

**Emotional well-being in people with sight loss:
Lessons from the grey literature**

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ABSTRACT Literature that is not peer-reviewed and distributed through a publisher is known as 'grey'. As it is used to inform policy and practice we reviewed the grey literature concerning emotional well-being in people with sight loss. We consulted and searched the websites of UK voluntary organisations, and scanned reference lists of previous reviews for reports available from 2001 to 2008. We summarised 24 studies in two sections: 1) observations that assessed psychosocial well-being or demand for support services (n = 15); and 2) evaluations of interventions that aimed to improve emotional well-being (n = 9). Observations showed that people with sight loss can report low emotional well-being, but their statistical and clinical significance requires testing. Interventions showed promise for counselling but also require further evaluation. We encourage service providers and researchers to collaborate and produce high quality research to more persuasively inform policy and practice.

Keywords *emotion, grey literature, psychosocial, review, visual impairment, well-being*

INTRODUCTION

Chronic illness poses a threat to emotional well-being. For example, prevalence rates of major depression in adults with a chronic illness are between 12.5 and 25.33 per cent in those with diabetes, coronary heart disease, HIV infection, stroke, Parkinson's disease, and multiple sclerosis (Katon, 2003). Adults with visual impairment show a similar rate of approximately 1 in 5 aged 65+ reporting depressive symptoms or being clinically diagnosed with depression, a rate of around twice that of their sighted peers in the community (Burmedi, Becker, Heyl, Wahl, & Himmelsbach, 2002). The negative feelings experienced by people with visual impairment have also been documented using qualitative approaches (e.g. Dale, 2008a; Stanford et al., 2009).

We were commissioned and funded by Thomas Pocklington Trust to review the evidence for reduced emotional well-being in people with sight loss and how best to provide emotional support via a synthesis of existing evidence. We have systematically reviewed published quantitative studies that recruited working age adults (Nyman et al., 2009a) and older people (Nyman et al., 2009b), the published qualitative literature, and we report here our review of the 'grey' literature. In contrast to the published literature (e.g. academic journals), grey literature is work that is available for public consideration but has not been externally peer-reviewed or disseminated through a publisher, for example, a report released on the Internet.

Our review is novel as academics (university-based professional researchers) do not attend as much to the grey literature because it has not usually been subject to external peer review, is difficult to locate as it is not listed in electronic bibliographic databases, and may be difficult to obtain due to limited distribution (Cook et al., 2001; Last, 2001). However, grey literature may report useful scientific findings (Coad et al., 2006; Last, 2001) and is recommended for inclusion in systematic reviews and meta-analyses to reduce publication bias, as studies finding statistically small or negative results are less likely to be published (Benzies et al., 2006; Conn et al., 2003; Hopewell et al., 2007; McAuley et al., 2000).

Findings from the grey literature are used to inform policy and outline best practice (McLaughlan, 2008); therefore a review is required of this literature. Whilst the grey literature on sight loss in regard to emotional well-being has been reviewed previously (e.g. Bosanquet & Mehta, 2009; Edwards & Keil, 2008; Stephens, 2007), these reviews have fused together the published and grey literature and so were unable to distinguish the contribution of grey literature to the field. In reviewing the grey literature separately, we were able to assess its relative contribution, particularly as studies in the grey literature may explore research questions not addressed elsewhere.

METHOD

We sent a request for research reports and unpublished papers reporting primary data on the 3rd of September 2008 to three key distribution lists: Visual Impairment Network for Counselling and Emotional Support (VINCE) (via www.vision2020uk.org.uk), the National Association of Local Societies for Visually Impaired People (NALSVI) (www.nalsvi.cswebsites.org), and VISION 2020 UK (www.vision2020uk.org.uk). Members of VINCE were over 90 service providers, counsellors, and others interested in emotional support and counselling for people with visual impairment; members of NALSVI represented 121 registered charities providing local services to people with visual impairment; and members of VISION 2020 UK represented over 40

organisations in the areas of service provision, health and social care, and academic research, as well as individuals interested in treatment, prevention, and service provision for people with visual impairment. We then searched the following websites for publications: Royal National Institute of Blind People (RNIB), Thomas Pocklington Trust, The Guide Dogs for the Blind Association, and VISION 2020 UK. Finally, we obtained a list of reports from the reference lists of literature reviews, each report included in our review, and our systematic reviews of the published literature (Nyman et al., 2009a; 2009b).

