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Resilience and vision impairment in older people

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ABSTRACT

Some people fare better than others when faced with adversity; they appear to be more 'resilient'. This article explores the concept of resilience in the context of vision impairment using two linked sets of narrative interview data from 2007 to 2010. Three case studies were analysed in detail using a framework approach based upon a social-ecological model of resilience and vision impairment. Within the model a range of assets and resources are identified which influence an individual's capacity for resilience. A set of criteria were used to establish the extent to which each individual appeared to be resilient at each point in time. Analysis revealed that it is not merely the presence or absence of individual, social, and community resources – but how these resources interact with each other – that influences resilience and can create a risk to wellbeing. To possess only some of these resources is not sufficient; there is a co-dependency between these resources which requires the presence of other resources for resilience to be achieved. Resilience is not a fixed state; individuals can become more or less resilient as their circumstances and resources change over time. We suggest that the concept of resilience has much to offer the field of vision impairment as it allows the identification of enablers as well as areas of barriers to improving people's health and wellbeing and suggests further opportunities for service providers to engage with clients, even those who appear to be supported, as people's social, economic and emotional landscapes continue to change over time, rather than identifying deficit.

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Introduction

In challenging circumstances, some individuals cope better than others; they are seen as 'resilient.' Whilst some people with vision impairment live fulfilled, independent lives despite significant impairment, others have a poor quality of life, even with lesser degrees of impairment (Hernandez Trillo & Dickinson, 2012; Thetford, Robinson,

Knox, Mehta, & Wong, 2011). There are around two million people with a vision impairment in the UK (Access Economics Pty Limited, 2009; RNIB, 2013a), the majority of whom are aged over 60 (RNIB, 2013a). This number is expected to increase to 2.25 million within 10 years, primarily due to population ageing, which is associated with increased burden of vision-related disability. Age is a risk factor for common conditions such as Age-related Macular Degeneration, cataract, glaucoma and diabetic retinopathy (RNIB, 2013a).

Vision impairment has negative impacts upon wellbeing and quality of life (Hernandez Trillo & Dickinson, 2012; Li et al., 2011; McManus & Lord, 2012), mental health (Barr, Hodge, Leeven, Bowen, & Knox, 2012; Hayman et al., 2007; Nyman, Gosney, & Victor, 2010; Thurston, 2010) and social participation (Alma et al., 2011). However, within the vision impaired

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population there is considerable variation in wellbeing and physical and mental health (McManus & Lord, 2012). Vision impairment has multi-faceted impacts upon people's lives; it impacts on functional ability and mobility (both in terms of getting out and about and individual functional mobility), which affects social interaction and psychological wellbeing (Gallagher, Hart, O'Brien, Stevenson, & Jackson, 2011; Grue et al., 2010; Hodge & Eccles, 2013). However, the relationship between severity of impairment and the impact upon wellbeing is not simple (Schilling, Wahl, Horowitz, Reinhardt, & Boerner, 2011); there is a range of influencing factors (Brown & Barrett, 2011). Hernandez Trillo & Dickinson (2012) found non-visual factors including physical and mental health to be better predictors of quality of life in people with a vision impairment than visual function, whilst Tabrett and Latham (2012) reported that personality traits influenced the occurrence of depression in vision impaired people. Amongst older people with vision impairment there is often considerable physical and emotional co-morbidity, which compounds the challenges they face (Court, McClean, Guthrie, Mercer, & Smith, 2014; Thetford, Robinson, Knox, Mehta, & Wong, 2008; Thetford et al., 2011; Thurston, 2010). In this article we consider how the concept of resilience might be applied in the context of vision impairment, in order to better understand how this complex array of individual and social–environmental factors operates to influence individual well-being. We examine two sets of related narrative data, gathered in 2007 and 2010, to explore the experiences of people with vision impairment.

Resilience

Resilience is commonly perceived to be a good outcome despite adversity (Masten, 2001), or the ability to bounce back following adversity (Young, Rogers, Greene, & Daniels, 2011). The concept of resilience offers a way to understand why some people fare better than others, given similar adversity. However, resilience is a contested concept; see Windle (2011) for a review and concept analysis. In the past, some conceptualisations have neglected the social processes which create risk (Ungar, 2012). This fails to recognise social and environmental factors and the relationships and networks which influence how individuals cope with adversity. However, there is now an emerging body of work, including the development of a 'social ecological' model of resilience, which recognises that social and environmental factors are at least as important as individual personality traits in determining resilience (Donnellan, Bennett, & Soulsby, 2015; Ungar, 2012; Young et al., 2011). This perspective makes clear that responsibility for optimising the resilience of individuals rests as much with the society in which they live as with the individuals themselves.

A growing interest in the value of resilience in healthy ageing has led to a number of studies seeking to explore resilience amongst older people (Gattuso, 2003; Hildon, Montgomery, Blane, Wiggins, & Netuveli, 2010; Hildon, Smith, Netuveli, & Blane, 2008; Wild, Wiles, & Allen, 2013; Wiles, Wild, Kerse, & Allen, 2012; Windle, 2012). Harris (2008) suggested that 'successful ageing' is the wrong goal and that we should instead be focusing upon striving for resilience in old age. Harris's argument has particular pertinence in the context of vision impairment; sight loss disproportionately affects older people, who also face other age-related health and social

challenges, but within models of successful ageing, there is a focus on prevention and avoidance of disability and ill-health (Harris, 2008). Resilience challenges the idea that poor health or disability, such as that resulting from vision impairment, cannot mean living well in old age (Hildon et al., 2010).

