

Exploring the role of an emotional support and counselling service for people with visual impairments

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Abstract

There is growing evidence of the need for services to address the emotional support needs of people with visual impairments. This paper presents findings from a mixed methods evaluation of an emotional support and counselling (ESaC) service delivered within an integrated low vision service, focusing primarily on the qualitative findings. Data collected using a standardised measure of psychological well-being (the CORE-OM) show an improvement in the psychological well-being of clients of the service between baseline and follow-up assessment. Qualitative findings from interviews with service users and service providers help to illustrate and explain the experiences underlying the quantitative findings. The ESaC services are shown to be helpful to service users in two particular ways: helping them to normalise their experiences by talking to an impartial listener; and helping them to accept and adapt to the physical, emotional and social changes in their lives resulting from their visual impairment.

Key words

Visual impairment, counselling, emotional support, psychological distress, low vision services

INTRODUCTION

The social and emotional effects of visual impairment

The social and emotional effects of visual impairment are becoming well-established. The negative emotional effects are particularly well demonstrated in relation to older people, with one review showing rates of depression of between 25% and 50% amongst older people with visual impairments, compared with rates in the general older population of 20% for mild depression and only 5% for more severe depression (Burmedi, Becker, Heyl, Wahl, & Himmelsbach, 2002b). Even studies which show lower rates of depression still show the same disparity between individuals with visual impairments and those without (J. Evans, Fletcher, & Wormald, 2007). Burmedi and colleagues also reviewed evidence for the social effects of visual impairment on older people, and found that it impacted negatively on mobility and on ability to engage in daily living activities and leisure activities (Burmedi, Becker, Heyl, Wahl, & Himmelsbach, 2002a). Another review showed that people with Age-related Macular Degeneration reported reduced quality of life, including a reduced ability to live independently and to engage in leisure activities (Mitchell & Bradley, 2006). Evidence also shows that older people with visual impairment are likely to experience reduced levels of social support and increased feelings of loneliness, both of which can affect their capacity to adapt to life with a visual impairment (Burmedi et al., 2002a; Verstraten, Brinkmann, Stevens, & Schouten, 2005).

There is less evidence for the social and emotional effects of sight loss on other sections of the population. However, a recent review of evidence relating to working age adults showed similar results as for older people, with lower levels of mental health, social

functioning and quality of life reported by adults with visual impairments than by their sighted peers (Nyman, Gosney, & Victor, 2010b).

The need for emotional support services

A number of articles published recently in this journal and elsewhere contribute to a growing body of evidence of the need for services to address the emotional support needs of people with visual impairments (Cairns, Herriotts, Douglas, Corcoran, & Pavey, 2009; Murray, McKay, & Nieuwoudt, 2010; Nyman, Gosney, & Victor, 2010a; Nyman et al., 2010b; Thurston, Thurston, & McLeod, 2010). There is increasing recognition of the need for emotional support services to be provided as part of integrated, multidisciplinary low vision services, (McBride, 2005; RNIB, 2008). As there is evidence to suggest that use of rehabilitation services is linked to lower rates of depression (Horowitz, Reinhardt, & Boerner, 2005; Tolman, Hill, Kleinschmidt, & Gregg, 2005), there is a clear case for integration: not only does emotional support have the potential to improve mental well-being in itself, if integrated into low vision services it might also have the potential to enhance use of rehabilitation services which in turn may further act as a protective factor against depression.

An important element in understanding the emotional impact of visual impairment is understanding it as a transitional process through different stages (Thurston, 2010; Thurston et al., 2010) in which people's emotional and other support needs change over time from diagnosis onwards (Douglas, Pavey, & Corcoran, 2008; Thetford, Robinson, Mehta, Knox, & Wong, 2008). Thurston et al.'s study highlighted the key role that counselling can play in helping people through key stages of that transition, particularly at

the time of diagnosis and during rehabilitation (Thurston, 2010). However, the Network 1000 study showed that only 2% of recently registered visually impaired people had received formal counselling or emotional support of some kind in the first year after diagnosis (Douglas et al., 2008), a finding that reflects earlier research (Vale & Smyth, 2002).

Despite the strong arguments for the provision of specialist counselling and emotional support services for people with visual impairments, published evidence for the effectiveness of such services is limited (Nyman et al., 2010a). An evaluation of a pilot face-to-face specialist counselling service in Bristol indicated a range of benefits, both to service users and related statutory services, including increased self-esteem, better relationships, reduced levels of depression and suicide risk and improved quality of life (Dale, 2008; Nicholls, 2005). An evaluation of telephone counselling has also suggested that service users experience improvement in well-being as a result of using the service (Saunders, 2005). However, as Nyman and colleagues point out, much of this evidence takes the form of 'grey' literature based on in-house service evaluations (Nyman et al., 2010a).

The ESaC pilot study

The research reported here is an evaluation of an Emotional Support and Counselling (ESaC) service provided as part of an integrated Low Vision Service (LVS). The evaluation was part of a three year pilot project commissioned by RNIB and funded by GlaxoSmithKline. The pilot was conducted in two sites: Gateshead and London. In Gateshead the service was delivered by Sight Service, a local voluntary sector provider. In London the service was delivered by RNIB to residents of the London boroughs of Camden and Islington. A research

team from the University of Liverpool was commissioned to conduct the evaluation, which was designed as an integral part of the pilot project.

