**Resilience and vision impairment**

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**Abstract**

Some people fare better than others when faced with adversity; they are more ‘resilient’. This article explores resilience in the context of vision impairment using two linked sets of narrative interview data from 2007 and 2010. Three case studies were analysed in detail using a framework approach based upon a social-ecological model of resilience and vision impairment within which a range of assets and resources are identified which influence an individual’s capacity for resilience. A set of criteria were used to establish whether or not each individual was 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 or creates risk to wellbeing. To possess only some of these resources is not sufficient; to enable resilience there is a co-dependency between these resources which requires the presence of other resources. Resilience is not a fixed state; individuals can become more or less resilient as their circumstances, and resources change over time. We suggest that resilience has much to offer the field of vision impairment; for individuals it identifies strengths as well as areas of weakness, allowing capacity building rather than focussing only upon deficit. However, for it to be useful there is a need for a far more detailed understanding of the relationships between the resources which enable resilience or create risk.

**Key words**

Resilience; successful aging; visual/vision impairment; AMD, older people, sight loss.

**Highlights**

* 3 longitudinal in-depth case studies of vision impaired older adults
* A range of inter-connected resources are required to facilitate resilience.
* Resilience cannot be achieved if some resources are missing due to inter-dependence.
* To enable resilience, available resources must be utilised.
* Resilience is not a fixed state; it can very over time.

**Introduction**

Some people fare better than others when faced with adversity; they are more ‘resilient’. Some people with vision impairment live fulfilled, independent lives despite significant impairment; whilst others have a poor quality of life, with lesser degrees of impairment ([Hernandez Trillo and Dickinson, 2012](#_ENREF_15), [Thetford et al., 2011](#_ENREF_39)). There are around two million people with a vision impairment in the UK ([Access Economics Pty Limited, 2009](#_ENREF_1), [RNIB, 2013](#_ENREF_33)), the majority of whom are older (aged over 60) ([RNIB, 2013](#_ENREF_33)). 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 as age is a risk factor for common conditions such as age-related-macular degeneration, cataract, glaucoma and diabetic retinopathy ([RNIB, 2013](#_ENREF_33)). Vision impairment has negative impacts upon wellbeing and quality of life ([Hernandez Trillo and Dickinson, 2012](#_ENREF_15), [Li et al., 2011](#_ENREF_21), [McManus and Lord, 2012](#_ENREF_27)), mental health ([Hayman et al., 2007](#_ENREF_14), [Nyman et al., 2010](#_ENREF_29), [Thurston, 2010](#_ENREF_40), [Barr et al., 2012](#_ENREF_3)) and social participation ([Alma et al., 2011](#_ENREF_2)). However, within the vision impaired population there is considerable variation in wellbeing, physical and mental health ([McManus and Lord, 2012](#_ENREF_27)). Vision impairment has multi-faceted impacts upon people’s lives; it impacts on functional ability and mobility, which affects social interaction and psychological wellbeing ([Grue et al., 2010](#_ENREF_12), [Hodge and Eccles, 2013](#_ENREF_18), [Gallagher et al., 2011](#_ENREF_9)). The relationship between severity of impairment and the impact upon wellbeing is not simple ([Schilling et al., 2011](#_ENREF_34)); there is a range of influencing factors ([Brown and Barrett, 2011](#_ENREF_6)). Hernandez-Trillo & Dickenson ([2012](#_ENREF_15)) 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 & Latham ([2012](#_ENREF_38)) reported that some vision impaired people are more disposed to depression than others due to factors such as personality traits. In this article we explore the concept of resilience in the context of vision impairment, examining individual and social-environmental factors. 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](#_ENREF_26)), or the ability to bounce back following adversity ([Young et al., 2011](#_ENREF_50)). However, resilience is a contested concept; see Windle (2011) for a review and concept analysis. In the past, conceptualisations have neglected the social processes which create risk ([Ungar, 2012](#_ENREF_41)); thus failing 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 et al., 2014](#_ENREF_8), [Ungar, 2012](#_ENREF_41), [Young et al., 2011](#_ENREF_50)).

