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A qualitative exploration of the effect of visual field loss on daily life in home dwelling stroke survivors

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Abstract

Objective: To explore the effect of visual field loss on the daily life of community-dwelling stroke survivors.

Design: Qualitative interview study.

Participants: Adult stroke survivors with visual field loss of at least six months duration.

Methods: Semi-structured interviews were conducted with a non-purposive sample of 12 stroke survivors in their own homes. These were recorded, transcribed verbatim and analysed with the framework method, using an inductive approach.

Results: Two key analytical themes emerged. 'Perception, experience and knowledge' describes participant's conflicted experience of having knowledge of their impaired vision but lacking perception of that visual field loss and operating under the assumption that they were viewing an intact visual scene when engaged in activities. Inability to recognise and deal with visual difficulties, and experiencing the consequences, contributed to their fear and loss of self-confidence. 'Avoidance and adaptation' were two typologies of participant response to visual field loss. Initially all participants consciously avoided activities. Some later adapted to vision loss using self-directed head and eye scanning techniques.

Conclusions: Visual field loss has a marked impact on stroke survivors. Stroke survivors lack perception of their visual loss in everyday life, resulting in fear and loss of confidence. Activity avoidance is a common response, but in some it is replaced by self-initiated adaptive techniques.

211/250 words

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Introduction

Stroke-related damage to the visual pathway, which links the retinal receptor cells to the visual processing centres, causes visual field loss. This persists in approximately 21% of stroke survivors, affecting an estimated 6.9 million people worldwide[1,2]. Visual field loss typically affects the same half of the visual field in both eyes, effectively making the person blind to one side of space[3]. This is compounded by consequent eye movement changes, as the smaller, repetitive movements increase the time taken to view an entire scene[4,5].

There is limited research into the effect of visual field loss on stroke survivors. Studies have been primarily quantitative, indicating that stroke survivors with visual field loss have poorer health-related and vision-related quality of life compared to non-stroke populations[6,7] with lower mental health scores[8]. The use of quantitative measurement scales with proven validity and reliability ensured the quality and comparability of these findings[9]. However, this may have reduced the level of understanding gained, by limiting participant's responses to pre-defined issues[10].

Qualitative methodology allows fuller exploration of the impact of visual field loss by capturing how stroke survivors themselves perceive these effects. Grooming and feeding, as well as driving, shopping and financial management have been identified as common areas of difficulty[11], with problems seeing objects or people in time described[12]. Rowe's interviews with 35 stroke survivors identified the broader impact on working and family life and explored issues of information and care provision[13]. However there have arguably been methodological limitations in these studies, with use of narrow interview topics which may have restricted participant responses[11,12], and primarily descriptive analysis techniques, which may have limited interpretation[13]. Additionally, these studies included a range of visual impairments[13] and non-stroke participants[11,12] limiting the applicability of this evidence. These limitations in the

current evidence mean that we do not fully understand the consequences of visual field loss for stroke survivors.

The aim of this study was to explore in-depth the effect of visual field loss on the daily life of home-dwelling stroke survivors.

Methods

Ethical approval was granted by the NHS West of Scotland Research Ethics Service (Reference 13/WS/0171). Participants were recruited from two Scottish vision rehabilitation centres. Purposive sampling was not used, as there was little evidence to inform sampling characteristics, and to maximise recruitment. Stroke-specialist Low Vision Rehabilitation Officers identified potential participants by conducting their routine home-based needs assessment, and then reviewing their notes, in order to apply the inclusion criteria. They explained the study to all those meeting study criteria and provided large print/audio information: all participants completed and returned a large-print written consent form.

Study inclusion criteria were: clinical diagnosis of stroke at least six months earlier, hemianopic visual field loss caused by the stroke, age 18 or over, medically stable, living in the community and no prior community visual training. Visual field loss was assessed using confrontation[14], with any pattern of binocular field loss in the same vertical hemifield accepted. Exclusion criteria were: unable to provide informed consent, non-stroke visual impairment, and involvement in another rehabilitation study.

A clinic-based assessment was firstly conducted to gather important demographic data, including the size of visual field loss (confrontation assessment[14]), presence of visual neglect (star cancellation test, score of <44 indicating the presence of neglect[15]), plus an open question on any non-visual stroke effects they still experienced. Semi-structured interviews were then conducted (by CH) in each participant's own home. These allowed in-depth discussion of participants' experiences of visual field loss, with follow-up questions to gain fuller understanding[16,17]. A topic guide helped ensure core topics were covered and to reduce interviewer biases[18,19] (Supplementary material 1).