THE EMOTIONAL SUPPORT AND COUNSELLING INTERVENTION

At each site, the ESaC service was delivered between 2007 and 2011 by one professionally qualified part-time counsellor, employed for three days a week. As the service was integrated into the low vision service, all clients who attended the LVS were given information about the ESaC Service with details of their low vision appointment. Clients could be referred by other members of the LVS (e.g. optometrists and rehabilitation workers), by external professionals such as Eye Clinic Liaison Officers (ECLOs) or GPs, or they could self-refer. After referral, the counsellor telephoned the client to arrange an initial assessment. At assessment, the counsellor invited the individual to explore their emotional support needs and, if appropriate, offered them time limited individual counselling or emotional support: usually between 6 and 12 weekly, 50 minute sessions.

The decision to offer emotional support as well as counselling was taken because, whilst many people affected by sight loss want to talk through their feelings, not everyone is able or willing to engage in formal counselling. In recognition of this the counsellors could work at less depth in a less formalised approach, but still using counselling skills, giving clients the opportunity to talk in a confidential setting and to have their feelings normalised.

Sessions usually took place in the LVS, although recognising the particular needs of this client group, both telephone counselling and home visits were conducted where necessary. With the consent of the service user, an integrated approach was sometimes adopted, with the counsellors providing support to enable a client to engage more productively in

rehabilitation work. For example if a client was working on mobility skills with a rehabilitation worker, and was experiencing anxiety about travelling alone they could explore this in more depth with the counsellor.

Although no specific model of counselling was adopted when the pilot project was set up, all three counsellors who were employed on the project worked within a humanistic approach. Humanistic counselling contrasts with psychoanalytic and behaviourist models which tend to be deterministic in their underlying concept of the human psyche and, therefore, of how to address psychological problems. The humanistic approach assumes a more positive view of human nature, emphasising choices, individual autonomy and the capacity for personal growth (Joseph, 2010). It is also much more holistic than other counselling models, taking greater account of both the physical and social contexts of people's lives. This is particularly important in the context of counselling disabled people, as it recognises that the role of the counsellor is to help people to cope not only emotionally, physically and practically with their impairment, but also with society's responses to them.

STUDY DESIGN

The study used qualitative and quantitative methods to assess the impact of the emotional support and counselling intervention. The main body of data was collected from clients of the ESaC services, with additional data collected from service providers and from supporting relatives and friends of service users, in order to generate a broader understanding of the functioning and impact of the services. The counsellors acted as co-researchers in the study, responsible for collecting demographic and questionnaire data from service users. Basic demographic and clinical information was obtained from all service users who gave their consent for this data to be collected (n=98). Further consent was sought from service

users to participate in the evaluation by completing two sets of questionnaires: one at their first counselling session and another at their final session. The questionnaires consisted of one validated quantitative measure of well-being, the CORE-OM (Clinical Outcomes in Routine Evaluation – Outcome Measure) (C. Evans, Connell, Barkham, Margison, McGrath, Mellor-Clark et al., 2002) and one qualitative assessment of needs and expectations. A total of 35 service users completed the CORE-OM at both baseline and post-intervention, with 30 also completing a qualitative questionnaire at both assessment points. A brief summary of findings from the CORE-OM data is provided below; full findings are reported in detail elsewhere (Barr, Hodge, Leeven, Bowen, & Knox, 2012; Hodge, Barr, & Knox, 2010).

To add depth to the study, semi-structured qualitative interviews were conducted with a sub-sample of participants who completed the questionnaires. Everyone who provided complete CORE-OM data was also asked if they would like to take part in a qualitative interview. A total of 30 individuals expressed an interest in being interviewed. The list of potential interviewees from each site was reviewed by the project counsellors, and nine individuals were identified as not being appropriate to contact at the time the interviews were taking place, due to illness or admission to hospital. Of the 21 individuals finally invited to take part in an interview, 14 consented to do so: 7 in Gateshead; 7 in London. The purpose of these interviews was to explore service users' experiences of the service. As relatively little counselling research has focused on the client experience of counselling (Manthei, 2005), this element of the study provides a valuable additional layer of evidence that is absent from many service evaluations. It also helps to further fill the gap in the literature relating to the emotional impact of sight loss which, as Thurston et al (2010) point out, is dominated by quantitative studies. The interviews were all conducted face to face by

the first author between November 2009 and April 2010. The interviewer followed a topic guide which covered participants' experience of sight loss and its impact on their lives; their prior experiences of services related to their sight loss; and their experience of the ESaC services including the referral process, their reasons for deciding to use the service, its perceived benefits to them, and any ways in which they felt it might be improved. Semi-structured qualitative interviews were also conducted with key service providers (n=15: 7 in Gateshead, 8 in London) including rehabilitation workers, optometrists and the counsellors from the two Low Vision Services. These also followed a topic guide covering participants' experiences of working with people with sight loss in the context of low vision services, as well as their experience of the ESaC service. All the interviews were audio-recorded, transcribed in full and the transcripts analysed thematically by the first author.