Windle’s ([2011](#_ENREF_46)) 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: p163](#_ENREF_46)). Windle and Bennett ([2011: p220](#_ENREF_48)) represent the relationships between these resources in a model of resilience in 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). Windle’s ([2011](#_ENREF_46)) definition recognises resilience as a *process* rather than a stable trait or characteristic. It can however also be conceptualised as an outcome, rather than a process, as operationalised by Bennett ([2010](#_ENREF_5)), through the application of a set of four criteria: to be considered resilient, her participants had to view their current life positively; be actively participating in life; returning to or maintaining a life that had meaning or satisfaction; be coping and not be distressed. Developing both these papers further, Donnellan et al. (2014) operationalises resilience as an outcome.

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](#_ENREF_10), [Hildon et al., 2010](#_ENREF_16), [Hildon et al., 2008](#_ENREF_17), [Wild et al., 2013](#_ENREF_44), [Wiles et al., 2012](#_ENREF_45), [Windle, 2012](#_ENREF_47)). Harris ([2008](#_ENREF_13)) suggested that ‘successful ageing’ is the wrong goal and that we should instead be focussing upon striving for resilience in old age. Harris’s argument has particular strength 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](#_ENREF_13)). 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](#_ENREF_16)). Here we explore the concept of resilience in the context of vision impairment, through the analysis of in-depth longitudinal data.

**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 and 2013). . In the first study ([Thetford et al., 2011](#_ENREF_39)) narrative interviews were conducted using the Biographical Narrative Interpretive Method (BNIM) ([Wengraf, 2005](#_ENREF_43)) which uses a single question to elicit a narrative response; in the second, follow-up study with the same cohort three years later, these people were re-interviewed using semi-structured interviews ([Mason and Dale, 2011](#_ENREF_25), [Silverman, 2011](#_ENREF_35)) to explore how their lives had changed ([Hodge et al., 2013](#_ENREF_19)). These interviewing methods produced rich data which enabled participants to construct their own narratives of experiences of sight loss and use of services, identifying issues of salience in a way meaningful to them. The interviews provided thick descriptions ([Geertz, 1973](#_ENREF_11)) of the social and cultural contexts within which these individuals existed, 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 and Guba, 1985](#_ENREF_23)).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, as reported in Hodge et al ([2013](#_ENREF_19)).

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 for three cases are presented here from interviews at two points in time. These data were previously analysed with a thematic approach ([Coffey and Atkinson, 1996](#_ENREF_7), [Silverman, 2012](#_ENREF_36)) and are reported elsewhere as part of the larger data sets (cite author’s work 2011 and 2013). This work was used to inform the development of a model of resilience specific to vision impairment based on Windle & Bennett’s ([2011](#_ENREF_48)) model of resilience in caring relationships (figure 1). This model was then used to undertake a ‘framework approach’ to analysis, similar to that described by Richie & Spencer ([2002](#_ENREF_32)), Smith & Firth ([2011](#_ENREF_37)) and Pope et al. ([2000](#_ENREF_31)).

Each case was examined at two points in time to explore experiences of vision loss and the impact of this upon the lives of these three individuals. The model components were used to assess each case; associations between themes were explored, and accounts developed. An assessment of whether each individual was resilient or not was made using Bennett’s ([2010](#_ENREF_5)) criteria for resilience at each point in time (participants had to view their current life positively; be actively participating in life; return to or maintain a life that has meaning or satisfaction; be coping and not be distressed) (see also Donnellan et al., 2014).

Where individual cases or issues within cases did not appear to fit emerging accounts, these were used to refine themes and findings ([Patton, 1999](#_ENREF_30)). 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 collection of one set of the interview data. One of the other researchers involved in analysis was responsible for collection of the second. 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 and Guba, 1985](#_ENREF_23)).