The inclusion criteria for this review were that studies recruited adults (sample 16+ years) who had visual impairment, reported empirical quantitative and / or qualitative data concerning emotional well-being, and were available in English from January 2001 to September 2008. For emotional well-being we included psychological indicators (depression, mental health, anxiety, and quality of life) and social indicators (social functioning, social support, and loneliness), as well as studies that evaluated rehabilitation and other services / interventions that aimed to improve emotional well-being. Whilst physical functioning is related to emotional well-being, studies that exclusively focused on these areas were excluded. Studies were also excluded if only the abstract was published, the data had been published in an externally peer-reviewed journal, or if no primary data was reported (commentaries, editorials, and reviews).

RESULTS

We identified 24 studies that investigated either emotional well-being or evaluated an intervention for its influence on emotional well-being in working age and older adults with sight loss. We present our results in two sections according to whether studies were observational (e.g. studies that employed surveys, $n = 15$) or evaluated interventions (e.g. pre and post designs, $n = 9$).

Observation studies

The observation studies reviewed are summarised in Table 1. The 15 reports represented 13 separate studies (reports from the same sample: Douglas et al., 2006; 2008; plus: Hanson et al., 2002; Percival, 2003). Each study was conducted in the UK, eight by voluntary organisations, four by academic institutions, and three by a collaboration of academic and voluntary institutions. The studies recruited a total of 5,634 participants with sight loss, of which 14 were cross-sectional and one longitudinal. For data collection, studies used either mixed ($n = 8$), quantitative ($n = 5$), or qualitative ($n = 2$) methods. For the studies using quantitative methods ($n = 13$), eight were explicit about the outcome measure investigated, nine used single items, one employed a non-validated scale that was intended to measure attitude to life, and only three used validated scales; the Control, Autonomy, Self-realisation, and Pleasure self-completion booklet (CASP-19; Hyde et al., 2003); the Mental Health Composite Score (MCS) of the Short Form health survey (SF-12; Ware et al., 1996); and the National Eye Institute-Visual Function Questionnaire (NEI-VFQ-25; Mangione et al., 2001). We subgrouped the studies reviewed according to the key outcomes of psychological well-being, social well-being, and demand for support services.

<Table 1 about here>

Psychological well-being

The studies indicated that people with sight loss can report reduced emotional well-being in the form of shock, fear, depression, grief, vulnerability, and self-doubt and lack of confidence (Gibson et al., 2006; Gjonça & Nazroo, 2006; Hanson et al., 2002; Vale, 2001). Feelings of depression were reported by individuals because of a lack of intellectual stimulation and social isolation (Percival, 2003), and insensitivity from ophthalmologists was suggested as an aggravating factor for poorer well-being (Vale, 2001). However, reduced emotional well-being such as depression may only be experienced by the minority of individuals with sight loss. A survey of 400 people aged 55+ with sight loss revealed that most participants responded positively in regard to emotional well-being, with 46% reporting a positive attitude to life and 38% feeling that 'life was alright'. Only 16% reported a negative attitude to life (Hanson et al., 2002), though differences in attitude according to variables such as duration of vision loss were not considered.

Three studies used validated outcome measures. A study of 37 adults using the NEI-VFQ-25 found that mental health and social functioning subscale scores were below average for the general population (Thetford et al., 2008), though the actual subscale scores were not reported, so it is unknown how far below average the scores were. A study calculated a 'minimum acceptable level' of well-being by categorising scores on a range of items including three from the SF-12 and found that 37% of their sample was not experiencing this acceptable level (Pey et al., 2007). The face validity of this study was supported with the finding that well-being and mental health were significantly correlated with better levels of mobility and activities necessary for independent living (Pey et al., 2007). However, when we compared the mean MCS scores with the normative data reported, there was either no or only a slight significant difference between participants' scores and those of their sighted peers (mean differences of 0.9-5.6/100). The inability to find a clinically significant difference (i.e. a large enough difference to be meaningful in practice) between participant and normative mental health scores may well be because the Short Form health survey is an insensitive measure of mental health and social functioning (Nyman et al., 2009b).

