010	6.5/6.5	Medium
The comparative effectiveness of individual and group brief motivational interventions for mandated college students	Hustad et al, 2013	7/8	Medium

All of the studies included were randomised trials, with three being randomized controlled trials, and one a randomised clinical trial. Table D6 summarises the data extracted from the selected papers to allow easy comparison of the methodologies used. Upon review of table D6, it is apparent that there is little consistency with the interventions delivered, and the outcome measures utilised.

As can be seen in table x, there are a variety of MI based interventions used in these studies, including the CHOICES programme, Motivational Enhancement Therapy, in addition to non-manualised MI approaches using the spirit and techniques of MI. Not all studies reported their detailed statistical analyses, and whilst many used RAPI and drinks per drinking day as outcome measures, it was not possible to conduct a meta-analysis on the data.

Despite not being able to perform a meta-analysis, this review will focus on the information detailing the efficacy of the group MI interventions with reducing alcohol use, and any additional benefits observed.

The results will be presented in terms of outcome measures used, commencing with the primary purpose of alcohol consumption related measures.

3.1 Blood Alcohol Content/Concentration (BAC)

Two studies used BAC as a measure. Alfonso et al, (2013) used BAC as an outcome measure, whereby BAC was calculated using the formula BAC = [(consumption/2) x (gender constant/weight)] – (0.016 x hours) rather than utilising biomarkers such as blood tests or breathalysers.

The authors reviewed the average BAC level over a four-week period, plus the peak BAC level over the same four-week period. Results showed that an individual MI approach had a statistically significant effect on peak BAC ($F(1,166) = 6.304$, $p = .013$). The authors noted that the group intervention was approaching significance for both peak ($F(1,166)=3.77$, $p=.054$) and average BAC ($F(1,166) = 3.791$, $p = .053$). The electronic intervention had no significant effect. Hustad et al (2014) also used peak BAC, recorded over a 30-day period, reporting no significant differences between interventions, although both

interventions had significantly lower peak BAC at 1,3, and 6-month follow-up (Ests = .04, ps ≤ .001).

3.2 Drinks Consumed

One of the most frequently used outcome measures is that of alcohol consumption. Table D2 shows the mean drinks consumed.

Table D 2 - Drinks Consumes

Study & Measure	Group Intervention		Comparison 1		Comparison 2	
	Baseline	Follow-up	Baseline	Follow-up	Baseline	Follow-up
	M (SD)	M (SD)	M (SD)	M (SD)	M (SD)	M (SD)
Alfonso et al (2013) – Peak drinks in one sitting	7.46 (4.53)	6.73 (4.88)	7.02 (5.00)	5.49 (4.23)**	6.38 (4.03)	6.55 (5.41)
LaChance et al (2009) – Average drinks per drinking day	5.98 (2.40)	5.29*[1] (1.84)	6.00 (2.25)	5.91*[2] (2.10)	6.15 (2.37)	6.12*[3] (2.75)
		5.24*[1] (1.81)		5.95*[2] (2.15)		6.40 (2.71)

Note. * = p<.05, **=p<.01; comparison 1 for Alfonso et al (2013) = individual MI, comparison 2 = electronic intervention; comparison 1 for LaChance et al (2009) = Focus on Alcohol educational group, comparison 2 = Alcohol information only group; [1]both follow-ups were significantly different to baseline; [2]both follow=ups significantly different to baseline, although three month follow-up is significantly better than six month follow-up; [3]three month follow-up significantly different to six month follow-up.

Alfonso et al., (2013) used the measure of peak drinks per sitting in the previous four-week period using time-life follow back. As expected given the BAC results above, the group approach did not yield a significant result. The individual counselling approach, however, did result in a significant reduction in peak drinks per sitting (F(1,166) = 7.079, p = .009).

LaChance et al., (2009) used the drinks per drinking day measure using the alcohol use history questionnaire, measuring consumption over the past three months. The group MET intervention was significantly better than both comparison interventions at three months (F(2,24)=3.68, p <.05) and six months (F(2,24)=5.81,p<.01) follow-up.

Cimini et al., (2009) utilise the daily drinking questionnaire to measure average drinks per drinking day over a 30 day period, then asked participants to estimate their highest number of drinks in one occasion over the past 30 days. There were no statistically significant differences between any of the three interventions (t=-1.7 to 1.15, p=ns). An overall analysis of the results showed an increase in both measures at three-month follow-up.