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**Findings**

Eva, Isabel and James had wet Age-related Macular Degeneration (AMD), ([Lim et al., 2012](#_ENREF_22)) a common condition which affects central vision, potentially causing considerable loss of vision function ([Wong et al., 2014](#_ENREF_49)). 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 of these individuals 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](#_ENREF_22)). At the time of the first interviews, treatment options available through the NHS were limited to laser treatment, though 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 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 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 (figure 1), and a table summary of resources presented for each to show change between the first and second interview. A second table is presented for each individual presenting assessment of whether each is resilient at each point in time based on the criteria outlined in Bennett ([2010](#_ENREF_5)). Ages presented are at second interview. Interview 1 or 2 is indicted after the quote as T1 or T2.

**Eva (age 75)**: Eva lived with her husband in a comfortable suburban home. In both interviews she reported heavy dependence on her husband for support and her increasing withdrawal from everyday activities and society. In her first interview she reported losing confidence and withdrawing from 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 withdraw quite early at night times and let him get on with television or whatever he wants to watch. I just go and listen to my story or my music.” (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. By then her physical health had also deteriorated, creating some mobility problems.

 “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 any more because I cannot see what I’ve got on my plate when I eat and I find it very embarrassing.” (T2)

Eva 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.

“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)

In her second interview, Eva reported that she had been offered rehabilitation several times but she had declined this, because she had practical support from her husband and did not wish to undertake the training. This quote suggests that service providers recognise her need for support of this type and have made it available to her:

“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)

There was evidence in her second interview that other people had also encouraged her to do more, including her ophthalmic consultant and her daughter:

*“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)

Eva kept in touch with voluntary organisations through newsletters, though rarely had personal contact. Although her sight impaired registration status indicated that she had the most functional vision of the three cases (the others were registered 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.

“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)

“I don’t like going out very much at all any more. So, it’s and I never go out on my own, I am always with [husband] or somebody.” (T2)

She recognised the value of rehabilitation services which might enable her to be more independent. Whilst she declined offers of assistance to learn new skills or join peer groups, she also described herself as ‘determined’.

“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 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)

“I get these paper clip cuttings out of magazines and papers and goodness knows what, and then [husband] has got to read it to me, and then he reads it and starts off very clear with the first and then he forgets that he has got to read it to me and he reads it for himself and I, I keep saying I have got the first two sentences, how does it carry on.” (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 and Eccles, 2013](#_ENREF_18)).

Table 1: Summary of resources influencing risk or resilience for Eva: change over time between T1 and T2

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Individual resources T1** | **Individual resources T2** | **Community resources T1** | **Community resources T2** | **Social resources T1** | **Social resources T2** |
| **Biological**: Generally good health.  | **Biological:** Deteriorating health problems affecting mobility (moderate).  | **Family**: Husband very supportive – does a great deal for her. Some emotional needs unmet. Local daughter helps when she could, other daughter abroad. | **Family:** Husband continued to meet material and practical needs. Emotional needs increasingly unmet. Local daughter helps. Sees daughter abroad when possible. | **3rd sector**: In touch with organisations via newsletters but not in person.  | **3rd sector:** Was offered support but not accepted. Helped access financial support. |
| **Psychological**: Although she stated she is determined and continued to try to do many things she was very down, frustrated and withdrawn. Tendency to withdraw from social situations. Lack of confidence.  | **Psychological:** Although reported being more accepting of vision loss, she was also more withdrawn and felt less confident in social situations | **Social participation**: Poor participation: she had withdrawn from most aspects of social life. | **Social participation:** Poor and worsening participation as she withdrew further. | **Rehabilitation**: Has not sought services as did not feel they were for her as she had support from husband. | **Rehabilitation:** Was offered rehabilitation but not accepted it – believed it was for people who do not have family support; and was not confident enough.  |
| **Activities of daily living**: Struggled with everyday activities. Presence of other resources and absence of major health problems suggests potential to learn/adjust new strategies. | **Activities of daily living:** Continued to struggle with everyday activities. Refused to accept offers of training and rehabilitation. | **Housing**: Comfortable, well maintained home. | **Housing**: No change. | **Social policies**: Applied for financial support which helps to pay forthings that are important to her sense of wellbeing, such as getting her hair done. | **Social policies**: No change. |
| **Mobility**: Despite some health problems was generally physically capable. Lack of confidence restricts mobility to when husband took her out. Potential to develop skills. | **Mobility**: Continued lack of confidence and highly dependent on husband.  | **Peer support**: Groups in the local area she could join but did not feel they were for her. | **Peer support**: Not joined any of the peer support groups in the area. Felt they were for people who do not have other sources of support. | **Health and social services**: Had not engaged with services as she depended heavily on her husband.  | **Health and social services**: No change.  |
| **Material**: Reasonably comfortable. | **Material**: No change |