SUMMARY OF QUANTITATIVE FINDINGS

The primary aim of this paper is to present the findings from the qualitative interviews with service users. However, in order to set those findings in context we will first present a summary of the quantitative findings from the CORE-OM data.

The CORE-OM is a 34-item validated measure of psychological well-being and social functioning that looks at four domains: subjective well-being; problems/symptoms; functioning; and risk to self and others. It has been designed to be used both as part of routine clinical practice and for evaluation purposes (C. Evans et al., 2002). Clinical 'cut-off' values have been established from previous studies conducted with non-clinical populations using the CORE-OM (Connell, Barkham, Stiles, Twigg, Singleton, Evans et al., 2007; C. Evans et al., 2002). These allow the scores for study populations to be compared against those for general population samples, in order to determine whether the presence of a clinical level

of psychological distress is indicated. Figure 1 shows summary CORE data for the 35 participants who completed the assessment at both their first and final counselling session, and also indicates (with heavy horizontal bars) the clinical cut-off levels.

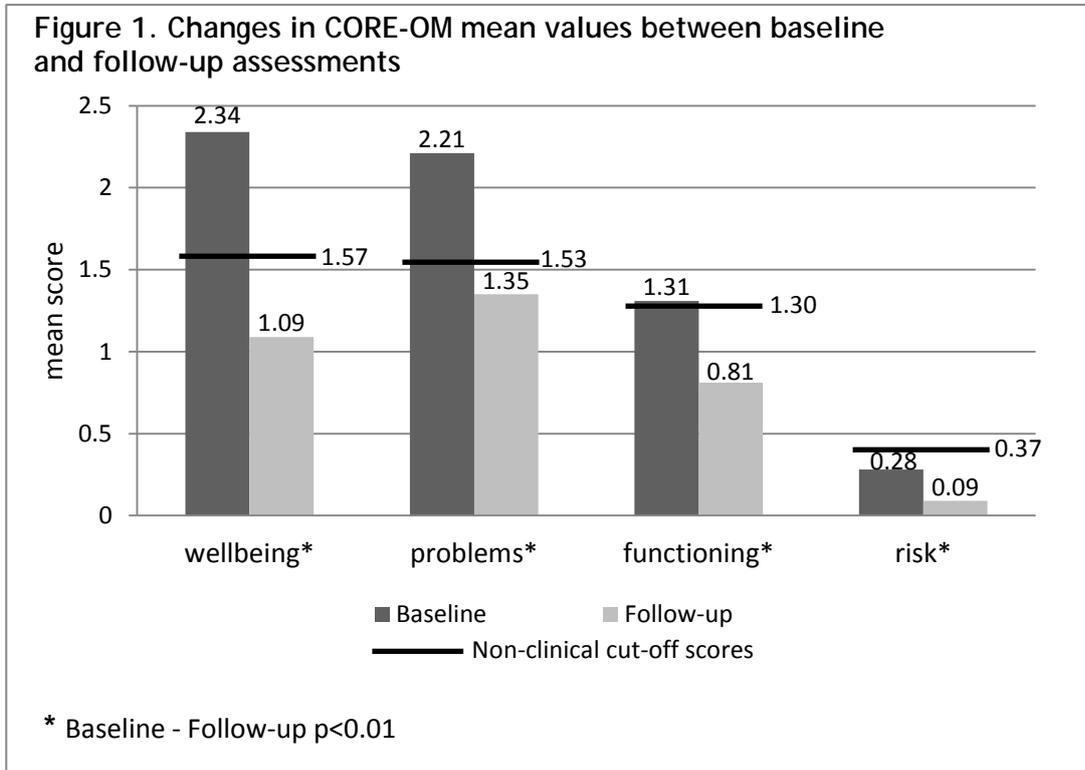


Figure 1 shows that at the baseline assessment the sample fell within the realm of a 'clinical population' in all of the domains the CORE measures except 'risk', and particularly in the domains of well-being and problems/symptoms. In other words, their scores indicated clinical levels of psychological distress in those domains.

Figure 1 also shows that by the time of their follow-up assessment at the end of their counselling, participants' CORE scores had fallen to levels which now took them below the clinical cut-off levels i.e. they no longer represented a clinical population. These changes were not only statistically significant ($p < 0.01$ in all four domains), but also, because of the

extent of change and the shift from a clinical to non-clinical population, reflect a clinically significant and reliable improvement in psychological well-being. Although no causal relationship can be inferred from these data between the improvements in CORE scores and the counselling intervention, they do suggest that the improvements were related to the counselling received. These findings are discussed in more detail elsewhere (Barr et al., 2012). In the remainder of this article we draw on findings from the qualitative component of the study to develop a more in-depth understanding of some of the experiences underlying the quantitative findings, and to explore some of the ways in which the ESaC services may have helped to address the emotional support needs of users of the low vision services.