Prompts were refined during the study to explore unexpected responses and emergent themes[20,21]. When carers were present (to support those with memory or language impairments) they were encouraged to let the stroke survivor speak un-interrupted. Interviews were audio recorded, with field notes made after each baseline assessment and home visit to enable reflexivity[17,22]. These notes included any personal biases noted, emotional responses, observations and possible patterns emerging from gathered data. Data collection took place from October 2013 to August 2014.

Transcribed interview audio files were analysed inductively with a five-stage thematic framework method[23–25] using NVivo v10 software. The aim of analysis was two-fold: to describe the effect of visual field loss on daily life and to gain deeper understanding of stroke survivor's experience of this[23,24]. Firstly, two analysts (CH, BD) independently developed a 'feel' for the data, by reading the transcripts and field notes, and listening to interview recordings. Secondly a thematic framework was then created from the first two transcripts, with each analyst independently applying a 'code' to what was described or important. Following discussion, 'codes' were agreed and arranged into a framework of 'categories'. This process was repeated by these analysts for two more interviews to allow framework refinement. Thirdly this framework of codes was applied to the remaining transcripts, and fourthly charts were created with individual participant data displayed in rows, and codes (grouped by category) forming the columns. Summarised transcript data was entered into the appropriate cell. Finally, data was interpreted, looking along a row to identify emergent connections or 'themes', and progressing to comparing across rows and columns, to look for more general characteristics or patterns. Stages three, four and five were conducted by one analyst (CH) with input throughout from a topic expert (AP) and methodological expert (AT).

Results

Twelve stroke survivors took part and their demographic and clinical data are shown in table 1.

Table 1 here

Through analysis, 60 unique codes were identified (Supplementary material 2) and grouped into eight categories (Table 2). Working through to the final stage of data interpretation, two analytical themes were indicated: 'perception, experience and knowledge' and 'avoidance and adaptation'.

Table 2 here

Perception, experience and knowledge: experience of visual field loss

Participants often began their accounts by describing the practical consequences of visual field loss. These included difficulties with household tasks, such as problems seeing cooker dials, missing areas when dusting or hoovering, and suffering injuries due to unseen cupboard doors and cooker rings:

> *it's the dials on the cooker and the hob - I'm never sure which burner I've got on when I'm cooking*
>
> *Participant 4 (right field loss)*

Many also reported problems with mobility and navigation, due to failure to see obstacles, especially in unfamiliar or changing surroundings, where they could not rely on their memory of the scene. Crossing roads was especially difficult:

> *I really struggle… because although in the right-hand side I'm fine, it's on the left-hand side… so I can see that there's no traffic coming, however within minutes that can change and I have no perception of that*
>
> *Participant 8 (left field loss)*

Within participants' descriptions a complex experience of, and understanding of, visual field loss became apparent. This is seen within descriptions of reading, which was a problem for all participants:

> *I was reading a paragraph and I'm thinking 'this isn't making sense' and then I'm realising I'm not reading the whole line. I'm getting to where I think the end of the page should be but it's not there, it's actually a bit further on and there's words that I've missed*
>
> *Participant 2 (right field loss)*

Here the participant describes being unaware of the loss of an area of their vision: it is only through finding that the world "isn't making sense" that they determine they've not read the whole line. Stroke survivors repeatedly described this intrinsic lack of

perception of their lost vision. Linked to this, they report continuing to believe, or assume, that what they have seen is an accurate, intact visual scene. This belief persists unless something clearly indicates otherwise, such as when reading (above) or when watching sport on television:

> *(before you would) look to the game and you can see every aspect of the game just basically looking […] whereas now (I think) 'there's no sign of play here! It must be over there…. ah, there it is. It's a strange sensation* *Participant 5 (right field loss)*

This confusion occurred despite participants having knowledge and understanding of their visual field loss. This knowledge was often gained during their time on the stroke wards:

> *when the Occupational Therapist was doing exercises with me in hospital…they were saying, it is more to do with my field (of) vision*
> *Participant 8 (left field loss)*

Stroke survivors recognised and could discuss this conflict within the interview context. In everyday life, however, participants described instinctively trusting their perception of an intact visual image, even when experience and knowledge told them their perception was not true, such as when trying to cross a busy supermarket carpark:

> *it's just that you look and you...you assume it's right. And it's not, it's nonsense* *Participant 1 (left field loss)*

This complex experience was central to the emotional impact of visual field loss. Participants frequently struggled to integrate conflicting information, leading to confusion and uncertainty, and undermining their self-confidence:

> *my confidence is affected, because I tell myself not to do things, not to assume… that I have seen the whole picture of a street because I may not have seen that vehicle that has come around the corner*
> *Participant 10 (right field loss)*

Participants identified the need to suppress the instinctive belief in their perception, but noted great difficulty in doing so.