Table 2: Summary of resilience over time using Bennett’s (2010) criteria: Eva

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Time** | **Views current life positively** | **Actively participating in life** | **Return to or maintain life with meaning or satisfaction** | **Coping and not distressed** | **Resilient** | **Change over time** |
| T1 | No | No | No | Coping but some emotional issues | No |  |
| T2 | No – more negative than T1 | No – more withdrawn than T1 | No – less satisfied than T1 | Coping but increasingly distressed | No | Deteriorated by T2 |

When Eva was considered using Bennett’s (2010) criteria, she was not resilient in either her first or second interview. Eva’s account reflected decline over time as her vision impairment worsened and physical health deteriorated slightly. During this time, she became more socially isolated. Eva reported that she had withdrawn from her working life altogether because of her vision impairment and from most of her social life, including much informal family time, particularly in her second interview. 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 provide by her husband in particular 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, mobility and so on. 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 et al., 2008](#_ENREF_24), [Walters et al., 2001](#_ENREF_42)). 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 village home. Isabel liked to have a busy social life and tried to facilitate this 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 was resistant to external support, which Isabel reported restricted what she could do and increased pressure on her.

“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.”*

By her second interview, Isabel’s husband had died and 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.

“Well I am determined to. I am not going to become a couch potato. I absolutely refuse to be stuck inside four walls, I will find some way of getting myself out.” (T2)

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

“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)

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 travelling alone.

Table 3: Summary of resources influencing risk or resilience for Isabel: change over time between T1 and T2

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Individual resources T1** | **Individual resources T2** | **Community resources T1** | **Community resources T2** | **Social resources T1** | **Social resources T2** |
| **Biological**: Had problems but finds ways around these. | **Biological:** Increasingly used services and technology to find ways around increasing health problems to continue to do the things she wants and to live independently. | **Family**: Husband provided support but he also has demanding care needs.Other family provide some limited support. | **Family:** Not at close hand but were supportive. Had them support her on her own terms. | **3rd sector:**  Support good once sources fully identified. | **3rd sector:** Support continued to be good. |
| **Psychological**: Determined though times when very down. | **Psychological:** Positive and determined outlook though still some days when down and frustrated.  | **Social participation**: Developed some friendships but limited ability to get out restricted these. | **Social participation:** Able to further develop friendships now she could get out more. Has found ways to ensure she is active and involved in the community and gets a lot out of it.  | **Rehabilitation**: Has made use of different courses available. Plans to do more.  | **Rehabilitation:** Continues to develop new skills through courses available. Funding an issue sometimes. |
| **Activities of daily living**: Manages many daily activities despite vision impairment and health problems. | **Activities of daily living:** Found ways to do many things – adapts and finds sources of support which enable independence. | **Housing**: Comfortable, well maintained house. | **Housing**: No change. | **Social policies**: Was able to engage with current systems which required her to identify and acquire sources of support.  | **Social policies**: Some services/funding threatened but otherwise no change.  |
| **Mobility**: Found ways to manage this but is a key concern which limits what she can do. | **Mobility**: Continued to be a key concern, particularly in the context of funding issues and cuts. | **Peer support**: Member of a couple of peer support groups. | **Peer support**: Very good – member of several groups. Able to participate more now. | **Health and social services**: Made use of what is available but they do not always meet her needs particularly surrounding emotional needs.  | **Health and social services**: Continued to make use of what is available – able to use more now. Aware of dependency on services and fearful of cuts. |
| **Material**: Quite comfortable. | **Material**: No change. |

Assessment of resilience over time: Isabel

At her first interview Isabel was coping and exhibited traits of resilience ([Bennett, 2010](#_ENREF_5)); despite her vision impairment and health problems, she maintained a social life even if it was not as full as she would have liked, and she was coping, 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 who she missed, she had become resilient through the mobilisation of resources and was able to do other things which gave her life more meaning and satisfaction.