FINDINGS FROM THE QUALITATIVE INTERVIEWS

Demographic characteristics of the qualitative sample

In their demographic make-up, participants in the qualitative interviews were broadly similar to participants in the overall sample of 98 and the CORE sample of 35. The fourteen people interviewed were drawn equally from the two sites: seven from Gateshead; seven from London. Of the total, eight participants were female, six were male. Their mean age was 65, ranging from 16 to 77. In terms of occupational status, five were retired, four were unemployed, three described themselves as 'long term sick', one was currently working, and one was at school. Nine people lived alone, the remaining five living with other family members. The majority of participants described themselves as White British, with two people being non-White and born outside the UK. The primary cause of visual impairment varied more widely across the interview sample than across the overall sample of 98, 45% of whom reported Age-related Macular Degeneration (AMD) as the primary cause. For the

interview sample there was no single predominant cause, with conditions reported including Stargardt's Syndrome, Cataract, Glaucoma, Multiple Sclerosis and Ushers Syndrome, as well as AMD.

Overview of interview findings

The data from the interviews with service users were analysed separately from those from the interviews with service providers; however, there was some correspondence between themes across the two sets of data, allowing different perspectives on certain themes to be explored. From these two sets of analysis an overarching thematic framework evolved, around which key themes were organised: the ESaC way of working; embedding the ESaC services within low vision services; the role of the ESaC services in the context of living with visual impairment; and valued features of the ESaC services. In the rest of this paper we will present findings relating to the last two of these thematic categories. A full report on the findings can be found elsewhere (Hodge et al., 2010).

Living with visual impairment: understanding the role of the ESaC services

Within this thematic category are several key themes which, between them, capture the main elements of the experience of living with visual impairment reported by interviewees. These are the 'sight loss journey'; depression and psychological distress; loss of confidence, social withdrawal and isolation; getting about; reading; education; relationships; bereavement; and physical health problems. We will report here on the first three of these themes as they map most directly onto the CORE findings.

The 'sight loss journey'

The loss of sight is often described as a 'journey'. It has also been described as a transitional process from sightedness to blindness with various stages at which people experience different emotional impacts (Thurston, 2010). The first stage, for many people, is that of diagnosis or sudden loss of sight, a key point at which people may have particular emotional support needs, as they experience feelings of shock and loss. It is a reaction which has become part of the work of the ESaC counsellors:

I guess nothing could quite have prepared me for the, I'm thinking about the experience of sitting in the room with somebody who is newly diagnosed and very, very frightened. (Counsellor, Gateshead)

The sense of shock associated with diagnosis is vividly described by one service user:

She [ophthalmologist] said you could go to bed tonight and you mightn't be able to see tomorrow. It's as easy as that. So the look on my face must have been enough, she looked at us for a few minutes and I said can I ask you a question, and she said yes of course. I said am I going to go completely blind? Because my inside was literally churning with the fear of it, it was, honest. She looked at us and waited quite a few seconds before she answered and then she said, I don't know. Well that wasn't the answer I was hoping for... (Bill, Gateshead)

This individual's experience highlights continuing problems with the way in which diagnoses of degenerative eye conditions are given to people, with a seeming lack of awareness on the part of many clinicians of the emotional impact that such news can have. This individual

received better care than some: he was at least referred directly to the Eye Clinic Liaison Officer (ECLLO) whom he saw immediately after his ophthalmology appointment, and from there was referred on to the ESaC service.

Other service users interviewed described a more gradual realisation that their sight was failing, with diagnosis not figuring as a key event. However, these narratives still often have a turning point in them. For four of the participants, this was the point at which they started to lose the sight in their second eye, as in Sara's case:

I got a speck in the eye and the optician, I was getting some new glasses, looked and said oh, I said I've got some sort of speck here, so she sort of looked a bit dubious, took off my glasses and starting wiping them like mad you know, and I said it's not the glasses. And it went on from there. Then I saw various people, I saw, I mean sadly I would've been all right if the second eye hadn't gone, that was the biggest blow because you can manage with one eye...(Sara, London)

Sara recognised that it was the combination of her deteriorating sight and the death of her husband that had impacted on her emotional well-being, accentuating her sense of loss and leading her to take up the offer of referral to the ESaC service:

I mean I'm a widow actually, my husband died seven years ago now but I'm still trying to get used to it, and so that was a big blow and then oh this started (...) I'm not normally a pessimistic person but I am more so now than I used to be. (Sara, London)

Amongst service providers there is also a recognition that people's needs for support can change over time, as they adjust to their loss of sight, and as other circumstances change:

...there are other things that happen, you know if your circumstances change, if your husband or your wife dies or something, and things happen that alter the dynamics of your life then even with a long standing visual impairment there might be a need for emotional support under a different set of circumstances. (Optometrist, Gateshead)

In the initial stages of setting up the ESaC service it was thought that the main point of need for the service would be at initial diagnosis and/or the onset of visual impairment. However, as the services evolved it became clear that there was a need to work with people at all stages of their journey through sight loss.

Depression and psychological distress

Findings from the CORE-OM data show clearly that the study participants represented a clinical population: that is, at the start of counselling their level of psychological well-being fell well below what would be expected in a healthy population. This finding is reinforced by evidence from the interviews with service users. Although the interviews did not ask directly about depression, a few service users explicitly use the term depression in talking about their own experience:

I find it very difficult to do things. I know it's all bound up in my – I suppose depression makes you not willing to do things. (Ian, London)

I do get depressed, there's no question about that. (Sara, London)

Others talk about experiencing mental health problems which have led them to seek help from mental health services, and one individual reports having made suicide attempts in the past, which were partly linked to his sight loss. Three individuals report feeling that their mental well-being was so low at the time they went for counselling that they had either had thoughts of ending their lives or just wished they were dead:

This place here saved my life really, I'd have been dead if it wasn't for this place. (...)