A study reported that vision status was correlated with a measure of quality of life; the CASP-19 (Gjonça & Nazroo, 2006). The proportion of those reporting a 'good' quality of life score was lower in those with poor vision or blindness (34.6%) compared to those with good or excellent vision (64.3%). This difference of 29.7% is likely to be statistically significant, though not reported.

Social well-being

The studies reviewed suggested adults with sight loss are not satisfied with their level of social contact and activity, as people with sight loss have reported feelings of loneliness, exclusion, and social isolation (Douglas et al., 2006; Living Options Devon Visual Impairment Group, 2004; Nash, 2008; Percival, 2003). A quarter of one sample did not feel sufficiently in touch with people, and over half did not feel engaged with their community and wanted to go out more often (Percival, 2003). A study by Vale (2004) found that 76% of their sample reported getting out the house less often than they used to or were rarely getting out, and 18% reported receiving a visit less than once a week and 11% less than once a month or never. A similar study reported that 43% of their sample wanted to go out more, and a third of these cited their sight loss as a barrier to doing so (Douglas et al., 2006). Whether these measures accurately reflect emotional well-being is

for future research to discover. Whilst people with sight loss may have fewer face-to-face interactions with family and friends they were more likely than sighted peers to be in contact by telephone (Gjonça & Nazroo, 2006). However, it is unknown whether telephone contact was considered to be a suitable substitute for socialising face-to-face.

Demand for support services

Whilst an emotional support service is sought after by people newly diagnosed with sight loss (McBride, 2001; Thame, 2005), it was reported that such a service was not offered at the point of diagnosis or soon after (Browne, 2002; Living Options Devon Visual Impairment Group, 2004; Vale, 2001). This is an important finding as if support is not provided at the point of diagnosis people with sight loss may not seek or be offered support later (Thetford et al., 2008). Only one in five of a sample of 400 recalled receipt of an offer for rehabilitation or support since the onset of their visual impairment (Hanson et al., 2002), and 75% of another sample reported only receiving physical support (Thame, 2005). After diagnosis 70% of a studied sample wanted to talk to someone about their fears and concerns, but only 19% had been offered this opportunity, and 61% would have liked to have been able to call someone after the appointment to discuss issues, but only 10% were given this opportunity (McBride, 2001). In another case, only 9% of people were offered emotional support when newly diagnosed with sight loss, and 91% of these found the support helpful (Living Options Devon Visual Impairment Group, 2004).

A survey of eye clinics reported 7% of patient services recommended counselling, 10% suggested home visits, 6% suggested contact with local societies, and 26% offered a 'what happens next' discussion (Browne, 2002). However, this survey also noted that 94% of services reported providing emotional support, and so what is deemed as an 'emotional support' service may vary. In addition, not every study has found that support beyond usual care is in demand from the majority of people with sight loss. One study found that 70% (n = 395) of their sample felt satisfied with the service received at the point of diagnosis (Douglas et al., 2008), and another found only 10% would have liked emotional support prior to registration (Thame, 2005). Finally, the results from the second wave of Network 1000 - a UK survey of 1000 people with visual impairment - emphasised the importance of family counselling to address the emotional support needs of the whole family rather than just the individual with sight loss (Douglas et al., 2008).

Intervention studies

The intervention studies reviewed are summarised in Table 2. Each of the nine papers represented separate studies, as we only included the final reports of the RNIB Bristol counselling projects (Dale, 2008b; Nicholls, 2004) and not the intermediate annual reports using the same data. Each study was conducted in the UK, eight by voluntary organisations and one by an academic institution. The studies recruited a total of 243 participants with sight loss and the designs were either cross-sectional (post-intervention) (n = 6), pre and post (n = 2), or longitudinal (n = 1). For data collection studies used either mixed (n = 4) or qualitative (n = 5) methods. For the four quantitative studies, three were explicit about the outcome measure investigated, one used single items, one employed a non-validated scale that was intended to measure psychosocial well-being, and only the two RNIB face-to-face counselling projects used a validated scale used in counselling; the Clinical Outcomes in Routine Evaluation-Outcome Measure (CORE-OM, Barkham et al., 2006). A range of interventions were represented including referral to an eye clinic liaison officer, workshops, tele-befriending, and face-to-face and telephone-based

counselling.