Nyamathi et al., (2010) reported the number of participants that have either reduced drinking by 50% or achieved abstinence. The authors state that at six month follow-up 22% are abstinent, and 49.8% have reduced their alcohol consumption by 50%. No statistically significant differences were found between intervention groups. Table D3 shows that the MI group had a marginally higher percentage of reducers than the comparison groups.

Table D 3 - Nyamathi et al., (2010) Rates of Reduction and Abstinence

	Group MI	1:1 MI	Hepatitis Nurse
	N = 90	N = 79	N = 87
>50% reduction	54.0%	46.6%	49.4%
Abstinence	20.3%	22.2%	23.3%

John et al., (2003) reported no statistically significant differences between individual MI and group MI with regard to alcohol consumption. Table D4 shows the number in each group reporting abstinence or still drinking.

Table D 4 - John et al., (2003) Abstinence Rates

	Group MI	1:1 Counselling
	N = 161	N = 161
No Information	46.6%	39.1%
Drank	36.0%	37.3%
Abstinent	17.4%	23.6%

Hustad et al., (2013) reported the number of drinks consumed per week, although reductions were not significant for either of the interventions. There was a reduction in average drinks per week in the group intervention over the 6-month period (M=11.41 (10.24) to M = 9.16 (8.25)), whereas in the individual intervention there was a marginal increase.

3.3 RAPI – Rutgers Alcohol Problem Index

This is the most consistently used measure in this review, with three of the papers using the RAPI to assess the negative effects of alcohol use.

Alfonso et al., (2013) reported a significant reduction in RAPI score for all interventions, except the group MI, where the mean score increased marginally (see table D5).

LaChance et al., (2009) reported that the group MET intervention significantly reduced RAPI scores, at both three and six-month follow-up, with the group intervention being significantly better to both the FAC and AI interventions at six-month follow-up ($F(2,24)=4.91$, $p<.05$).

Cimini et al., (2009) reported no between-group differences on the RAPI scores, and at six-month follow-up mean RAPI scores had increased slightly on their overall sample (9.44 (10.31) to 9.58 (12.49).

Hustad et al., (2014) reported significantly lower RAPI scores in both interventions (IRRs = .62 - .77, ps ≤ .001), and there were no significant between-group differences.

Table D 5 - RAPI Scores

Study	Group Intervention		Comparison 1		Comparison 2	
	Baseline	Follow-up	Baseline	Follow-up	Baseline	Follow-up
	M (SD)	M (SD)	M (SD)	M (SD)	M (SD)	M (SD)
Alfonso	17.87 (22.30)	18.00 (27.01)	21.26 (23.19)	12.33** (20.11)	19.00 (23.85)	9.18** (17.44)
LaChance	10.35 (11.49)	8.14* (8.79)	9.83 (9.30)	8.75*[1] (6.73)	12.71 (10.86)	12.44* (11.46)
		6.22* (7.25)		9.45 (9.56)		12.24* (12.10)
Hustad	5.29 (4.94)	4.20 (5.57)	6.19 (5.41)	4.71 (5.97)		
		3.05 (5.21)		4.22 (6.45)		
		3.30 (6.01)		3.84 (6.41)		

Note. * = p<.05, **=p<.01; comparison 1 for Alfonso et al (2013) = individual MI, comparison 2 = electronic intervention; comparison 1 for LaChance et al (2009) = Focus on Alcohol educational group, comparison 2 = Alcohol information only group; [1] Significant difference between three-month follow-up and both baseline and six-month follow-up.

3.4 AUDIT – Alcohol Use Disorders Test for Hazardous Drinking Symptoms

Only LaChance et al., (2009) used the AUDIT as a measure within their study. The authors reported a significant reduction in AUDIT scores at three-month follow-up, and at six-month follow-up, whilst the comparison interventions' mean scores increased. At three-month follow-up the group MET was significantly different to the comparison interventions ($F(2,24)=6.75$, $p<.01$) and at six-month follow-up ($F(2,24)=5.31$, $p=.01$).

3.5 Help Seeking

John et al., (2003) reported that the group intervention resulted in significantly more people seeking support from self-help having completed treatment, than those who attended one to one counselling (41 vs. 22, $p=.001$).