I was ready to do myself in. (Michael, Gateshead)

I think if I'd been still in the same mood that I was the first time I went to see [counsellor], with them black trees, if I'd been like that, I don't think I'd have been here now, I think I'd have done something silly or serious. (Bill, Gateshead)

These quotes illustrate the level of psychological distress experienced by some of the participants in the study. They also give some indication that the ESaC services had helped in alleviating their distress.

Loss of confidence, social withdrawal and isolation

Mirroring findings from previous research (King, Gilson, & Peveler, 2006; Mitchell & Bradley, 2006; Verstraten et al., 2005), the impact of visual impairment on participants' social functioning is also clearly evident in the interviews, seen in the theme of loss of confidence, social withdrawal and isolation:

...for five years I was cooped up in the house and I just excluded myself from everybody and I just felt like there's no way, there's no way I can do anything and I felt like I was the only person that can't see anything in the world. (Lydia, Gateshead)

I sort of grew away from people, sort of became a recluse you know, I still don't get out often, but before I couldn't go out and do my own shopping and stuff like that, I couldn't get out the house at all. (Michael, Gateshead)

In both cases quoted above the individuals are reflecting back to how they felt before they attended the ESaC service, and in both cases they directly link the improvement in how they felt to their experience of counselling. Others, particularly the older interviewees, don't report such an improvement in this aspect of their life. One individual in his 70s describes how he is dependent on technology to keep him in touch with people, and how the recent breakdown of his computer meant that he was completely cut-off from the outside world:

...not being able to use the e-mail, because my computer has broken down, how am I going to keep in touch with all these people that I know? Well I'm not, I'm going to become a recluse... (Ian, London)

Another participant, in his 60s, explains that he suffers from agoraphobia which, combined with the practical difficulties he faces because of his visual impairment, means that he no longer goes out:

I used to have an active social life and then it stopped. I sit here and I think tonight I'm going to get ready and I'm going to go out for a game of snooker, and it gets to about six o'clock, seven o'clock, eight o'clock, nine o'clock and I'm still sitting here and at 10 o'clock it's too late so I go to bed. That's the way it works. (George, Gateshead)

For others, social withdrawal is reported more simply as a response to the risks of venturing outside the relative safety of the home with impaired sight, although this may eventually also result in psychological effects as they participate less in activities outside the home:

I haven't been out for the last six weeks actually properly, but I do go of course if there's something I want to go to. Although, I think I'm less likely to go, in the winter as now, you know the dark evenings are a bit off-putting I have to say... (Sara, London)

As discussed in the introduction, loss of confidence, social withdrawal and isolation are all well-recognised and reported features of the experience of visual impairment (Thetford et al., 2008; Verstraten et al., 2005). Some of those interviewed report an increase in confidence and a decrease in isolation which they link to their contact with the ESaC services. Amongst the younger people interviewed there was generally recognition of the need for them to overcome their inclination to withdraw socially, even if living with visual impairment meant that they had to accept certain restrictions on what they could do. However, for older participants, the risk of social withdrawal leading to loneliness and isolation appeared to be greater, particularly with loss of sight coming on top of other issues such as bereavement, ill health, other impairments such as hearing loss and memory loss, and a fear of burdening others.

Valued features of the ESaC services

The second set of themes reported here relate to features of the ESaC services that were explicitly identified by service users as being valuable and helpful to them. Four themes were identified: talking to an impartial listener; accepting and adapting to visual

impairment; the quality of the counselling relationship; and knowing the ESaC service was there. In this section we focus on the first two of these themes, as these are most helpful in understanding how the services worked with clients and what aspects of them might have contributed to the improvement in psychological well-being indicated by the CORE findings.

Talking to an impartial listener

One of the first and most important tasks of any counsellor is to help the client to talk about their difficult feelings and experiences in order to normalise them (Perren, Godfrey, & Rowland, 2009). This was an important aspect of both the formal counselling and the emotional support elements of the intervention offered by the ESaC service. Whilst service users do not talk in terms of 'normalising' their feelings, one of the themes to emerge most strongly from the service user interviews is the value placed on being able to talk openly and freely to someone outside their family and friends:

I think it's just good talking to someone who's like impartial like to your situation and you can, because like I think it's harder to talk to like your friends or your family, because (...) like a counsellor you can just say, anything, anything you want and she can't like say anything about it... (Rachel, Gateshead)

No matter what I said, she never commented, oh you shouldn't have done that (...) You could unburden and she was good for me [counsellor]. She really was. (George, Gateshead)

The important thing is that the counselling relationship is non-judgemental:

... she's somebody who listens, you know she would listen, she would suggest, she's not laying it on you, you have to do this, you should expect this or, do you follow me, no she lets you speak, you speak and then she will just gently add something if you look at it this way or you look at it that way (Alicia, London)

Being able to talk to someone neutral and non-judgemental helps to normalise the client's experience (Perren et al., 2009). It is an important element of the client experience of counselling, and an element that is necessary for personal change to occur (Carey, Carey, Stalker, Mullan, Murray, & Spratt, 2007). Only when this process has taken place can the individual start to adjust to the changes in their life resulting from their visual impairment or from other difficulties.