<Table 2 about here>

Eye clinic liaison officers (ECLOs)

Whilst eye clinic professionals made referrals to ECLO services and felt they impacted positively on patients, very few patients (N = 20) realised they had been referred to non-medical care (Douglas et al., 2005). In addition, a study in Northern Ireland showed that whilst optometrists were willing to refer patients for non-medical support (N = 24), the support provided did not focus on emotional support, but rather, practical advice e.g. about assistive devices (RNIB, 2008). This suggests that the potential for ECLOs to provide emotional support has yet to be realised.

Workshops

The RNIB provide a five-day workshop for a group of adults with recent vision loss. The residential workshop provides interactive sessions to explore problems and solutions around vision loss for both the individual and their sighted companion (Saunders, 2005b). A sample of all 10 women that participated in a workshop reported that it helped them cope with everyday life. Eight participants stated they were better equipped mentally to deal with daily life, and every participant felt that meeting people experiencing similar difficulties was a positive experience (Saunders, 2005b). However, this study did not include a long term follow up and so it is unknown how long the workshop was perceived to be helpful.

Tele-befriending

In a qualitative study it was found that people with sight loss gained much from tele-befriending sessions in terms of more confidence and less isolation and loneliness. Of those that were still using the service after a year, 23/25 participants identified the peer support group as a significant part of their social life and support network (Saunders, 2008).

Counselling

A six-week course in face-to-face counselling has been evaluated through two RNIB Bristol Counselling Projects. In 2004, a statistically and clinically significant improvement post-counselling was reported (13/13), and for reductions in feelings of mild, moderate, and severe depression (48/48 pre vs. 12/48 post), bereavement or loss (48/48 vs. 16/48), anxiety or stress (48/48 vs. 9/48), and risk of suicide (24/48 vs. 2/48) (Nicholls, 2004). Similarly, in 2008 it was reported that 36/38 clients had made a statistically and clinically significant improvement in emotional well-being post-counselling, including a reduction in unexplained physical symptoms (headaches, nausea, dizziness, insomnia, and appetite loss) (22/38 pre vs. 4/38 post), and a reduction in risk of suicide (26/38 vs. 1/38) and self-harm (14/38 vs. 1/38) (Dale, 2008b). However, intention to treat analysis (the more conservative statistical analysis that includes drop outs from the intervention group as negative scores) was not conducted with the original sample of 120 participants; instead, the analysis was only performed with the 38 participants who provided complete data.

Similar positive results were found for a face-to-face counselling intervention conducted in Northumberland and Tyneside (n = 32) (Smith, 2003). The intervention demonstrated feelings of

empowerment and a decrease in feelings of isolation post-counselling. Participants reported insight into their fears and frustrations associated with sight loss and an appreciation for the opportunity to talk to people other than family members, both of which helped them come to accept their sight loss (Smith, 2003).

Telephone-based counselling has been evaluated, finding fewer reports of depressive symptoms and feelings of isolation post-intervention (RNIB, 2007; Saunders, 2005a). Of the sample, 26/30 adults reported that the emotional support they received generated positive feelings that had a continuing impact on their lives, and 29/30 believed the emotional support service to be very important and that it should be readily available (Saunders, 2005a). However, with no direct comparison between types of counselling, it is unknown what the relative efficacy of telephone-based counselling is when compared to face-to-face or no counselling.

DISCUSSION

We reviewed the grey literature to investigate the emotional well-being of people with sight loss and whether interventions improve emotional well-being in this client group. In reviewing the grey literature separately we were able to assess its contribution to the evidence-base in regard to emotional well-being in people with visual impairment. We identified 24 studies and presented our results in two sections according to whether the design was observational (n = 15) or of an evaluation of an intervention (n = 9).

Observation studies

The findings concerned psychological well-being, social well-being, and demand for support services.