Table D 6 - Extracted Data

Study Title and Authors	Year	Country	Study Population	Study Characteristics	Intervention and Setting	Outcome Data
Feedback-based alcohol interventions for mandated students: An effectiveness study of three modalities Alfonso et al.,	2013	USA	-Mandated college students -Mean age = 18.77 -Non-dependent drinkers -Enrolled: 269 -Included: 173 -No report of drop-outs. -Male = 57%	-Randomised Clinical Trial -Randomisation computer generated -Follow-up: 3 months	-Group – 120 minute session using CHOICES format Comparisons – 1 to 1, 2 x 50 minute sessions using BASICS format; Online system. -MI: facilitators received 60 hours (didactic and experiential) training, weekly supervision. Adherence to MI – No specific detail, although the CHOICES programme contains the use of evocation, collaboration, autonomy and support, direction, empathy, and the MI Spirit.	-BAC (Peak and Average) – Blood Alcohol Content -Peak Drinks per sitting -RAPI (Negative Alcohol-Related Consequences) -There were no statistically significant differences between baseline and follow-up results for any of the measures. The electronic intervention reported a statistically significant response for reducing RAPI and the individual intervention statistically significant reductions in peak BAC, peak drinks consumed in one session, and RAPI.
What makes group MET work? A randomized controlled trial of college student drinkers in mandated alcohol diversion LaChance et al.,	2009	USA	-Mandated college students -Mean age = 18.6 -Enrolled = 225 -Included = 206 -3m = 164 -6m = 157 -Male = 63%	-Randomised controlled trial -Randomised by roll of a dice -Follow-up 3 and 6 months	-Group MET - 1x 180 minute session -Comparisons – 1 x 180 minute information only control; 2x180 minute educational workshop -MI: facilitators trained -Adherence to MI – decisional balance, reflections, open-ended questions, affirmations, summarizing, develop discrepancy between ideal and current alcohol use, elicit statements for change, personalized feedback, goal setting and planning	-Average drinks per drinking day -AUDIT -RAPI -The GMET was statistically significantly better than both comparison groups at 6 month follow-up. The information only group actually resulted in worse results for both drinks per drinking day and AUDIT.

Study Title and Authors	Year	Country	Study Population	Study Characteristics	Intervention and Setting	Outcome Data
Assessing the effectiveness of peer-facilitated interventions addressing high-risk drinking among judicially mandated college drinkers Cimini et al.,	2009	USA	-Mandated Undergraduate students -Mean age not stated but 48.8% were freshman, 36.4% sophmores, and the remainder being juniors (13/3%) and seniors (1.6%). -Enrolled = 685 -Included = 479 -Male = 62.7%	-Randomised trial -Method of randomization not stated -Follow-up = 6 months	-Small group MI (1x120 minutes) -Comparisons – Motivationally enhanced peer theatre (1x120 minutes); interactive education program (1x120 minutes) -MI facilitators: trained with 2 hours a week of supervision -It was noted that the MI was delivered with "below-par adherence to MI principles". Adherence to MI - Used values and goals, plus kept to the spirit of MI.	-RAPI -Peak drinking- Drinks per week -Reported that there were no statistically significant differences between the MI group or peer theatre and the education conditions. Overall, the mean scores show that there has been an increase in all three measures at 6 month follow-up.
Effect of motivational interviewing on reduction of alcohol use Nyamathi et al.,	2010	USA	-Moderate to heavy alcohol users on methadone script -Mean age = 51.2 -Enrolled = 393 -Included = 256 -Male = 59.2%	-3 arm Randomised controlled trial -No detail of method of randomization -Follow-up = 6 months	-Group MI = 3x60 minutes -Comparisons – Nurse led hepatitis health promotion group (3x60 minutes); 1 to 1 MI (3x60 minutes) -MI facilitators: Trained psychologist and Master of Social Work PhD student, both experienced and trained in MI. No details of supervision. Adherence to MI - MI Spirit (evocation, collaboration, autonomy); MI Principles (empathy, roll with resistance, developing discrepancy, enhancing self-efficacy); and, MI microskills (eliciting change talk, reflections, and affirmations)	-Reduced alcohol use by 50% -No significant differences between the three groups, although all three groups had statistically significant numbers of participants reducing their drinking by 50%