> *(it's) very much a problem in the left-hand side. But I have to keep reminding myself and a lot of the times I forget*
> *Participant 3 (left field loss)*

Awareness of their inability to recognise and deal with their visual difficulties heightened the levels of fear and anxiety experienced in daily life, further reducing self-belief and confidence:

> *I'm frightened I'll bump into things. ... I thought 'I'll get the bin in'... and you kind of stumble a bit and stuff. And I'm never sure is it my vision or is it me* *Participant 1(right field loss)*

In summary, stroke survivors' experience of visual field loss was a conflict between intellectual knowledge of plus actual experience of the consequences of visual field loss, yet without any direct perception of that visual loss, with clear practical and emotional consequences.

Avoidance and adaptation: response to visual field loss

Fear was one of most commonly discussed emotional impacts. It arose in response to both practical difficulties and accidents, and the loss of self-confidence arising from participants lack of perception of the visual field loss underlying these accidents, as described above. Participants' fear had two linked facets, with individuals reporting they were afraid to do a task because they were afraid of the consequences of making a mistake.

> *I was afraid I wouldn't see something properly and trip on it and what-not. You know?* *Participant 8 (left field loss)*

Participants also stated that they no longer felt safe, especially when alone or having to rely on themselves. The specific fear of an injury was mentioned in relation to using stairs, working in the kitchen, walking outside and crossing roads.

A very strong connection was appreciable between participants' accounts of fear and their lack of confidence. For some, this was the key effect of visual field loss:

> *I've lost a lot of confidence. I think maybe that's the main issue*
>
> *Participant 1 (left field loss)*

Participants responded to fear and reduced confidence in a range of ways: some described analysing situations very carefully, others became wary, acting cautiously and

slowly when undertaking activities, to prevent accidents. The most common response was activity avoidance:

> *but I could... I should be able to... but I don't go out on my own because I'm frightened Participant 6 (left field loss & neglect)*

Participant's fear of the consequences of their actions included the way in which people responded to them. Participants frequently expressed a desire to maintain an appearance of pre-stroke ability, to avoid others' negative opinions or comments. To avoid such comments, participants would limit their activities even further:

> *it's because of the vision […] I don't like looking stupid and I think I look stupid […] I feel as though I look handicapped or something like that because I'm looking at all different things and I don't know exactly what they say […] So I don't like going into the shops to get my groceries Participant 9 (right field loss)*

Through our analysis, it was clear that all participants displayed an initial defensive, avoidance approach; in many this persisted. However, a number of participants described learning to adapt and compensate for their visual loss. Adaptation involved changes in the way participants used their vision; increasing their eye movements and using a scanning motion to compensate for their lost vision, for example when reading a line of text:

> *maybe not word for word, but I can't just look for a paragraph and go, right that says that… I've really got to scan it.*
> *Participant 12 (left field loss)*

Scanning was often performed by moving the head, such as when trying to find an object in a room:

> *before it would have been… a momentary glance without even moving my head to see it, whereas if I did that now I still wouldn't be able to see it…. I'm having to tell my brain 'To do that you have to turn your head to do it' Participant 5 (right field loss)*

These eye and head movements appear initially to be performed quite consciously and took time:

> *it's like I've got to tell myself 'turn and see who it is' whereas before it would just be ((snaps fingers)) you would do it without thinking about it. […] it's as if I'm doing things in slow motion*
> *Participant 7(right field loss)*

However, eye and head movements became more natural with time and practice, with the timescale varying across individuals:

> *I have to learn to take my time and look at things. But I'm not at that stage yet* *Participant 1 (left field loss)*

Those participants who were developing adaptive strategies showed a greater return to pre-stroke activities, describing less limitations in daily tasks, and leaving the house and engaging social events more than those who remained at the avoidance stage.

> *now I would say… I'll mop the floors, I'll scrub the bathroom, stuff like that, that I couldn't have done six months ago* *Participant 1 (left field loss)*

In summary, two patterns of response appear evident in participants' reports, an initial avoidance of challenging tasks, based on the fear of making vision-related mistakes, and (amongst a smaller number of participants) adaptation to visual field loss, by using new head and eye movements in a scanning pattern.