Windle's (2011) definition of resilience recognises individual characteristics and the social and environmental factors which influence resilience: "Resilience is the process of effectively negotiating, adapting to, or managing significant sources of stress or trauma. Assets and resources within the individual, their life and environment facilitate this capacity for adaptation and 'bouncing back' in the face of adversity" (Windle, 2011: p. 163). Windle and Bennett (2011: p. 220) represent the relationships between these resources in a model of resilience within caring relationships, highlighting the relationships between the challenges individuals face, the resources a person has (society, community and individual resources), how each of these relate to each other, and the consequences, or outcome of this (resilience, compromised wellbeing or further challenges). Whilst Windle's (2011) definition recognises resilience as a *process* rather than a stable personality trait or characteristic, it can also be conceptualised as an outcome that results from the adoption of a particular outlook or response to a combination of circumstances (Bennett, 2010; Donnellan et al., 2015).

Drawing on Bennett's idea of resilience as a process, we explore the concept in the context of vision impairment in older people, through the analysis of in-depth longitudinal data. Taking a social–ecological approach, we examine the impact of, and relationships between, a range of social, community and individual resources which may determine an individual's capacity for resilience.

Supports and services for people with vision impairment in the UK: a brief overview

Provision of support for people with vision impairment in the UK is varied and somewhat complex. A range of financial supports and concessions are available dependent on individual and means-tested circumstances (RNIB, 2013b). Services may be provided by statutory providers; predominantly Local Authority services that provide rehabilitation assessments and services after individuals have been certified as Sight Impaired (SI) or Severely Sight Impaired (SSI) by a Consultant Ophthalmologist and placed on the Local Authority Register. In some areas, Local Authorities may commission other providers, including voluntary organisations, to provide these services. The amount and type of services offered vary by the Local Authority, as well as by an individual's assessed entitlements. However, services offered may include: rehabilitation (including mobility training and life skills); aids and adaptations to the home; help with personal care (such as bathing, getting up and going to bed); help with shopping; answering correspondence; cleaning; and help with cooking. Often, statutory services are supplemented by national and local voluntary organisations which provide services, some of which are free and some of which they charge for. In some areas there are now emotional support services, though during the period of data collection a formal counselling service was not available in the areas from which participants were recruited.

Method

In-depth analysis was carried out on three cases from a sample of data from two linked studies which used qualitative interviews with people with a vision impairment to explore experiences of sight loss over time (cite author's work 2011, 2013, 2015). In the first study (Thetford et al., 2008; Thetford et al., 2011; Hodge et al., in press; Hodge et al., 2013) narrative interviews were conducted using the Biographical Narrative Interpretive Method (BNIM) (Wengraf, 2005) which uses a single question to elicit a narrative response. After providing a background to the project, the participant was advised of the style of interview and the type of information we were interested in. They were then presented with the single question to induce a narrative response: "can you tell me about your story of sight loss, including all those events and experiences which were important for you, and what emotional and practical support you received during this time?" In the second, follow-up study with the same cohort three years later, semi-structured interviews (Mason & Dale, 2011; Silverman, 2011) were used to explore how their lives had changed (Hodge et al., in press; Hodge et al., 2013). The topic guides for these interviews were developed based upon the findings of the first study, and from key issues and events identified from each individual's first interview. These interviewing methods produced rich data which enabled participants to construct their own narratives of experiences of sight loss and use of services, identifying salient issues in a way meaningful to them. The interviews provided 'thick descriptions' (Geertz, 1973) of the social and cultural contexts within which these individuals lived, and as such allowed us to explore the relationships between the resources which influenced their capacity to be resilient but also to consider the transferability of our findings to other settings (Lincoln & Guba, 1985). These interviews did not set out to elicit data on resilience; data analysis revealed resilience to be a theme which emerged from the experiences described.

Thirty-seven participants were recruited to the first study through voluntary organisations working with people with vision impairment. Informed consent was obtained, along with consent to contact them to invite them to participate in the follow-up study. In the second study, 21 (57%) of the original sample were re-interviewed. Of the other 16, six declined to take part, eight had died and two were untraceable. All interviews were digitally recorded and transcribed verbatim.

Data from three cases are presented here from interviews at two points in time. A selection of a small number of cases permitted a truly in-depth analysis of the data. The three cases were selected on the basis of their ability to facilitate a comparison of the experience of very similar eye disease (all three cases had wet AMD and cataracts and similar levels of vision impairment). However, it was important that they each had different social, individual and community circumstances to allow comparison of the impact of and relationships between these resources.

These data were previously analysed with a thematic approach (Coffey & Atkinson, 1996; Silverman, 2012) and are reported elsewhere as part of the larger data sets (Thetford et al., 2008; Thetford et al., 2011; Hodge et al., in press; Hodge et al., 2013). This work was used to inform the development of a model of resilience specific to vision impairment based on Windle and Bennett's (2011) model of resilience in caring

relationships (Fig. 1). This model was then used to undertake a 'framework approach', similar to that described by Richie and Spencer (2002), Smith and Firth (2011) and Pope, Ziebland, and Mays (2000).

Each case was examined to explore the experiences and impacts of vision loss upon the lives of these three individuals. The model components were used to assess each case; associations between themes were explored, and accounts developed. The cases selected did not permit exploration of every aspect of the model which was designed to accommodate most individuals with vision impairment. For example, none of the cases discussed having a guide dog. Also, we were not able to make full comparisons about ethnicity as all three cases were White and, the neighbourhoods they lived in were predominantly White, though this characteristic is noted and taken into consideration. One participant however did originate from mainland Europe and this is noted in the contextual information.

An assessment of whether each individual was resilient or not was made using Bennett's (2010) four criteria for resilience at each point in time and all criteria had to be met to be considered resilient. Therefore participants had to: (a) view their current life positively; (b) be actively participating in life; (c) return to or maintain a life that has meaning or satisfaction; and (d) be coping and not be distressed. See also Donnellan et al. (2015).