Study Title and Authors	Year	Country	Study Population	Study Characteristics	Intervention and Setting	Outcome Data
Motivational interviewing: An individual counselling vs a group treatment approach for alcohol dependent in-patients John et al.,	2003	Germany	-In-patient alcohol dependent clients who live near self-help groups with no psychosis, and have been in rehab or detox less than 10 times previously -Age 21-65 (no mean given) -Male = 72%	-Randomised controlled trial -Randomised using different envelopes upon admission -Follow-up = 2 years	-MI Group = 9 x 90 minute sessions -Comparison group: individual MI (3 x 40 minutes). -MI Facilitators: experienced psychologist, no mention of MI training and supervision. -Adherence to MI – development of an understanding of the problem behaviour, fostering self-efficacy, motivation to seek help, as part of a multi-component intervention looking at preparing for work, relapse prevention, coping mechanisms.	-Utilisation of self-help groups -Alcohol drinking and abstinence -There were no significant differences between groups for the alcohol consumption. Although, for the group treatment 23.6% reported being abstinent at 12 months opposed to 17.4% from the individual counselling condition.
The comparative effectiveness of individual and group brief motivational interventions for mandated college students Hustad et al.,	2014	USA	-Mandated university students -Mean Age = 19.08 -Enrolled = 278 - Completed 100% of surveys = 137 -Completed at least 1 follow-up = 141 -Male = 68%	- Randomised Trial -Method of randomisation not stated -Follow-up = 6 months	-The study is not explicit in stating the time allocated to each intervention. It is suggested that the group has a mean time saving of 3 hours, with an average of 4 people per group, it would seem reasonable to assume that both the group and individual sessions last 1 hour. -MI Facilitators: Masters Degree holders. 4 out of 5 had experience delivering interventions. 2 days of training, individual and peer supervision weekly, plus a Bried MI manual. -Adherence to MI: Decisional balance, reflections, scaling questions, OARS. Plus personal feedback.	-Peak BAC -Av Drinks per Week -Young Adult Alcohol Consequences -There were significant reductions in peak BAC in both interventions, maintained at 6 month follow-up. Average number of drinks a week did not significantly decrease, although the reduction in the brief group intervention was greater. Alcohol-related consequences scores were significantly lower in both interventions at 6 months. No significant differences between the two intervention groups.

4 Study Characteristics

The purpose of this review was to assess the efficacy of group motivational interviewing interventions for the treatment of alcohol misuse. Only five studies met the criteria for inclusion: that is unexpected in the current climate of cost-effective recovery orientated treatments.

4.1 Intervention Setting

Two of the studies were based in alcohol treatment centres, one inpatient detoxification unit in a psychiatric hospital in Germany (John, Veltrup, Driessen, Wetterling, & Dilling, 2003) and the other outpatient clinics in Las Angeles (Nyamathi et al., 2010). The remainder used mandated students in a college setting (Alfonso, Hall, & Dunn, 2013; Cimini et al., 2009; Hustad et al., 2014; LaChance, Feldstein Ewing, Bryan, & Hutchison, 2009).

4.2 Duration of Intervention

John et al., (2003) delivered the intervention with the highest number of sessions: nine group sessions of 90 minutes, whilst Nyamathi et al., (2010) delivered three 60-minute sessions. The remaining studies used single-session interventions, with LaChance et al., (2009) using a 180 minute intervention; Cimini et al., (2009) and Alfonso et al., (2013) using a 120 minute intervention; and, Hustad et al., (2014) delivering a 60 minute intervention (although M=55.47 minutes). Extant reviews have concluded that brief interventions can be highly effective within male populations, with no real benefit from a greater number of sessions delivered (Kaner, Beyer, Dickinson, Pienaar, Campbell, et al., 2007), although the benefits are not maintained at 1 year follow-up (McQueen, Howe, Allan, Mains, & Hardy, 2011).