Discussion

Our study has shown that visual field loss has a broad range of effects on the daily life of home dwelling stroke survivors, causing limitations in practical abilities, loss of social role and activities and a profound effect on emotions. In-depth analysis suggests that these effects result from conflict between participants' perception of an intact visual scene, versus their knowledge of, and experiencing the consequences of, having visual field loss. Resulting fear and reduced self-confidence were described by some as the most important effect of visual field loss. Two possible patterns of response to visual field loss were identified – avoidance of tasks and activities and, amongst a smaller number of stroke survivors, adaptation based on using new head and eye movements.

These findings on the practical effects generally agree with the few other qualitative explorations of visual impairment after stroke[11,13]. Questionnaire-based studies also found reduced social function and mental health, limitations on driving and increased dependency, as noted here[6–8]. This study therefore supports prior work but has highlighted the depth and range of emotional effects and how central these were to

participants' experiences. Comparison with the literature on non-stroke related visual impairment shows common emotional responses including changes in self-perception and sense of dependence[26–28], and reflects models of the grieving process as applied to visual loss[29].

The strength of this study is that we gathered views directly from stroke survivors (avoiding the use of questionnaires) providing a rich description of the daily effects of visual field loss amongst a stroke specific population. The use of a theory-based inquiry method, semi-structured interview techniques and a rigorous analysis process, have increased the understanding provided by these accounts, and provided valuable new insight into this issue. But several limitations must be noted. Our 12 participants may not represent the wider population of those with visual field loss after stroke: as they were recruited from those presenting to a vision rehabilitation service, may therefore represent those more severely affected by visual field loss. The study focussed solely on visual field loss and other visual impairments such as double vision, visuo-spatial neglect or perceptual disorders were not explored. The presence of neglect was assessed using the star cancellation test, which has a diagnostic sensitivity of 80% and specificity of 91%[30]. It is possible some participants (with left-sided visual field loss) also had undiagnosed neglect: this may have further impacted on the daily life impact they experienced, but not have been fully explored in this analysis. Those with severe aphasia were excluded. It is also not clear if data saturation was reached, and the full breadth of experience represented. However qualitative data does not try to represent an entire population, rather providing insight to key issues that could be applied to the wider visual field loss population in further exploration. A non-purposive sample was used; but participants covered a broad range of ages and had an almost equal mix of side and size of visual field loss and gender. There was potential for the researchers to influence the responses of participants and the themes identified during analysis; the use of an interview prompt, audio-recording with full transcription and involvement of a number of analysts will have minimised the risk of this bias. Within the sample a number of participants had some memory difficulties (Table 1), which may have affected their ability to recount or communicate their experiences, a difficulty inherent in interviewing individuals post-stroke[31].

Our study has provided a unique conceptualisation: participants' experience of daily life was founded on an inherent lack of visual perception of their visual field loss, and the conflict this creates. Participants were receiving, and trying to make sense of, conflicting information: intellectual knowledge that they had visual field loss, experience of the consequences of visual field loss in daily activities, yet an absence of perception that what they saw was not correct (Figure 1). It is important to note that this was not due to visual neglect, a cognitive disorder where an individual "fails to report, respond, or orient to novel or meaningful stimuli presented to the side opposite a brain lesion"[32]. Whilst one participant had neglect, lack of perception of visual field loss was identified across the participant group.

A lack of perception of visual field loss has been raised infrequently in the stroke literature, with greater importance placed on the loss of vision and changes in eye movements[33,34]. Previous qualitative work has (briefly) noted lack of perception as one of several issues experienced in this population[13], rather than the fundamental aspect suggested in this study. It must be noted that identifying this phenomenon is inherently difficult, given that stroke survivors themselves struggle to recognize it. The term 'awareness' has been used, and the provision of information on visual field loss proposed as a rehabilitation strategy[35]. However, we suggest that targeted change in participants' knowledge of their visual field loss through information provision is unlikely to alter their visual perception of a scene. The lack of perception of visual field loss described here may be similar to "hemianopic anosagnosia", a deficit in which there is no direct experience of the absence of vision[36]. Critchley (1949) described awareness of vision loss as consisting of discrete stages, ranging from full awareness to none, hypothesising that a person progressed through these stages over time[37]. His proposed stages of awareness appear similar to the three elements identified here (knowledge, experience, perception; Figure 1), however rather than being separate and occurring sequentially[37,38] we suggest these elements are concurrent and conflicting.