Where individual cases or issues within cases did not appear to fit emerging themes, these were used to refine themes and findings (Patton, 1999). A collaborative approach was taken between the researchers to explore alternative interpretations of the data, particularly in making judgements about whether individuals were resilient or not. The majority of the analysis was conducted by the first author who was responsible for the collection of one set of the interview data. One of the other researchers involved in the analysis was responsible for the collection of the second set. Through detailed discussions, contextual details and analytical meanings were verified. This triangulation of analysis provided a check on selective perception and facilitated multiple approaches to understanding the data (Lincoln & Guba, 1985).

Findings

The nature of the interviews allowed participants to identify issues of greatest salience to them, with no set topic areas. However, many of the issues raised by the different participants were similar, and this allowed us to compare and contrast the data using the model in Fig. 1. We present the findings here, providing contextual information about each individual.

Eva, Isabel and James had wet Age-related Macular Degeneration (AMD) (Lim, Mitchell, Seddon, Holz, & Wong, 2012) a common condition which affects central vision, potentially causing considerable loss of visual function (Wong et al., 2014). Visual deterioration from wet AMD can occur rapidly and, in most cases, eventually affects both eyes. Until relatively recently it was essentially untreatable. All three participants had received laser treatment for their AMD; James and Isabel had also received the more effective anti-VEGF treatment (Lucentis injections) (Lim et al., 2012). At the time of the first interviews, treatment options available through the National Health Service were limited to laser treatment, though

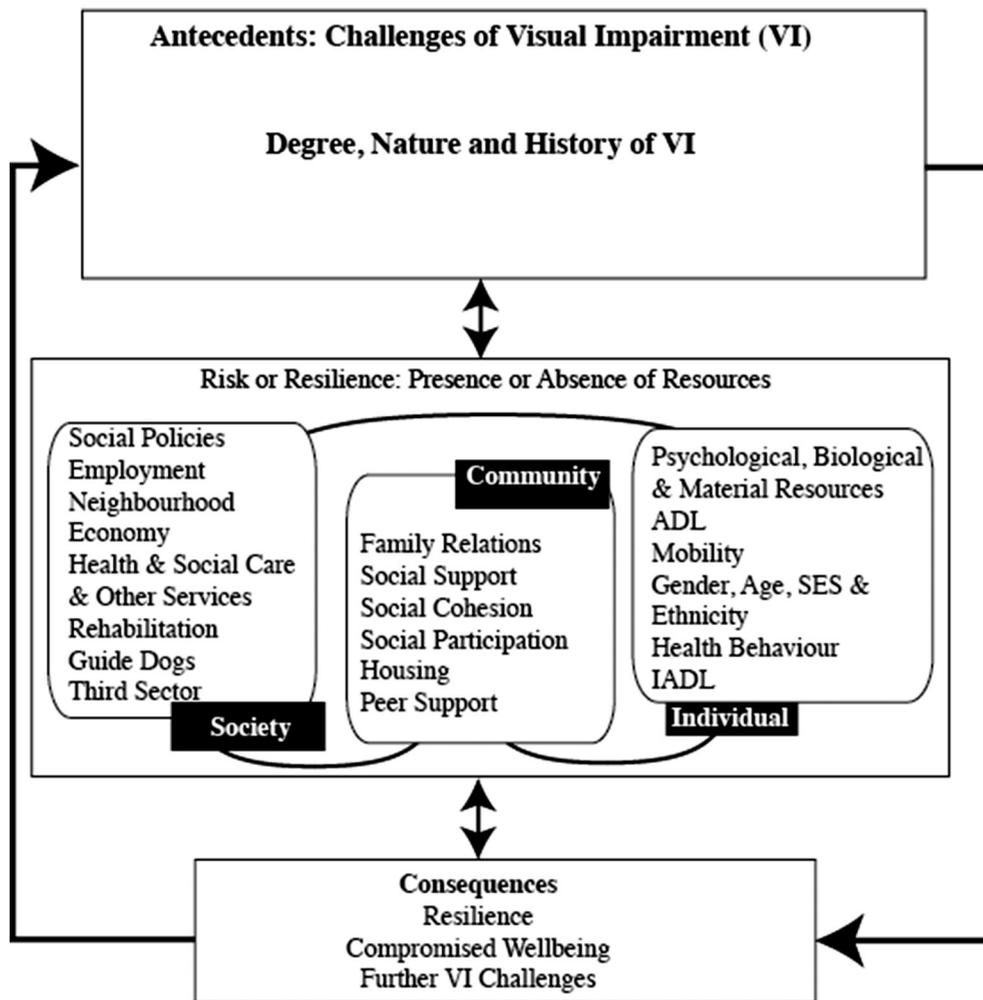


Fig. 1. The resilience framework applied to visual impairment. Adapted from [Windle and Bennett \(2011\)](#) 'Biological resources' includes genetic resources. In the cases examined, only physical health was considered, however, the model includes the wider 'biological resources' in order to capture issues surrounding genetic conditions. ADL and IADL: activities of daily living and instrumental activities of daily living. The difference is that activities of daily living are basic activities, such as getting out of bed, going to the toilet, dressing, eating, and personal care. Instrumental activities are higher level activities once ADLs have been achieved, and include things such as shopping, banking, and driving.

James had received anti-VEGF treatment as part of a clinical trial after several laser treatments. In the second interview Isabel reported having received anti-VEGF treatment, also after having laser treatment. In all cases, treatment for AMD had ceased as it no longer offered benefit. All three also had cataracts, compounding their visual problems; at the time of the second interview, Isabel was expecting her cataracts to be treated soon, whilst Eva had been advised that hers would not be treated yet; James had not received any treatment for his. Isabel and James reported being registered as Severely Sight Impaired in their first interview. Eva had recently been registered as Sight Impaired at her first interview, and this remained the same at her second interview after having regular ophthalmic reviews between interviews, suggesting that her vision impairment was not as severe as that of Isabel or James.

A brief synopsis of each case is provided for context. Each case is then considered in relation to the resilience and vision impairment model ([Fig. 1](#)) and an assessment is made about whether they are resilient or not using [Bennett's \(2010\)](#)

criteria. Ages presented are at second interview. Interview 1 or 2 is indicated after the quote as T1 or T2.