Accepting and adapting to visual impairment

Visual impairment, particularly when combined with other life-limiting factors associated with old age or illness, can have a profound effect upon the life of the individual affected. What the findings from the qualitative interviews show is that the ESaC services were helping people to come to terms with their visual impairment and with the resulting changes in their lives. Learning to live differently, perhaps within limitations, is particularly important for younger people, as for Dawn, who is in her 40s and has Multiple Sclerosis:

I'm trying to stay calm. Because that's what sets it off. I can sort of control it because normally you know when you get up and you're like dashing for work, like I'll just go all to pot, so if I sort of take a step back and take a deep breath and just calm down, just say well I can't, but this is what the lady at the counselling sort of helped us to do. I can still get around but differently. (Dawn, Gateshead)

This individual directly credits her work with the counsellor for the adjustment that she has learned to make. For others the adaptation process is more about adjusting their goals and ambitions for the future, as for this young woman who has changed her plan to go to university in another city, so that she can remain living near to her parents:

I think that's one of the hardest things like accepting it. (...) I fancied going like to Manchester Uni (...) and this kind of has - in a way but I'm not really bothered about that - it's changed, like I'm quite happy to be here and do it. Because like I can still move out and have like my independence but be close enough, so that's fine.

(Rachel, Gateshead)

Although she reports being happy with her decision, there is also ambivalence in the way she talks about it. For her, counselling helped her to view the future more positively, even though she is still coming to terms with the altered future she is constructing for herself.

Others in the sample also describe having been helped by their counsellor to come to terms with their deteriorating sight by envisaging new roles for themselves, helping to reconstruct their disrupted sense of identity:

How was it helpful with [counsellor]? Because it brought to my attention that there's a life after, even if you do go blind it doesn't mean it's the end of the world, she actually filled me in as to how to cope with it. She helped with that way, the things that you could actually do in the voluntary sector, that didn't mean you were finished with work or whatever... (Bill, Gateshead)

Another way in which some interviewees report having been helped to cope better as a result of counselling is by being helped to focus on the present or immediate future:

I'm always concentrated on tomorrow. That's the important day tomorrow. That's when it's going to happen, and you just keep on doing that. (George, Gateshead)

Another individual talks about being helped by counselling to develop a more positive attitude, also highlighting the importance of having her experience of sight loss normalised and coming to understand that she is not alone in her experience of visual impairment:

It's not only me, many people have eyesight problems as well. But the most important thing is how to be positive. (...) Last year, I was very unhappy and I sat here hating myself and it was very negative. I feel I'm - I feel calm nowadays. (Hannah, London)

Similarly, Alicia talks about being helped to a more positive, forward-looking attitude by learning that she is not alone, and that there are sources of support available:

And you know, what she's trying to do is not to be too afraid, do you follow me, so allay your fears, as such that there are services there you know, it's not the doom and gloom you think it is, you know, there are helpful people around who are willing to support. (Alicia, London)

For Bill, it is the combination of receiving counselling and, at the same time, seeing other people with visual impairments who are coping with their lives that has helped to restore

his confidence, highlighting the value of the ESaC intervention being provided as part of an integrated Low Vision Service:

I went the following week and met some more people and had another interview with [counsellor] which went very well and as the weeks progressed and I was feeling much more confident in myself that if it did come to the worst and if I could rally the way these people had rallied and the inspiration they've given me, I said I really have got nowt to worry about, it's not the end of the world you know. But I hadn't said that the first day, as you can understand. (Bill, Gateshead)

The study shows that the psycho-social impacts of visual impairment are wide-ranging: depression, anxiety, loss of confidence, social withdrawal and isolation being common experiences. Findings from this study reinforce those reported in previous research (King et al., 2006; Mitchell & Bradley, 2006; Nyman et al., 2010b; Thurston et al., 2010; Verstraten et al., 2005). The process of coming to terms with visual impairment is thus a multi-dimensional process, requiring the individual to adapt emotionally, physically and socially. The ESaC services can be seen to have been helping people to do this in various different ways, according to the individual's particular situation and style of thinking.

It is in relation to coming to terms with visual impairment that the counsellors' use of a humanistic model of counselling comes most to the fore. Being able to accommodate to the altered sense of self and to the practical changes that living with a visual impairment involves seems to be vital to the process of coming to terms with being visually impaired. This is very much in keeping with the humanistic emphasis on the capacity of the individual for personal growth as well as with its emphases on embodiment and social context.