Table 4: Summary of resilience over time using Bennett’s (2010) criteria: Eva

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Time** | **Views current life positively** | **Actively participating in life** | **Return to or maintain life with meaning or satisfaction** | **Coping and not distressed** | **Resilient** | **Change over time** |
| T1 | No | Yes but limited by caring role.  | Yes but limited | Coping but increasingly distressed.  | No |  |
| T2 | Yes – has new horizons | Yes: very much so | Yes | Coping well.  | Yes | Not resilient at T1, resilient at T2 |

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.

**James (age 75)**: James and his wife lived in a modest house in a suburban area and reported some 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 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 lot 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 was resource-poor. 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. 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 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 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 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 him 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 growing care 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 he had 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.

Table 5: Summary of resources influencing risk or resilience for James: change over time between T1 and T2

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Individual resources T1** | **Individual resources T2** | **Community resources T1** | **Community resources T2** | **Social resources T1** | **Social resources T2** |
| **Biological**: Very poor health with multiple problems which restrict mobility and cause considerable pain. | **Biological:** Deteriorating health and vision, creating much challenge to daily living. | **Family**: Good support from wife, though her health poor. Good support from daughters but their work and other care responsibilities restrict what they could offer. | **Family:** Good support from family though their efforts now focussed on his wife. His wife now unable to offer support and he had now become her carer. | **3rd sector**: Very supportive and in process of helping to apply for financial support.  | **3rd sector:** Continued to be very supportive in a range of ways.  |
| **Psychological**: Stoic, humorous approach, determined despite considerable challenges. | **Psychological:** Remained somewhat stoic and humorous but also overwhelmed and losing hope. | **Social participation**: Poor and missed opportunities because of other problems caused by vision impairment, physical health, mobility problems and finances. | **Social participation:** Other opportunities very limited due to vision impairment, health problems and mobility issues. | **Rehabilitation**: Much not suitable or accessible due to mobility and health problems.  | **Rehabilitation:** Accessing some computer training. |
| **Activities of daily living**: Very limited but determined and continued to try, even if a struggle. | **Activities of daily living:** Remains determined, if tired, though activities becoming increasingly challenging. | **Housing**: Modest housing. Struggled with stairs due to mobility, physical health and vision impairment. | **Housing**: Problems had intensified. | **Social policies**: Insufficient practical or financial help though applying for further assistance.   | **Social policies**: Financial assistance was provided and some support had been put in place once his wife became very ill though this has proven to be insufficient and they are at breaking point.  |
| **Mobility**: Constrained by finance, physical health and vision impairment.  | **Mobility**: Although financial assistance has helped, care responsibilities and increased health problems now constrain mobility.  | **Peer support**: Wished to attend groups but unable to due to mobility problems.  | **Peer support**: Accessed peer support groups which have been very helpful, though rarely attends these now due to care responsibilities. | **Health and social services**: Insufficient support available. | **Health and social services**: Insufficient support available, particularly now that his wife is very ill. Reaching ‘breaking point’.  |
| **Material**: Finances problematic and cause problems with other aspects of living. | **Material**: No change. |

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 care responsibilities, meant that he was not able to benefit from this, demonstrating that the relationship between these resources can also work negatively.