Eva (age 75)

Eva was originally from Germany and lived with her husband in a comfortable suburban home in northern England. She had two adult children, one of whom lived in Germany, and the other a short drive away who she saw reasonably regularly. Prior to her vision loss, she and her husband had their own business, though her eye condition had forced her to give this up, which was one of a number of things she reported to feel sad to have lost as a result of her vision impairment. In both interviews Eva reported heavy dependence on her husband for support and increasing withdrawal from everyday activities. In her first interview she reported losing confidence and reduced social activities:

"I'm always worried about opening the door because I cannot see the faces and, you know, when you just really

don't know, especially when say the electric, people coming to read the meters and things like that." (T1)

"I'm not terribly happy about going on buses and things like that to travel round. So I probably just wouldn't, I just wouldn't travel if it wasn't for [husband]." (T1)

In her second interview, these issues appeared to have intensified and she spoke about increasing isolation and withdrawal from social and family activities:

"I never go out on my own because I can't recognise people and that is embarrassing as well. They must think that I don't want to speak to them." (T2)

"I don't like going out very much anymore because I cannot see what I've got on my plate when I eat and I find it very embarrassing." (T2)

By then her physical health had also deteriorated, creating some mobility problems:

"It's quite painful I can't stand for any length of time or walking is quite painful for when I am out I have got to always find somewhere where I can sit down. I have got it [arthritis] in both hips and in my lower spine now, yes that was established earlier this year I think I had an X-ray and they did that because I had constant back pain." (T2)

At the time of her first interview, Eva only kept in touch with voluntary organisations through newsletters, and rarely had personal contact. She was aware of sources of support available, such as peer groups and rehabilitation training, but she felt they were not for her, particularly as she had a supportive husband; she considered these services to be for people whose vision was worse than her own and who lived alone:

"I have got [husband] here so, you know, I feel secure." (T1)

When asked if she had completed any rehabilitation training, Eva explained she had not, reasoning that she had her husband to assist her, though she also suggested that she would need to feel more confident before undertaking it:

"No, no they [voluntary organisation] haven't [provided rehabilitation/training]. Possibly because [husband] is around. Again, if I was probably living on my own there probably would be something. I don't know, maybe it's just me, I perhaps need to be a little bit more confident or something." (T1)

By her second interview, Eva reported that she had been offered training in how to use computers several times but had declined it:

"They keep saying to me why don't you go and in [voluntary organisation] they teach you how to use the computer, I said well what's the point I can't see the screen and you know I have difficulty with the, with the buttons. They said, well we teach you how to use the buttons, instead of a picture screen

you have a talking screen. To be quite honest I am not terribly interested in it. [Husband] gets all the information." (T2)

The quote above suggests that service providers have recognised that Eva has needs for intervention as it seemed that they had made these offers of training on more than one occasion. There was also evidence in her second interview that other people who knew her had also encouraged her to do more to regain some of her independence, including her daughter. However, her husband has offered a different form of assistance, in the form of someone doing tasks for her rather than enabling her to do things for herself which was what she wanted:

"I think she [daughter] has probably got an attitude, she doesn't want me to sit down and do nothing so she probably encourages me to struggle rather than, but if it's something we, I really need then she will and yes but I don't have, [husband] keeps saying would you like somebody to come in to clean, you know come and clean the house, and well I don't think I have reached that stage just yet, so there might, depending on how bad it goes and I don't sort of have any other support." (T2)

It was not clear from the data however, exactly what prevented Eva from accepting the varying forms of support on offer to her and which, by her second interview, she had been encouraged to accept. In particular, she did not want to take part in social activities she once enjoyed due to the difficulties presented by her vision impairment:

"I feel, I have sort of withdrawn a little bit more. I probably still enjoyed going out not much but more than I do now. I have got no urgency in my going out." T2

She was also struggling to come to terms with no longer being able to do certain things:

"I just feel stupid sometimes. I keep saying well for goodness sake I ran two businesses at one stage and I took care of the house, and you know everything and then suddenly it's sort of like it's wiped from under your feet." (T2)

In any case, services had not found a way to engage with her or had not offered her a service which met her requirements and thus her needs for support remained unmet as a result. Although her Sight Impaired registration status indicated that she had the most functional vision of the three individuals (the others were registered as Severely Sight Impaired), and her health problems were not reported to be as serious as James's, her sight loss was having a considerable negative effect on her wellbeing and quality of life. Eva reported struggling with everyday tasks and, as a consequence, was increasingly frustrated and feeling down. She perceived that her problems lay in no longer being able to do the things she used to do because of her vision loss and being reliant on her husband. She did appear to recognise the value of rehabilitation services which might enable her to be more independent; her accounts suggest that it was the loss of her sense of independence which was the cause of her emotional problems and loss of confidence:

"I've always been independent and, you know, I used to do so much and then sort of, having really knocked from under your feet." (T1)

Whilst she declined offers of assistance to learn new skills or join peer support groups, she also described herself as 'determined'. This was one area which suggested that whilst she was not resilient at that point, there was potential for resilience:

"I struggle, even though I don't do things perfect any more, I struggle doing it because otherwise I'd go round the twist if I just had to sit here with absolutely nothing to do." (T2)

Eva indicated that she felt that her family were not always sensitive to her emotional needs, despite the considerable practical support they provided. Thus whilst she seemingly had a great deal of support, her over-dependence upon this appeared to be having a negative impact upon her psychological wellbeing and her emotional needs were unmet:

"What is also frustrating is I can't, anybody sending pictures on the computers, he [husband] says, oh I have got a picture here, he will turn around the next minute and say, well you won't be able to see it anyway. And I don't even look at it, and well my daughter just come back from holiday, or we have been on holiday and they all go on computers now don't they, with the pictures, they all get together and I just sit by the side because I know I can't see it, and I feel like crying sometimes." (T2)

Without intervention, Eva was vulnerable because of her heavy dependency on her husband, and was in a 'spiral of decline' associated with reduced everyday activities and social interaction which impact on psychological wellbeing (Hodge & Eccles, 2013).