4.3 Intervention Components

Motivational interviewing is a framework on which clinicians can base their approach, although specific techniques are used in the process, such as the decisional balance, eliciting change talk through a series of reflections and summaries (Miller & Rollnick, 2013; Rollnick, Miller, & Butler, 2008). The

majority of the studies state interventions are based on MI principles yet provide little detail of any specific techniques. LaChance et al., (2009) specified the use of the decisional balance, allowing participants to weigh up the pros and cons of drinking. Non-MI components were also included, with John et al., (2003) using a multi-modal approach incorporating job application skills training, trips to self-help groups, relapse prevention sessions, and information delivered in the forms of videos regarding alcohol dependence, diet, and personal hygiene. Whilst this paper was successful, it is difficult to assess fully whether the MI component of the group was effective, or whether it was the multi-component aspect, although existing research suggests a multi-component intervention is equally as effective as a single-component intervention (Foxcroft & Tsertsvadze, 2011). Three of the interventions incorporated a normative feedback component, whereby peer norms were compared to the individual participant's current drinking levels (Alfonso et al., 2013; Hustad et al., 2014; LaChance et al., 2009). Whilst this feedback isn't a component of MI (Arkowitz, Westra, Miller, & Rollnick, 2008), it is used in motivational enhancement therapy (Miller & Rollnick, 2013). Within a student population there are mixed findings for feedback, with the method of feedback delivery being an important factor (Moreira, Smith, & Foxcroft, 2009).

4.4 Skills, Qualifications, Experience, and Competence of Facilitators

Cimini et al., (2009) used peer facilitators in their study, whereby extant peer facilitators received training in how to deliver the interventions being tested. Facilitators were given 1-hour group supervision, plus 1 hour of individual supervision. This study assessed adherence to MI principles using MITI coding, finding the delivery of MI to be sub-par. Recordings of interventions were reviewed and discussed during supervision, with the aim of improving treatment fidelity. This is potentially a key factor in the failure of this study. The remaining studies involved more qualified facilitators. The two most successful interventions involved qualified psychologists, with one facilitator in Nyamathi et al (2010)'s study having 15 years experience with substance misusers, plus received training from an expert in MI; with John et al., (2003)'s main facilitator having 5 years experience in delivering group interventions to alcohol misusers.

There was no specific mention of supervision for either of these interventions. Hustad et al., (2014) provided facilitators with post-graduate educations, of which 80% had experience in delivering substance misuse interventions, with 2 days of training in MI, plus an hour of delivering MI in group settings, and group work skills training. Facilitators in this study received 1-hour group, and 1-hour individual supervision per week. Alfonso et al., (2013) utilised clinical psychology doctoral students, who each received 60 hours of training, plus weekly supervision. These facilitators were students, and MITI coding of sessions identified that the MI being delivered was between beginner and competent standards. LaChance et al., (2009) used facilitators with a post-graduate education, trained in MI by a co-author of the paper. The findings suggest that qualifications and experience in intervention delivery make a significant difference in intervention efficacy when delivering MI, excepting in the case of LaChance et al., (2009), although within this study there is little mention of past group work experience.

4.5 Follow-up period

Alfonso et al., (2013) utilised a follow-up period of 3 months; John et al., (2003) utilised a follow-up period of 1 years; and, the remaining used a follow-up period of 6 months. With a recent review finding results of brief interventions not being maintained at 1 year follow-up (McQueen et al., 2011), the follow-up periods used in all but one of the included papers is insufficient to verify efficacy.

4.6 Randomisation

Three papers stated their methods of randomisation, with Alfonso et al., (2013) using a computer generated method; LaChance et al., (2009) utilised the roll of a die; and, John et al., (2003) utilised envelopes to randomise participants. The remaining were randomised but did not state the method of randomisation (Cimini et al., 2009; Hustad & Borsari, 2010; Nyamathi et al., 2010b). Evidence has shown that studies that do not explicitly state their method of randomisation are more likely to misrepresent the magnitude of the findings (Odgaard-Jensen, Vist, Timmer, Kunz, Akl, et al., 2011).

4.7 Comparison/Control

None of the studies utilised a waiting list control, therefore it is not possible to fully assess the efficacy and full additive value of the studies, although all studies had some comparative interventions. Cimini et al., (2009) used peer theatre and an interactive education programme as comparison interventions; Alfonso et al., (2013) also had two comparative interventions, one being an online intervention, and the other a one-to-one MI based intervention. LaChance et al., (2009) did have an information only control, in addition to two educational workshops. Nyamathi et al., (2010) also had two comparison groups, a nurse led hepatitis health promotion group, plus a one-to-one MI intervention. John et al., (2003) used a one-to-one individual MI intervention, delivered over three sessions lasting 40 minutes, compared to a nine-week 90-minute group MI intervention. Hustad et al., (2014) used single-session individual brief motivational interviewing, the authors note that the individual sessions were slightly more brief than the group sessions. The only study to find that group MI was significantly better than the comparative interventions was that of LaChance et al., (2009), although the two comparison interventions were merely educational and did not include a MI based comparison, unlike the remaining studies. Excepting the studies by John et al., (2003) and Alfonso et al., (2013), the comparative interventions were the same length in time.