DISCUSSION

The quantitative findings from the study show clearly that at the start of their counselling participants in the study had high levels of psychological need which by the end of their counselling had reduced significantly (Barr et al., 2012). What the findings from the qualitative interviews offer us is an understanding of the difficulties facing those who have used the ESaC services and of some of the ways in which the services have helped them to address those difficulties. The importance of understanding the different stages of the 'sight loss journey' is highlighted, as is the need for the ESaC services to work with people at different stages of that journey including at the point of diagnosis, sudden loss of sight or at other turning points such as loss of sight in a second eye, bereavement or other significant life changes. Although the importance of understanding visual impairment in terms of a transitional process is not a new one (Thurston, 2010; Thurston et al., 2010) these findings do add further evidence to support that analysis.

The service user interviews illustrate the level of psychological distress experienced by users of the ESaC services, with some individuals reporting that they had been helped to overcome suicidal thoughts through counselling. Although on its own this evidence cannot be used to make a claim for the protective effects of the ESaC intervention against suicide, it should be considered in the context of evidence for the link between visual impairment and increased risk of suicide (De Leo, Hickey, Meneghel, & Cantor, 1999; Lam, Christ, Lee, Zheng, & Arheart, 2008; Mitchell & Bradley, 2006; Waern, Rubenowitz, Runeson, Skoog, Wilhelmson, & Allebeck, 2002). The interviews also illustrate the ways in which visual impairment can lead to social withdrawal and isolation, with several participants reporting that they had been helped to become less socially withdrawn by their experience of

counselling through the ESaC services. This is significant as it has been shown that loneliness can reduce the individual's ability to adapt to visual impairment (Verstraten et al., 2005). However, despite reporting that they had been helped by the ESaC intervention, other interviewees were still struggling with feelings of isolation and loneliness.

Two specific elements of the ESaC intervention valued by service users have been explored through the interview data. Firstly, being able to talk to an impartial listener: the intervention works by enabling service users to normalise feelings and experiences which they have been unable to articulate and process. What service users find important is being able to talk to someone who listens, understands and is neutral and non-judgemental. This is a vital element of the counselling process, as it helps to normalise the client's experience (Perren et al., 2009).

The second key element of the ESaC intervention is its role in enabling people to accept and adapt to life with a visual impairment. This process takes different forms for different people: learning to live within physical limitations, adjusting life and career goals, learning to adjust to a different sense of self, recognising that they are not alone or just learning to focus on the present. This process can usefully be understood sociologically in terms of the reconstruction of a 'disrupted biography' associated with chronic illness (Bury, 1982). It involves developing not only different attitudes or ways of thinking about the self, but also different strategies which enable the individual 'to mobilise resources and maximise favourable outcomes' (Bury, 1991: 462). Again, the value placed by service users on having been enabled to adapt is suggestive of the effectiveness of the ESaC intervention. It is in enabling people to come to terms with living with a visual impairment that the appropriateness of the humanistic model of counselling adopted by the counsellors is seen

most evident, with its emphasis on the capacity of the individual for personal growth and emotional recovery (Joseph, 2010).

CONCLUSION

The findings presented here suggest that specialist emotional support and counselling provided as part of an integrated low vision service is a valuable addition to health and social care provision for people with visual impairments. Coupled with quantitative findings from the study, the qualitative findings underscore the impact of visual impairment on people's emotional well-being and social functioning. They also indicate that service users perceived themselves to have experienced some clear benefits from the ESaC services. These relate to two key therapeutic processes: being able to normalise their experiences and feelings, and then being helped to adapt to the physical, emotional and social changes in their lives resulting from their visual impairment. It is suggested that a humanistic model of counselling is particularly well-suited to the work of the ESaC services.