In assessing whether or not Eva was resilient using Bennett's (2010) criteria, the data from Eva's interview presented conflicting evidence and was the source of considerable debate amongst the research team. We concluded that she was not resilient in either her first or second interview, though she showed potential for resilience as she had a range of resources to draw upon, as well as a sense of determination. Her account reflected decline over time as her vision impairment worsened and physical health deteriorated slightly, and she became less resilient. In neither her first nor second interview did she describe feeling positive about life. Instead, she described a sense of loss. However, not all of her account was negative; she spoke of being thankful that she had a supportive husband:

"I am just sort of accepting that I am limited, that I won't ever be able to do the things that I have done, and I have just got to live with it, and I am just so fortunate that I have got my husband around because for people who are on their own completely it must be, must be dreadful." (T2)

Eva had not 'bounced back' and 'returned to a life with meaning or satisfaction' and instead reported ongoing and increasing emotional problems:

"You get very low moments, so I think you reminisce and you probably think about what you have been able to do and the curtailment now..." (T2)

However, Eva had a range of resources which would support resilience, including offers of rehabilitation, a supportive husband, financial support, and psychological determination. However, her over-reliance on the support provided by her husband may in fact have been contributing to her declining emotional wellbeing. Thus whilst the support he provided could be considered a resource which might help support resilience, it may also be conceived as a barrier to enabling resilience because of the way it interacted with Eva's psychological resources.

Eva had not taken up offers of rehabilitation which would likely have positive impacts on a range of other resources, such as social participation, activities of daily living, and mobility. The reasons for this remain unclear; they may be the result of a lack of awareness and understanding of rehabilitation, or perhaps associated with her current emotional state and reduced confidence, and possibly age-related cultural beliefs and expectations surrounding service provision and utilisation (Mackenzie, Scott, Mather, & Sareen, 2008; Walters, Iliffe, & Orrell, 2001). In any case, it appears that she would benefit from intervention to enable her to mobilise some of these resources and prevent further deterioration. Additionally, interventions may need to involve her husband in order to prevent the support he offers from having a negative impact.

Isabel (age 80)

At the time of her first interview Isabel lived with her husband, whom she cared for, in a comfortable middle-class village home in a rural area of northern England. However, by the time of her second interview her husband had died.

Isabel's vision impairment was severe (she was registered as Severely Sight Impaired) and she reported that it created a number of difficulties for her because of what she could no longer do:

"I was a big reader but I also had quite a few hobbies. I used to do tapestry work and I did needlework, I could make things, I used to knit, I did puzzles and not crosswords I was never into crosswords, but puzzle books." (T2)

However, Isabel spoke only briefly about the things she could not do and the difficulties she faced. Instead, her narrative was dominated by details of how she had sought and developed strategies, services and solutions to prevent the challenges of vision impairment stopping her from doing what she wanted. In particular, Isabel spoke a great deal about transportation issues in her rural community, which were compounded by her declining physical health:

"I get a lot of back pain. And I had an X-ray early last year and I have got bone thinning and arthritis in my spine, at the lower part, erm and I find that if, well I have only got to carry the shopping in off the doorstep cause the Royal Support

Driver brings the shopping and puts it on the doorstep and I bring it in bag by bag and I have only got to carry the bag from there into the kitchen and if it's heavy I know all about it. Erm, so I mean I couldn't possibly carry heavy shopping from the village." (T2)

Isabel facilitated her busy social life by making use of a range of external supports including community transport, shopping services, rehabilitation, and peer support groups.

"I go to the Macular [support group] once a month, and from September to June I belong to a sort of club in the village where we meet once a month for about an hour and a half in one afternoon and we all take it in turns, four of us at a time of actually running the meeting, getting a speaker, and you know just doing it generally, getting the tables and chairs out, making the tea, taking the biscuits and which is quite nice actually because you get to talk to other people and it's an out." (T1)

Though they had the financial resources to pay for more help with care and support around the home, her husband had been resistant to external support, which Isabel reported restricted what she could do:

"We have a cleaning lady comes in for two hours a week which we pay for ourselves, we found her ourselves. And we have a chap that helps look after the garden because we were both keen gardeners we used to do it all ourselves, but we can't do it now, so he comes in for an hour a week and cuts the grass and tidies up and does what he can, but that is about it. I think I sometimes feel I could do with some space.... I have spent so much time dealing with [his] Parkinson's and everything that goes with it I tended not to do very much for me." (T1)

Isabel was coping at this time, though reported some emotional problems for which she had unsuccessfully sought help:

"I did get depressed, again there was nobody really to talk to and my husband had made contact with the community mental health people who were actually visiting him but the lady that came when she was talking to me, and I think she realised that I needed perhaps a bit of help or somebody to talk to me, so she was going to come and see me but before the appointment time she was told she wasn't allowed to."