4.8 Populations

Two studies consisted of adult problem alcohol using populations, one in-patient programme (John et al., 2003), the other an out-patient programme (Nyamathi et al., 2010). The remaining studies consisted of mandated college student populations (Alfonso et al., 2013; Cimini et al., 2009; Hustad et al., 2014; LaChance et al., 2009). The two studies using problem alcohol using populations had higher success rates, although this is not in-line with extant research which shows that voluntary and mandated client groups experience equal efficacy from treatment programmes (Howard & McCaughrin, 2009; Mastroleo, Oakley, Eaton, & Borsari, 2014). The heterogeneous nature of these two population groups make comparison quite unfair, with those accessing treatment through an in, or out-patient programme reporting much higher drinking levels prior to treatment.

4.9 Incentivisation

Four of the included studies used financial incentives for responding to the follow-up questionnaires (Cimini et al., 2009; Hustad et al., 2014; LaChance et al., 2009; Nyamathi et al., 2010b), whilst one study adopted a scheme whereby participants paid for their treatment, refunded at follow-up (Alfonso et al., 2013). The two most effective studies used either no incentive (John et al., 2003), or a nominal incentive of $5 per session (Nyamathi et al., 2010b). The extant research on incentivising treatments is mixed, with regard to alcohol it appears to not affect efficacy, although does affect client retention with student populations (Patrick, Singer, Boyd, Cranford, & McCabe, 2013), yet with other behavioural interventions incentives can help promote behaviour change (Strohacker, Galarraga, & Williams, 2013; Volpp, Troxel, Pauly, Glick, Pulg, et al., 2009).

5 Discussion

The evidence does suggest that GMI interventions can be an efficacious and cost effective treatment modality to facilitate some behaviour change in problem alcohol users. Due to the high levels of inconsistency in the use of outcome measurements, methodological quality, and the paucity of trials on GMI interventions, this is however difficult to fully qualify.

There is little consistency in the delivery of GMI interventions, some being single session, others being many sessions with MI as a framework and a component of the treatment plan. It has been shown that sessions longer than 20 minutes in length are more beneficial than very brief MI interventions, and multiple sessions can have a small additive effect on the intervention's efficacy (Lai, Cahill, Qin, & Tang, 2010). This could explain the reasons why two of the studies were more effective.

A picture is emerging that for MI interventions to be effective a number of requirements should be met. This review is adding to the existing knowledge of the factors that may facilitate a more effective delivery of MI interventions. This review partially supported the findings that manualised interventions are less

beneficial due to an adherence to a rigid structure (Hettema et al., 2005). Previous reviews into MI have identified a lack of detail regarding the components of MI used (Britt, Blampied, & Hudson, 2003; Lai et al., 2010). This was also the case with this current review. The lack of detail regarding the components delivered means it is challenging to assess whether MI was delivered as a whole, or in part. More successful interventions appear to be delivered by more qualified and experienced. It has been suggested that training for MI varies considerably, with the average course lasting between 9 and 16 hours (Madson, Loignon, & Lane, 2009), yet the skills required cannot necessarily be taught in the classroom alone. It is unclear how long is required to train as a competent MI practitioner, but whilst the components of MI can be learned quickly, it can take longer to become confident and skilled in delivering MI interventions (Britt, Hudson, & Blampied, 2004). This could explain why the two most effective interventions were successful. Whilst it was not specified what level of MI training was received, the facilitators were qualified psychologists and social workers with experience of delivering interventions. This highlights the possible importance of the ability to build rapport within groups. Rapport and client engagement is a key component of MI (Miller & Rollnick, 2013). It has been shown that interventions delivered by practitioners who have a high level of rapport with their clients, such as general practitioners, are more effective (Lai et al., 2010).

5.1 Publication Bias

As this review searched the main databases containing the psychological literature, with no grey literature searches being performed and no authors being contacted to assess relevant unpublished material. Due to this, this review may suffer publication bias.