Psychosocial well-being

Studies suggested that compared to their sighted peers, people with sight loss report a lower level of emotional well-being and can report lower levels of social well-being in the form of reduced social activity, loneliness, and disengagement with the community. Whilst these findings were not tested for statistical and clinical significance, they have face validity as they mirror the published literature with both working age adults and older people (Burmedi et al., 2002; Nyman et al., 2009a; 2009b).

Demand for support services

Studies have suggested a demand from people with sight loss for emotional support services, a gap in its provision, and that support services tend to meet practical rather than emotional needs. These grey studies reviewed are important, have face validity, profile the users' view, and reflect issues that are less likely to be published in academic journals due to lack of interest in such applied research questions.

Intervention studies

There have been relatively few studies that have evaluated emotional support services / interventions for people with sight loss, a trend also observed in the published literature (Nyman

et al., 2009a; 2009b). To date, the grey literature has not utilised the gold standard design of a randomised controlled trial (RCT), and has yet to evaluate emotional support services in the form of peer support groups, organised social activities, rehabilitation, and support with employment. Face-to-face counselling has received the most research attention, prospectively, and with a validated counselling measure. The RNIB counselling projects were particularly useful pilot studies for future research to build upon to determine the clinical and cost-effectiveness of this intervention in comparison to a control group, how long the effects of the intervention last, which psychological therapy to adopt, and when and how best to deliver the intervention. In terms of the published literature on older people with sight loss, there have been a number of pilot studies and two American RCTs that suggest training in problem-solving or self-management of sight loss can prevent the onset of depression for up to two months and six months respectively (Brody, Roch-Levecq, Thomas, Kaplan, & Brown, 2005; Rovner & Casten, 2008).

Limitations of the studies reviewed and suggestions for future research

The studies reviewed were of mixed quality, particularly as some did not have emotional well-being at the centre of their design (in particular the observation studies). Studies with poorer methodological quality had limitations in their scope, samples recruited, design, and data analysis.

Scope

Only one study considered the emotional impact of sight loss on the wider family, and therefore further research could explore how the close social network emotionally adjusts to sight loss and how best to provide support to this group.

Samples recruited

Whilst six observation studies recruited large samples of 400 - 1428 participants, the intervention studies recruited small samples of 10 – 48 participants (with complete data) and so the results from these studies are less reliable. The recruitment of control groups was uncommon and if controls were included detail was omitted about whether they were matched to those with sight loss. Recruiting a control group not only provides a comparison group for observational studies, but provides data to refute a placebo effect in intervention studies. Further, samples appeared to be mainly (but not always) self-selected and recruited through convenience sampling, and so the results may not generalise to the wider UK population. The generaliseability of studies could also be enhanced by providing data on dropouts and their characteristics, and by recruiting members of ethnic minority groups.

Design

A key limitation was the lack of employment of validated outcome measures to assess the key concepts. The use of single items or non-validated outcomes limits the usefulness of results in that it is unknown how accurately they measure emotional well-being and limits comparison with other studies using different outcomes. As with the published literature (Nyman et al., 2009a; 2009b), the majority of studies used a cross-sectional design and therefore could not inform of the longitudinal pattern of emotional well-being in individuals with sight loss. It has been previously emphasised that the experience of sight loss and therefore support needs of those with sight loss change over time (Cruse, 1999; Thetford et al., 2008), and so future research is required to capture the dynamics of these changes.

In regard to interventions, in both the published and grey literature there are relatively few evaluation studies with currently no substantial evidence base to recommend a particular form of rehabilitation or emotional support intervention to improve the emotional well-being of working age and older adults with sight loss. A starting point for future studies would be for service providers to evaluate their existing services. Indeed, in a scoping survey of UK counselling services for people with sight loss, only 3/28 could provide an evaluation report of their services, and of these only one collected prospective data (Nyman, Gosney, & Victor, in press). Ideally, evaluations are to be conducted independently, as if the service provider is used to collect data – as was the case in the intervention studies reviewed here – there is potential for social desirability bias in that clients may feel obliged to report that the intervention was beneficial. Future research could also provide more detail about the interventions used to allow others to replicate successful research studies / and or services.