After her husband's death, Isabel reported that although she had experienced a couple of difficult years, she had more recently found a new lease of life:

"The first two years after my husband died it was a very dreary time and just not good.... During the last 12 months my horizons have brightened and widened, life is much more worthwhile living." (T2)

"I rang up the Community Car Service and got transport which was, I mean that was a great help because to get to [voluntary organisation] which is the other side of [city]. I can get the bus into [city] but then when I get into [city] I have got to have a taxi. Yes, so that the Community Car

Service was a bonus, I mean it really was. So that was fine I went along to the Activities Club and joined it and that, I mean that has really broadened horizons for me because in the summertime we were out and about [day trips]." (T2)

Isabel had been on holidays alone and had days out with friends; she reported feeling determined despite describing herself as shy:

"I was very brave after my husband died. I decided if I didn't get on and do something I wouldn't do it, so I actually booked to go down to Cornwall, to the hotel that my husband and I had been to which was run by [voluntary organisation] I think. I got, my daughter booked me on the train and booked assistance for me, I had to change at Birmingham, which was a bit daunting." (T2)

Although the oldest of the three people considered here, Isabel appeared to be coping well, and by her second interview was viewing life positively. Unlike the other two, she lived alone and did not have other people readily available to provide a great deal of support. Despite facing a number of challenges, including severe vision impairment, physical health problems and mobility issues, Isabel identified various forms of support and mobilised resources to do what she wanted. She had times when her sight loss and other problems made her feel down and impacted on her wellbeing, though she overcame these by using her financial resources, community transport services, shopping services and rehabilitation training. She recognised her vulnerabilities and dependency on community transport services however, as these services had been threatened due to cuts:

"I don't know what I would do without that [bus service] to be perfectly honest because we have got the [convenience] shop down the road, it means having to carry shopping home which I have got other problems that I can't carry heavy things anymore." (T2)

Isabel reported emotional problems at her first interview. Some of these were associated with not being able to do what she wanted, and struggling to accept different aspects of her vision impairment. At her second interview she had mobilised a range of resources to enable her to live independently and achieve a good sense of wellbeing. She was making plans for the future, including another holiday.

Despite facing considerable challenges, and having times when she felt very down and in need of more support than was available to her, she identified and made use of a range of supports and services that enabled her to continue to live independently and undertake the activities that were important to her sense of wellbeing. She had a range of individual, community and social resources available which she identified and mobilised, each reinforcing the other to facilitate her resilience.

Isabel saw her daughter at weekends, who took her to places she needed to go, as well as providing assistance with form-filling and travel booking. Isabel accessed support from her daughter and son-in-law on her own terms, ensuring that this enabled her to live independently, rather than them doing things for her:

"I might make enquiries about getting somebody to come and help me with this paperwork. I feel it's unfair to load my

daughter with it. My son-in-law is at home now, he is retired but there are certain things I don't want him to know about. And it's better to have a stranger to deal with things like that, finances and personal things." (T2)

This approach is in contrast to Eva, who appeared to have retained little personal control over her life and how she was supported.

At her first interview Isabel was coping and exhibited traits of resilience (Bennett, 2010); despite her vision impairment and health problems, she maintained a social life even if it was not as full as she would have liked, she was coping well, and managing to continue to live independently. Isabel did, however, report emotional problems amongst other difficulties, becoming quite distressed at times. Although she had resources available to her, she was not able to make the most of these because of her role caring for her husband. By the time of her second interview, however, Isabel's life had changed as she was now alone and although she no longer had support from her husband, whom she missed, she had become resilient through the mobilisation of resources and was able to do other things which gave her life more meaning. She viewed her life positively and was actively taking part in a range of activities and was looking forward to the future.

James (age 75)

James and his wife lived in a modest house in a working class suburban area, with a large proportion of council (state) housing and he reported financial difficulties. At his first interview his physical health and vision were poor, though he remained reasonably optimistic and stoic in his outlook, despite considerable challenges:

"It's very, very difficult, especially when you have got more than one problem, I suffer with COPD [chronic obstructive pulmonary disease], and angina. I can't bend down because I have got hiatus hernia. In my ankles I suffer with cellulitis." (T1)

"[The doctor said] I have got good news for you, your blood pressure is all right. I must have looked funny at him and he said, what's that for? And I said, well that is just being in a six car crash and the fitter saying your windscreen wipers are still working. He always says to me, don't lose your sense of humour, it's the one thing you've got left. I said, well once that goes you might as well cut your throat." (T1)

James reported his vision impairment to be severe, and he was registered as Severely Sight Impaired. He detailed a range of ways in which his vision impairment made everyday life increasingly difficult. These include not being able to read and tasks which require dexterity:

"Even with the glasses it's got to the stage now where I can't manage at all. It's gone worse... 12 months ago I could use that to read, now it's a waste of time." (T2)

"I have... two little drawers, just pliers and screwdrivers and little bits and pieces, it took me three hours to put a plug on the other day. I can do it because I know how and I've

spent my lifetime engineering as I say but, it is so difficult and you've got to get it right and it's no good guessing, it's got to be right." (T2)

His low vision also caused him problems socially as he was not able to recognise people, and was unable to differentiate male and female toilets when out alone:

"I get very embarrassed, do you know when you go into The [hospital], you know how busy the front vestibule is, there's a ladies and gents and I go through, I know where to go through to the left to go through to [eye clinic], well I wanted to go to the toilet one day as I went in, after the ambulance had picked me up and I'm outside feeling the things on the doors to see if it's a ladies or gents and you feel awfully embarrassed when a lady opens the door and comes out and wonders what you're doing standing there feeling the door you know, when you're trying to make out whether it's a lady or a gent on the door." (T2)

James had a range of physical health problems which combined with his vision impairment to compound the challenges he faced. This is exemplified here in terms of his mobility around the home:

"I can go upstairs better than I can come down. I have great difficulty coming downstairs, partly because of my vision and partly because of my gout, I can't feel the stairs, I've lost all the sense. All the nerves in my feet have gone as well, that doesn't help." (T2)

James and his wife helped each other, despite their own individual problems. In his first interview, James described how his wife had accompanied him on trips to the eye clinic despite being in poor health herself:

"She will come with me to look after me, and by the time we leave here at eight-thirty in the morning to get there, we don't come out of there sometimes until five-thirty. It was killing her, it was a long day" (because of her diabetes). (T1)

By the time of his second interview his vision and health problems were worse and he had considerable mobility problems. He also reported that his wife was terminally ill and they were struggling to cope with a range of unmet support needs:

"She is supposed to be my carer and she can't get anything for me because she's got a pension herself. Look at the state of her. The pair of us are like that, we need somebody to help us. I can't manage to do the things I need to do because I can't see either." (T2)

James was determined to make the best of his lost but was feeling as though everything had gone wrong:

"We've had a rough time the last few years, everything's fell on us, everything's fell in on us. It's been very bad... everything that's happened has been rotten for us." (T2)

Compared with Eva and Isabel, James lacked a range of resources which might have enabled him to be more resilient. He did not have financial resources which might have made

some of his mobility problems easier to manage, or pay for help around the home. As a result, he was dependent upon welfare provision, which was restricted and at the time of his second interview, he reported these supports were inadequate to meet his needs. Whilst he had support from his daughters who also had their own families to care for, though their efforts were increasingly concentrated upon James' wife as her needs had increased.