5.2 Implications for practice

The evidence suggests that motivational interviewing is effective for the treatment of alcohol misuse (Burke, Arkowitz, & Menchola, 2003; Vasilaki et al., 2006). This review has corroborated this evidence, and added knowledge to suggest that group motivational interviewing can be as effective. Further high quality research is required, however, to demonstrate efficacy more thoroughly.

5.3 Implications for research

- Future studies should include:
    - Follow-up period in excess of 6 months to ascertain the longer-term efficacy of the treatment programmes.
    - More diverse participant pools (i.e. non-student populations)
    - More consistent outcome measures
    - The majority of the studies included were carried out in the USA, with one in Germany, indicating a real need for further clinical studies in other countries.
    - More emphasis on the competence of the MI delivery, ensuring that competence grows if insufficient.

5.4 Unanswered question

- Which MI components are most effective?

6 Conclusion

There are very few studies looking at the efficacy of group motivational interviewing for alcohol misuse. The studies that exist are not of high methodological quality and lack homogeneity with regard to study populations, treatment setting, and outcome measurements. The participants included within the aforementioned studies were from two very different environments, with heavy drinkers, versus students. Whilst it appears that group motivational interviewing is as effective as individual motivational interviewing, only one study (John et al., 2003) had long-enough follow-up period to allow that to be properly assessed.

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Appendices

D1 – Data Extraction Form

General Information	ID Number	
	Autors	
	Title of Article	
	Citation	
Study Characteristics	Aims & Objectives	
	Study Design	
	Inclusion/Exclusion Criteria	
	Recruitment Procedures/ Randomization	
Participant Characteristics	Age (M)	
	Gender (N)	
	Ethnicity (N)	
	SES (N)	
	Alcohol Misuse	
	Co-Morbidities?	
	Mandated (N)	
Intervention Detail	No. of Sessions	
	Length of Sessions	
	Training/Supervision	
	MI Components	
	Intervention Setting	

Methodology	Outcome Measures		
	Statistical Methods		
	Follow-up period		
	Participants	Enrolled	
		Included	
		Withdrawn	
		Lost to Follow-up	
Results	Outcome Measure 1:		
	Outcome Measure 2:		
	Outcome Measure 3:		
	Outcome Measure 4:		

D2 – Table of Excluded Studies

Study Title	Author	Year	Quality Scores	Reason for Exclusion
Effectiveness of the Bried Alcohol and Screening Intervention for College Students (BASICS) program with a mandated population	Difulvio, G.T., Linowski, S. A., Mazziotti, J. S., Puleo, E.	2012	4/4.5	Quasi-experimental trial, inadequate comparison group.
Preventing risky drinking in first-year college women: further validation of a female specific motivational-enhancement group intervention	Labrie, J.W., Hucting, K.K., Lac, A., Tawalbeh, S., Thompson, A.D., Larimer, M.E.	2009	7/6	Included participants under 18 years of age
A randomized motivational enhancement prevention group reduces drinking and alcohol consequences in first-year college women	Labrie, J.W., Huchting, K.K., Tawalbeh, S., Pedersen, E.R., Larimer, M.	2008	6/5	Included participants under 18 years of age
A campus-based motivational enhancement group intervention reduces problematic drinking in freshmen male college students	Labrie, J.W., Pedersen, E.R., Quinlan, T.	2007	3.5/3.5	No comparison group, non-problematic alcohol use, not randomized
A group motivational interviewing intervention reduces drinking and alcohol-related negative consequences in adjudicated college women	Labrie, J.W., Thompson, A.D., Huchting, K.K., Lac, A., Buckley, K.	2007	3.5/3.5	No comparison group, not randomized, non-problematic alcohol use.
Family history of alcohol abuse moderates effectiveness of a group motivational enhancement intervention in college women	Labrie, J.W., Feres, N., Kenney, S.R., Lac, A.	2009	4/4.5	Comparison group is literature only, short follow-up, non-problematic alcohol use
Motivational Interviewing in a group setting with mandated clients: a pilot study	Lincourt, P., Kuettel, T.J., Bombardier, C.H.	2002	5/5.5	Non-randomised, included participants under 18 years of age, no measure of alcohol consumption
Effects of a motivational interviewing intervention to decrease prenatal alcohol use	Osterman, R.L., Dyehouse, J.	2012	5/6	Focus on pregnancy, small sample, no-treatment comparison, no detail on randomization, no problem alcohol use