Data analysis

Quantitative data analyses were rarely considered in terms of statistical (with the use of inferential statistics) and clinical significance, and the role of mediating and moderating variables were often left unexplored (e.g. duration of sight loss, type of visual impairment, and sociodemographics such as age, gender, ethnicity, and socio-economic status). Unfortunately, qualitative analyses were rarely fully reported but reduced to a few quotations, and so often the depth of information from these datasets was unavailable.

Limitations of our review

Our review was limited in that due to the nature of the grey literature we may not have obtained every study reported. In hindsight, primary care trusts and local authorities could have been consulted for local evaluation reports, and only UK-based studies were obtained and so the results of this review may not generalise to other countries. The review period was not exhaustive, as we followed the review period of January 2001 to September 2008 in line with our reviews of the published literature (Nyman et al., 2009a; 2009b). In addition, as a proportion of the grey studies were conducted by or had input from academic researchers, these have been published in part in academic peer-reviewed journals and so these studies may be considered both grey and published.

The contribution of the grey literature

The main strength of the grey literature is that voluntary organisations have been a main contributor to the research, either independently or as a partner with an academic institution. The grassroots knowledge of those working directly with people with sight loss has been used so that that the research questions have an applied focus, with over a third of studies evaluating an intervention. However, the main weakness of the grey literature is the mixed quality of research design and reporting, which perhaps could be improved through the quality control of a peer-review process. Funding bodies could stipulate that work they commission be peer-reviewed and academic journal editors could attempt to broaden their contribution base to researchers working outside of academic institutions.

The grey literature reviewed does not provide conclusive evidence in regard to emotional well-being or interventions to improve emotional well-being in people with sight loss, however, four themes emerged from our review. First, visual impairment can clearly have a profound negative

emotional impact on individuals. Studies published in peer-reviewed journals provide the figures to show the increased risk of depression in those with visual impairment, and that a significant minority of people with visual impairment become depressed (Burmedi et al., 2002; Nyman et al., 2009a; 2009b).

Second, there are clear indications that people with visual impairment are dissatisfied with their level of social activity and / or feel lonely. Loneliness has been under researched in the published literature, and so future research with a validated scale could investigate the prevalence of loneliness in people with visual impairment and statistically identify its main predictors, e.g. difficulties with mobility as suggested by the studies reviewed in this paper.

Third, there is sufficient data to suggest that there is some demand for an emotional support service by those with newly acquired visual impairment and that such a demand is not being met. Published research tends to answer different research questions and so this has not been addressed in studies published in journals. Future research could investigate the level of this demand (e.g. whether all people with acquired vision loss desire emotional support or only those socially isolated or at risk of depression), how people want to be emotionally supported, and whether the services in the voluntary sector are subsequently meeting the demand not provided in the statutory sector.

Fourth, there is potential for a variety of ways of providing emotional support - workshops, telephone-based befriending and counselling, and ECLOs - but further research is required to evaluate these services with prospective trials (e.g. pre and post designs) to determine their efficacy. Tele-befriending has longitudinal data to support its potential, and face-to-face counselling has the most robust data to support this service. The published literature has yet to investigate the value of counselling or the other means of providing emotional support reviewed in this paper, and so future research could follow up the studies reviewed with controlled trials to provide the most refutable evidence for their provision. Such studies could simultaneously determine the demand for their services, their running costs, and control for the use of antidepressants and drop outs with the use of intention to treat analyses.

For future research we encourage service providers and trained researchers to collaborate to produce research that is both applied and robust. Future studies would benefit from the insight and experience of service providers who work with people with sight loss, and lead to persuasive reports of quality data as the research has been designed and conducted in collaboration with trained researchers. With persuasive reports of quality data the voluntary sector would be more able to convince policy makers of the need to emotionally support people with sight loss, and how to best provide this support. Thomas Pocklington Trust have been a leader in this approach in funding academic researchers to conduct research projects with the input of advisory groups that comprise service users and providers.

Conclusion

The grey literature has provided data to support the notion that people with sight loss have a poorer level of emotional well-being and for interventions to emotionally support this client group. The findings are important, have face validity, and profile the users' view. However, there are still gaps in current knowledge and for the field to advance we encourage service providers

and trained researchers to collaborate to produce data that is both applied and of high quality.