James recognised the value of support available to him through peer support groups, though his physical health, mobility issues, financial problems and vision impairment prevented him from joining one at the time of his first interview:

“I know they have a Breakfast Club every couple of weeks in [town]. I haven't been able to get there because I haven't been well enough to be honest, and you can't go up there sitting coughing, so you know, I would be only too glad to go and get, come when I feel well, go and get dressed and, decent clothes on and go up and have an hour there and talk to people. It would be lovely.” (T1)

“The way it's been since I got rid of the car it's costing me that much in taxis to go shopping and everything it doesn't leave a lot for socialising.” (T1)

James applied for benefits to help to pay for additional transport costs with the assistance of a local organisation:

“I am hoping that maybe with a little bit of luck it will give me enough to be able to afford transport to get into town to go to coffee mornings with people with low vision and things like this, and maybe get a, I haven't been able to, I haven't been to a pub for a drink in five or six years because I can't walk that far.” (T1)

By his second interview he had managed to attend and develop positive relationships at a peer support group through this financial assistance, though had not been going as much as he would have liked because of his caring responsibilities and his own poor health:

“You get a lot of things you wouldn't get anywhere else, you get a lot of friendship. Even the girls put their arm around your shoulder and talk to you, you know and you know who you are talking to. They all trust each other, they're lovely. You feel comfortable.” (T2)

“I ring up very often to the Tuesday club and say 'I'm not coming' and they know it's not me and I'm not well, it's because I won't leave the wife.” (T2)

James also recognised the value of learning new skills as his mobility problems and vision impairment increased, and had begun rehabilitation training. Again, his ability to undertake activities was restricted by his other problems but the training provided took account of this:

“They can do training, they are teaching me to touch type, because they know that I'm in a position where I won't be able to walk and I'm getting more housebound all the time.” (T2)

James faced many challenges, which in combination were having a hugely detrimental effect upon his wellbeing and quality of life. Whilst his health and vision conditions could no longer be treated effectively, his narrative suggests that if further support were available which not only took account of his individual situation, but also considered he and his wife as a unit, the effects of these conditions upon their lives might be mitigated. With the benefit of financial support, gained with the help of a voluntary organisation, James had been enabled to attend a peer support group, though because his caring responsibilities were not considered, the value of this had been all but lost. Vision loss had interacted with a number of other aspects of James' life to have an overwhelmingly negative impact on his quality of life and wellbeing. James had sought support from a range of sources, mobilising the resources available to minimise some of the effects of the multiple challenges he faced, though the scale and number of problems had created an unmet need for support, and had a consequent negative impact on his wellbeing.

Whilst Isabel was able to draw upon a range of resources which reinforced each other to enable and facilitate resilience, James' lack of resources meant that he was less able to be resilient, despite his stoicism and determination. Although he had received some help with particular challenges, such as financial support to enable him to attend social groups, his lack of resources in other areas, such as poor health and insufficient social support to assist with caring responsibilities, meant that he was not able to benefit from this, demonstrating that the relationship between these resources can also work negatively.

At his first interview, although lacking in many resources and faced with considerable challenges, particularly relating to physical health and a lack of financial resources, James had a more positive, optimistic outlook and a stoic approach to adversity. However, by his second interview, although some additional supports had been put in place, the adversities he faced had increased and compounded. Not only had his vision and health deteriorated further, but his wife's terminal illness in combination with all their other needs was of particular concern:

“The daughters do the shopping when they're well and things like that. I try to get the grandkids to come round and help me with the garden and things, but you know, even with the house, I mean she can't manage. It takes her all her time to get up the stairs to the bathroom or in the kitchen.” (T2)

This meant that he was unable to attend the peer support groups and was withdrawing socially. His sense of coping, hope, and satisfaction with life that was present at his first interview was no longer present. His wife was no longer able to offer him support; indeed he had now become her carer and they were at breaking point as they both had significant needs but did not feel that they had sufficient support from either formal or informal sources. He was becoming increasingly distressed and reported a strong sense of loss:

“I've gone through a lot in my life, in 75 years I've been and done and struggled, but I tell you, to lose your sight, you lose your independence and everything. You lose so much more. It's not just being able to help yourself, you lose a lot of

understanding too because you can't see what's going on around you, you really do miss that."

Discussion and conclusions

Although there are similarities between the three participants discussed here, in terms of age and degree of vision impairment, the impact of their sight loss upon wellbeing and quality of life was experienced and perceived quite differently by each individual.

Whilst Isabel displayed resilience, and had endured difficult times, she was able to mobilise her resources to tackle the challenges presented not only by her sight loss, but also by her physical health problems, mobility issues and widowhood. She was the eldest of the three, registered as Severely Sight Impaired and lived alone. With these 'risk' characteristics, it might have been expected that she would struggle most and the impact of sight loss would be greatest, however that was not the case. Indeed, particularly by her second interview, Isabel reported a strong sense of wellbeing and quality of life.

Eva had some health problems which compounded the issues around her sight loss, and she spoke of some financial constraints, though she lived reasonably comfortably with a husband who appeared to be willing to offer a great deal of support. She had access to a range of resources which could enable more independence and prevent further decline. However, she had not mobilised these resources to facilitate the independent life and sense of personal control that she reported she desired. Whilst the reasons for this are unclear, it may have been that her over-dependence on her husband's support was impacting negatively on her psychological wellbeing, which in turn reduced her motivation to make the most of other resources available to her.