Table 6: Resilience over time: James

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Time** | **Views current life positively** | **Actively participating in life** | **Return to or maintain life with meaning or satisfaction** | **Coping and not distressed** | **Resilient** | **Change over time** |
| T1 | No, though stoic, determined approach. Envisaged improvements to future.  | No, very limited – wants more  | No. Only to a limited degree – struggled. Determined despite considerable challenges.  | Copes with difficulty. Some degree of dissatisfaction and distress. | No, but had positive traits which suggest potential for resilience if supported.  |  |
| T2 | No. Things now too difficult. Sense of despair.  | No  | No – it is now too difficult.  | Increasingly distressing and stressful. At breaking point.  | No  | Deteriorated |

At his first interview, although lacking in many resources and faced with a range of 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 (with the financial support he had begun to attend the peer support group that he had much wanted to join and started a touch typing course), 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 now withdrawing his participation. 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 in the nature of our participants' vision impairment and they are all older people, 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, she also had difficult times, yet 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 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, though 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 her to live more independently, and which may 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 and missed so much, and which may help to improve the emotional problems she was experiencing. It was not entirely clear why this was the case, though it would seem that her over-dependence on her husband’s support impacted upon and was inter-related with her psychological wellbeing, which thus had an impact on her ability 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 ([Hodge et al., 2013](#_ENREF_19)). 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 and that where there are problems in one area, this can have multiple impacts in other areas.

These cases demonstrate that it is not merely the presence or absence of resources that impacts on whether and to what degree achieving resilience is possible, but how these resources interact with each other. This finding supports Windle & Bennett’s ([2011](#_ENREF_48)) model of resilience (figure 1), which stresses the inter-connectedness of the resources required to achieve resilience. These cases also demonstrate that a range of resources are required; it is not enough to have only particular types of resources. To be effective in achieving a resilient outcome, some resources are dependent upon 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 (such as good health, or sufficient social support) meant he was unable to mobilise some of these resources, (such as rehabilitation, peer groups etc.) and that what he had simply was not enough. By the time of his second interview, the enormity of the challenges he faced in relation to the resources he had was becoming too much and he was becoming overwhelmed. Although according to Bennett’s criteria ([2010](#_ENREF_5)), 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](#_ENREF_5)), these individuals may become resilient in the future, as demonstrated by Isabel, whose circumstances changed positively. This is demonstrated in the tables summarising the risks and resources available to each of the three individuals.

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, the deterioration in his health and wellbeing is captured in the summary. 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 Bennett and Windle’s ([forthcoming](#_ENREF_4)) commentary on ([Kalisch et al., forthcoming](#_ENREF_20)) we explored the factors that were required to be resilient (whereby resilience is defined as an outcome). Similar to Donnellan et al. ([2014](#_ENREF_8)) 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. ([2014](#_ENREF_8)), 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 rehabilitation training, material resources, transport, and reasonable physical health and so on, she did not make use of these, perhaps due to a lack of 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.

For people with vision impairment, the majority of whom are older and face increasing physical and other challenges associated with ageing, the concept of resilience may have 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](#_ENREF_46)). As highlighted above, the presence or absence of resources alone is insufficient to understand 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](#_ENREF_50)). 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](#_ENREF_50)) reported in the context of deafness.

Further work is required to explore the roles of individual, social and environmental factors and resources. There remains insufficient evidence of how these elements interact and which are of greatest importance in determining resilience. For example, are personal characteristics the most important factor, and once the social and environmental resources are in place, are resilient processes enabled? Or are personal traits less important, with social and environmental factors playing a greater part? Having established the importance of the interconnectivity of these resources underlines the significance of a holistic approach to interventions and service delivery. These cases demonstrate the need to look beyond the individual and to consider those close to them (such as a spouse, as demonstrated in each of these cases) to meet their needs. Our findings support other work, such as Donnellan et al. ([2014](#_ENREF_8)), 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 among 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 and Reidy, 2009](#_ENREF_28), [RNIB, 2013](#_ENREF_33)) and the expected growing number of people with a vision impairment as the population ages ([RNIB, 2013](#_ENREF_33)).

**Limitations**

This analysis is limited with regard to examining resilience amongst these individuals. The interviews did not set out to explore resilience and participants were not specifically asked questions about resilience. However, resilience emerged as a strong theme from narrative interviews which enabled participants’ freedom to identify issues of salience; this is a key strength. Future research which specifically addresses resilience amongst people with vision impairment would allow us to focus more closely on resilience specifically.

**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**

All authors have made a substantial contribution to the development of this article.

**Conflicts of interest**

The authors do not have any conflicts of interest arising from this work.

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