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Table 1. Studies observing emotional well-being in individuals with sight loss (N = 15, all UK-based)

Authors	Context	Method	N	Age details	Visual impairment	Researcher
Browne (2002)	Commissioned and executed by RNIB	Quantitative cross-sectional survey	158 eye clinic patient services	N/A	N/A	O'Brien
Douglas et al. (2008)	Mixed team comprising an academic institution and Vision 2020 UK, funded by Big Lottery Fund	Qualitative and quantitative cross section of second wave of a longitudinal study	884	Evenly distributed across age bands (18-29, 30-49, 50-64, 65-74, 75+)	Registered blind or partially sighted	70%
Gibson et al. (2006)	Mixed team comprising an academic institution and RNIB, funded by Big Lottery Fund	Qualitative and cross-sectional	45	65-93, median = 72 yrs	A range including ARMD, DR, cataracts, and glaucoma	100%
Gjonca & Nazroo (2006)	Academic institution funded by Thomas Pocklington Trust	Quantitative longitudinal survey. QoL measured with CASP-19	11,392: 455 (4%) poor vision / blind: 1367 (12%) fair vision	50+ yrs	A range; most commonly cataracts, and then ARMD, glaucoma, and DR	100%
Hanson et al. (2002)	Academic institution funded by Thomas Pocklington Trust	Quantitative cross-sectional survey with qualitative in-depth interviews and focus groups	Quantitative: 400 Qualitative: 75 interviews plus 3 focus groups	27% 55-74, 42% 75-84, 31% 85+ yrs	Not specified, though 92.5% had late onset; 168 registered blind, 1 and 97 registered partially sighted	100%
Living Options Devon Visual Impairment Group (2004)	Commissioned and executed by Living Options Devon in a user led project, funded by various sources	Quantitative cross-sectional survey	130	31-95, median = 80yrs	47 registered blind, 85 registered partially sighted, 6 did not know if registered	100%

McBride (2001)	Commissioned by RNIB and executed by an independent research company	Quantitative cross-sectional survey	200	69% 75+ yrs	47% blind and 49% partially sighted, of which 31% had sight problem for 15+ yrs
Nash (2008)	Commissioned and executed by Living Options Devon	Mixed methods and cross-sectional	158	74% 65+ yrs	Not specified, included those with hearing impairment and dual sensory loss
Pey et al. (2007)	Commissioned and executed by Guide Dogs	Quantitative cross-sectional survey. QoL measured with several items including 3 from SF-12	1,428	18-99, mean = 62.4 yrs	39% registered blind, 61% registered partially sighted. Mainly ARMD, glaucoma and cataracts
Thame (2005)	Independent researcher, on behalf of Living Options Devon, funded by RNIB	Mixed methods and cross-sectional	191	72% 65+ yrs	42% blind and 56% partially sighted
Thetford et al. (2008)	Academic institution funded by Thomas Pocklington Trust	Quantitative cross-sectional survey with the NEI-VFQ-25, and qualitative biographical narrative interviews	37	24-92, mean = 67 yrs	Most frequently AMRD (n=15), average duration almost 20 years
Vale (2001)	Improving Lives Coalition	Qualitative cross-sectional focus groups	Not specified	Not specified	Blind and partially sighted
Vale (2004)	RNIB report in collaboration with British Gas Here to Help Project	Quantitative cross-sectional survey plus qualitative case studies	588 plus 4 case studies	68% 75+ yrs	Blind and partially sighted

ADs = Assistive devices

ARMD = Age-related macular degeneration

CASP-19 = Control, Autonomy, Self-realisation, and Pleasure self-completion booklet (19 items) (Hyde et al., 2003)

DR = Diabetic retinopathy

MCS = Mental Health Composite score of the SF-12

NEI-VFQ-25 = National Eye Institute-Visual Function Questionnaire (25 items) (Mangione et al., 2001)

QoL = Quality of Life

RNIB = Royal National Institute of Blind People

SF-12 = Short Form health survey (12 items) (Ware et al., 1996)