James initially had a stoic and hopeful outlook on life, often reconciling adversity with humour. However, his vision loss was considerable and he reported this as limiting what he could do, particularly in combination with serious and limiting physical health problems; a finding reflected in the wider sample (Thetford et al., 2008; Thetford et al., 2011; Hodge et al., *in press*; Hodge et al., 2013). Whilst he had some resources, he had not been able to make the most of these, particularly by his second interview because of his deteriorating health, mobility and transport issues but also his caring responsibilities as his wife became terminally ill. Again, this reflects the inter-relatedness of resources; problems in one domain of life can have multiple impacts in other domains.

These cases demonstrate that it is not merely the presence or absence of resources that impacts on resilience, but how the individual reacts with the resources they have available and how the resources may interact with each other, as shown in Windle and Bennett's (2011) model of resilience (Fig. 1), which stresses the inter-connectedness of the resources required to achieve resilience. These cases also demonstrate that a range of resources, including individual, community and social resources are required. To be effective in achieving a resilient outcome, some resources require the presence of other resources. For example, in his first interview James had support from his daughters and despite considerable adversity he had a determined, stoic outlook. However, a lack of other types of

resources (including good health and sufficient health and social care support) meant he was unable to mobilise some of these resources (such as rehabilitation and peer groups) and that what he had was simply not enough. By the time of his second interview, the enormity of the challenges he faced in relation to the resources he had was too much and he was becoming overwhelmed. Although according to Bennett's criteria (2010), James was not resilient at his first interview, he did have some resilient qualities and potential to achieve resilience. By his second interview, his health and other influencing factors had deteriorated and so too had his capacity for resilience. However, this does not necessarily mean that he (and Eva, who was also not resilient) could not 'bounce back' and achieve resilience in the future. The analysis presented here has shown that resilience as an outcome is not a fixed or permanent state and can vary over time. With a change in circumstances, or the right kind of support – or, a 'turning point' (Bennett, 2010), these individuals may become resilient in the future, as demonstrated by Isabel, whose circumstances changed positively.

For Eva there was little change in her risks and resources, only some deterioration, which was reflected in her account of her quality of life and wellbeing. For James, there was deterioration in his health and wellbeing but also in his social and emotional circumstances. For Isabel, whilst the loss of her husband was profound, it also meant that many of the barriers which prevented her from mobilising resources to enable resilience were removed.

Like Bennet and Windle's (*in press*) commentary on Kalisch, Müller, and Tüscher (2014) we explored the factors that were required to be resilient (where resilience is defined as an outcome). Similar to Donnellan et al. (2015) these cases revealed a range of factors which 'facilitate' and 'hinder' the ability of individuals to achieve resilience. However, as reported by Donnellan et al. (2015), access to resources is not enough to achieve a resilient outcome; individuals have to be motivated to utilise the resources available to them. In Eva's case, whilst she had a range of resources and supports available to her, such as offers of computer training, material resources, transport, and reasonable physical health, she did not make use of these, perhaps due to poor psychological wellbeing. Eva's over-reliance on one of her resources (her husband) may have contributed to her poor psychological wellbeing. Thus what may appear to be a resource to enable resilience, may in fact serve as a barrier.

As an analytical tool that can help us to develop an understanding of the experiences of people with vision impairment, the majority of whom are older and face increasing physical and other challenges associated with ageing, the concept of resilience has much to offer. It enables us to identify strengths as well as weaknesses, and, from an intervention perspective, potentially to build capacity rather than focus upon a deficit approach to ageing (Windle, 2011). As highlighted above, the presence or absence of resources alone is insufficient for conceptualising resilience within people with vision impairment. For the concept of resilience to be of use in identifying need and developing interventions, we need a fuller understanding of the causal mechanisms at play; identifying protective factors only identifies associations (Young et al., 2011). The many processes and variables involved are complex; vision impairment interacts with a range of variables

and processes to impact upon wellbeing. We might view vision impairment as an *indicator* rather than a *mechanism* of risk – as Young et al. (2011) reported in the context of deafness.

If the concept of resilience is to be used to develop interventions which build and maintain resilience in older people with vision impairment, further evidence is needed of how individual, social, and community resources interact. Demonstrating the interconnectivity of these resources underlines the importance of taking a holistic approach to interventions and service delivery. These cases demonstrate the need to look beyond the individual and to consider the wider context of their lives, including their social, financial and personal circumstances. In particular, it is important to look at the individual systemically, in the context of their relationships with those close to them (such as a spouse, as demonstrated in each of these cases) in order to address their needs holistically. Our findings support other work, such as Donnellan et al. (2015), reinforcing that resilience should be examined from an ecological perspective, to develop enhanced understandings of the complex relationships between the factors which influence resilience at individual, community and wider societal levels.

Understanding resilience amongst people with vision impairment may hold value in developing preventative and cost effective approaches to tackling future demand for services. This approach could have particular value given the high financial costs associated with sight loss (Minassian & Reidy, 2009; RNIB, 2013a) and the expected growing number of people with a vision impairment as the population ages (RNIB, 2013a).

Limitations

This analysis is limited in that the interviews did not set out to explore, and participants were not specifically asked about, resilience. However, it emerged as a strong theme from narrative interviews which enabled participants to identify issues of salience. However, future research should focus more closely on resilience specifically. Similarly, we only asked participants to present a narrative beginning from the point at which they began their journey of sight loss. To better understand their individual capacity for resilience, a lifecourse approach in which their approaches to and ability to cope with other types of adversity would be useful.

Ethical approval

Ethical approval was obtained for both studies: from an NHS Research Ethics Committee (REC) for the first study and from a University REC for the second.

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Declaration of contribution of authors

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