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REFERENCES

- Barr, W., Hodge, S., Leeven, M., Bowen, L., & Knox, P. (2012) 'Emotional Support and Counselling for people with visual impairment: Quantitative findings from a mixed methods pilot study', *Counselling and Psychotherapy Research*.
- Burmedi, D., Becker, S., Heyl, V., Wahl, H. W., & Himmelsbach, I. (2002a) 'Behavioral consequences of age-related low vision', *Visual Impairment Research* 4(1): 15 - 45.
- Burmedi, D., Becker, S., Heyl, V., Wahl, H. W., & Himmelsbach, I. (2002b) 'Emotional and social consequences of age-related low vision', *Visual Impairment Research* 4(1): 47 - 71.
- Bury, M. (1982) 'Chronic illness as biographical disruption', *Sociology of Health & Illness* 4(2): 167-82.
- Bury, M. (1991) 'The sociology of chronic illness: a review of research and prospects', *Sociology of Health & Illness* 13(4): 451-68.
- Cairns, C., Herriotts, P., Douglas, G., Corcoran, C., & Pavey, S. (2009) 'Network 1000 Scotland: A report on the opinions and circumstances of blind and partially sighted people in Scotland', *British Journal of Visual Impairment* 27(3): 239-51.
- Carey, T., Carey, M., Stalker, K., Mullan, R., Murray, L., & Spratt, M. (2007) 'Psychological change from the inside looking out: A qualitative investigation', *Counselling and Psychotherapy Research: Linking research with practice* 7(3): 178 - 87.
- Connell, J., Barkham, M., Stiles, W., Twigg, E., Singleton, N., Evans, O., et al. (2007) 'Distribution of CORE-OM scores in a general population, clinical cut-off points and comparison with the CIS-R.', *British Journal of Psychiatry* 190(6): 9-74.
- Dale, S. (2008) *RNIB Bristol Counselling Project Report: Department of Health Section 64 Funded Project Report October 2005-June 2008*. London: RNIB.
- De Leo, D., Hickey, P., Meneghel, G., & Cantor, C. (1999) 'Blindness, fear of sight loss, and suicide', *Psychosomatics* 40: 339-44.
- Douglas, G., Pavey, S., & Corcoran, C. (2008) *Network 1000. Access to information, services and support for people with visual impairment*. Vision 2020 UK/University of Birmingham.
- Evans, C., Connell, J., Barkham, M., Margison, F., McGrath, G., Mellor-Clark, J., et al. (2002) 'Towards a standardised brief outcome measure: psychometric properties and utility of the CORE—OM', *British Journal of Psychiatry* 180: 51-60.
- Evans, J., Fletcher, A., & Wormald, R. (2007) 'Depression and Anxiety in Visually Impaired Older People', *Ophthalmology* 114(2): 283-8.
- Hodge, S., Barr, W., & Knox, P. (2010) *Evaluation of Emotional Support and Counselling within an Integrated Low Vision Service. Final Report*. Liverpool: University of Liverpool/RNIB.
- Horowitz, A., Reinhardt, J. P., & Boerner, K. (2005) 'The effect of rehabilitation on depression among visually disabled older adults', *Aging & Mental Health* 9(6): 563 - 70.
- Joseph, S. (2010) *Theories of Counselling and Psychotherapy - An Introduction to Different Approaches*. Basingstoke: Palgrave Macmillan.
- King, E. A., Gilson, S. E. L., & Peveler, R. C. (2006) 'Psychosocial needs of elderly visually impaired patients: pilot study of patients' perspectives', *Primary Care Mental Health* 4: 185-97.
- Lam, B., Christ, S., Lee, D., Zheng, D., & Arheart, K. (2008) 'Reported visual impairment and risk of suicide: the 1986-1996 national health interview surveys', *Archives of Ophthalmology* 126(7): 975-80.
- Manthei, R. (2005) 'What can clients tell us about seeking counselling and their experience of it?', *International Journal for the Advancement of Counselling* 4: 541-55.
- McBride, S. (2005) 'Patients with severe sight loss: Emotional support and counselling', *Optometry Today*: 36-7.
- Mitchell, J., & Bradley, C. (2006) 'Quality of life in age-related macular degeneration: a review of the literature', *Health and Quality of Life Outcomes* 4(1): 97.
- Murray, S., McKay, R., & Nieuwoudt, J. (2010) 'Grief and needs of adults with acquired visual impairments', *British Journal of Visual Impairment* 28(2): 78-89.

- Nicholls, T. (2005) *RNIB Bristol Counselling Project Report*. London: Royal National Institute for the Blind.
- Nyman, S., Gosney, M., & Victor, C. (2010a) 'Emotional well-being in people with sight loss: Lessons from the grey literature', *British Journal of Visual Impairment* 28(3): 175-203.
- Nyman, S., Gosney, M., & Victor, C. (2010b) 'Psychosocial impact of visual impairment in working-age adults', *British Journal of Ophthalmology* 94: 1427-31.
- Perren, S., Godfrey, M., & Rowland, N. (2009) 'The long-term effects of counselling: The process and mechanisms that contribute to ongoing change from a user perspective', *Counselling and Psychotherapy Research: Linking research with practice* 9(4): 241 - 9.
- RNIB (2008) *UK Vision Strategy: Setting the direction for eye health and sight loss services*. London: Royal National Institute of Blind People.
- Saunders, A. (2005) *RNIB Emotional Support Telephone Service Evaluation*. London: RNIB.
- Thetford, C., Robinson, J., Mehta, J., Knox, P., & Wong, D. (2008) *Final Report for Thomas Pocklington Trust: The Changing Needs of People with Sight Loss*. Liverpool: Health and Community Care Research Unit, University of Liverpool.
- Thurston, M. (2010) 'An inquiry into the emotional impact of sight loss and the counselling experiences and needs of blind and partially sighted people', *Counselling and Psychotherapy Research: Linking research with practice* 10(1): 3 - 12.
- Thurston, M., Thurston, A., & McLeod, J. (2010) 'Socio-emotional effects of the transition from sight to blindness', *British Journal of Visual Impairment* 28(2): 90-112.
- Tolman, J., Hill, R. D., Kleinschmidt, J. J., & Gregg, C. H. (2005) 'Psychosocial Adaptation to Visual Impairment and Its Relationship to Depressive Affect in Older Adults With Age-Related Macular Degeneration', *The Gerontologist* 45(6): 747-53.
- Vale, D., & Smyth, C. (2002) *Changing the way we think about blindness: myth and reality*. London: RNIB.
- Verstraten, P., Brinkmann, W., Stevens, N., & Schouten, J. (2005) 'Loneliness, adaptation to vision impairment, social support and depression among visually impaired elderly', *International Congress Series* 1282: 317-21.
- Waern, M., Rubenowitz, E., Runeson, B., Skoog, I., Wilhelmson, K., & Allebeck, P. (2002) 'Burden of illness and suicide in elderly people: case-control study', *BMJ* 324(7350): 1355.