Table 2. Studies evaluating interventions for change in emotional well-being in individuals with sight loss (N = 9, all UK-based)

Authors	Context	Method	N	Age details	Visual impairment
Dale (2008b)	RNIB, funded by Department of Health	Quantitative pre and post with CORE-OM, plus qualitative client feedback	Quantitative: 38 Qualitative: 13	18-100+, 40% 59+ yrs	Not specified, though 56% dual sensory loss
		<i>Face-to-face counselling</i>	36/38	clients clinically and reliably improved post-intervention. Clients reduced in use of anti-depressants / tranquilisers (3/38), unexplained physical symptoms (22/38 pre vs. 4/38 post), risk of suicide (26/38 vs. 1/38), and self-harm (14/38 vs. 1/38).	
Douglas et al. (2005)	Academic institution funded by Thomas Pocklington Trust	Qualitative cross-sectional	Eye clinic professionals: not specified	Patients: 20	Patients 51-90 yrs
				10 registered blind, 8 registered partially sighted (2 not registered)	<i>ECLLO</i> . Generally accepted by professionals that an ECLLO should provide non-medical / emotional support to help individuals come to terms with their sight loss.
Nicholls (2004)	RNIB, funded by Department of Health	Quantitative pre and post with CORE-OM, plus qualitative client feedback	Quantitative: 48 Qualitative: 13	20-59+, 60% 59+ yrs	Not specified
		<i>Face-to-face counselling</i>	48/48 pre vs. 12/48 post)	clients showed clinical and reliable improvement post-intervention (13/13), and reported reduced feelings of mild, moderate, and severe depression (48/48 pre vs. 12/48 post), bereavement or loss (48/48 vs. 16/48), anxiety or stress (48/48 vs. 9/48), and risk of suicide (24/48 vs. 2/48).	
RNIB (2007)	Commissioned and executed by RNIB	Qualitative and cross sectional			Not specified
		<i>Telephone counselling</i>			Feelings of depression were said to be alleviated. The ability to talk to someone unconnected but empathetic was important.
RNIB (2008)	Commissioned and executed by RNIB	Qualitative case study			
			40 referred by 24 optometrists	8-92, 87.5% 65+ yrs	Mainly ARMD (n = 23)
		<i>Referral by optometric practices for practical and emotional support</i>			A case study is presented in which RNIB provided a range of practical support and advice on ADs, but little in the way of emotional support.
Saunders (2005a)	Freelance researcher on behalf of RNIB	Quantitative cross-sectional survey plus semi-structured items	30	Not specified	Not specified
		<i>Telephone counselling</i>	20/30		who contacted the serviced cited depression as a concern. 26/30 felt the emotional support received generated positive feelings that had a continuing impact on their lives. 29/30 believed the emotional support to be very important and should be readily available.
Saunders (2005b)	Freelance researcher on behalf of RNIB	Quantitative cross-sectional survey plus semi-structured items	10 women	36-65+ yrs	Blind and partially sighted
		<i>Find Your Feet workshop</i>	8/10		said they were better equipped mentally to deal with day to day living as a result of the workshop. 10/10 felt that meeting people experiencing similar difficulties was a positive experience.
Saunders (2008)	Freelance researcher on behalf of RNIB	Qualitative, cross-sectional and longitudinal	25 cross-section, 25 longitudinal	52% 76+, mean = 73 yrs	Not specified
		<i>Tele-befriending</i>			After one year, 23/25 identified the peer support group as a significant part of their social life and support network and 12/25 preferred telephone friendship to face-to-face meetings.
Smith (2003)	Freelance researcher on behalf of RNIB, funded by Royal Victoria Trust for the Blind	Qualitative and cross-sectional			

/32 |Not specified |Not specified |*Face-to-face counselling*. Counselling helped with acceptance of visual impairment through insight into fears and frustrations associated with sight loss, and the ability to talk to people other than family members. | |ADs = Assistive devices

ARMD = Age-related macular degeneration

CORE-OM = Clinical Outcomes in Routine Evaluation-Outcome Measure (Barkham et al., 2006)

DR = Diabetic retinopathy

ECLO = Eye clinic liaison officer

RNIB = Royal National Institute of Blind People