We suggest there may be two distinct responses to visual field loss for those dwelling at home (i) avoidance of activities, and (ii) adaptation to compensate for lost vision. From these interviews there appears to be a sequence of events in this model of response (Figure 2): on returning home participants tried familiar activities, but made mistakes due to their visual loss, which they struggled to understand due to the lack of perception

of that visual loss. All consequently adopted the use of self-protective avoidance strategies, with a small number progressing to an adaptive response, using new head and eye movements (Figure 2). Within stroke literature, an avoidance response to fear and loss of confidence after stroke has been identified[39,40], and the development of adaptive or compensatory behaviours to deal with post-stroke impairment[41] or vision loss[42] has also been reported. However, this study identifies a very specific adaptative mechanism in the context of visual field loss, which involves the self-directed use of broad scanning eye and head movements.

There are several important clinical implications arising from this study. Healthcare professionals should be aware of the fear and loss of self-confidence associated with visual field loss and offer suitable support to stroke survivors, their family and carers. Given the conflict between stroke survivors' knowledge of visual field loss and the inaccurate perception of unimpaired vision; healthcare professionals should (i) ensure that stroke survivors have adequate knowledge of their condition and (ii) implement strategies aimed at helping stroke survivors understand and make sense of this conflict. Stroke survivor's avoidance response, that leads to loss of activities and social networks, appears clearly linked to their negative initial experiences within the home environment. This suggests that the provision of rehabilitation support early in this process may be of value in limiting this response, and historical guidance on waiting up to six months before beginning therapy should be reconsidered.

We require additional research into the lack of perception of visual field loss experienced by stroke survivors, and how this may be addressed in rehabilitation. This study prompts further research into why stroke survivors have different responses to visual field loss, the role these responses have in rehabilitation effectiveness and whether rehabilitation could expedite the transition from avoidance to adaptation behaviours. This study also provides evidence that scanning eye and head movements may be beneficial to people with visual field loss, and therefore adds weight to calls for research to investigate the effectiveness of scanning training, which aims to teach such behaviour[43,44].

Clinical Messages

- Clinicians should be aware that stroke survivors with visual field loss experience practical, social and emotional effects, notably fear and loss of self-confidence
- Despite having knowledge of their visual field loss, a stroke survivor may not perceive that they are missing part of their vision when engaging in everyday activities
- Stroke survivors may respond to visual field loss by avoiding activities, while others may adapt by using new patterns of head and eye movements

Conflict of Interest Statement:

The Authors declare that there are no conflicts of interest.

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Tables

Table 1 Baseline data for participants

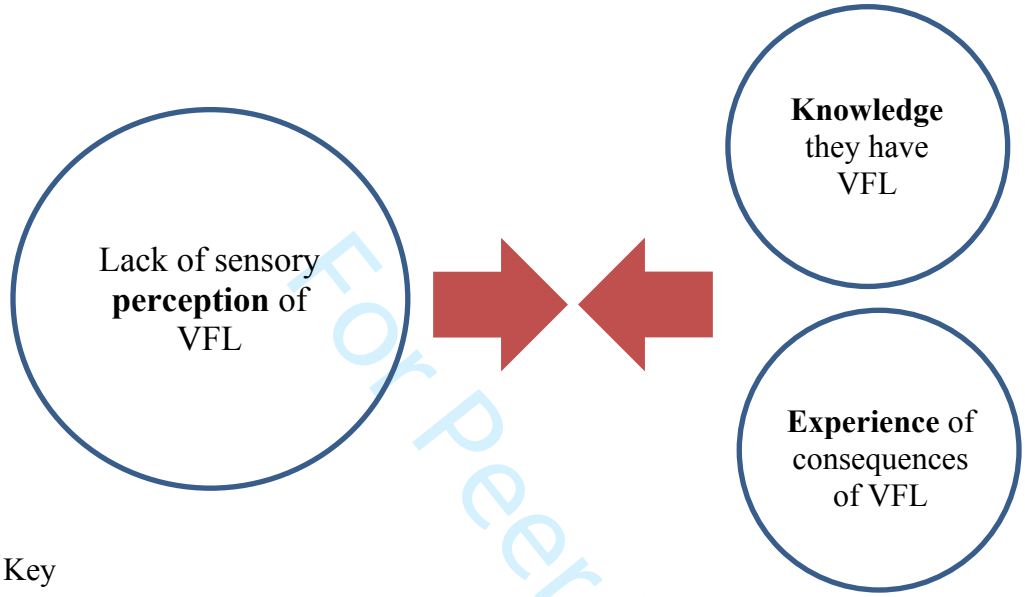
Characteristic		Participants (n=12)
Age (years)		Median: 55.5 Range: 42-80
Male/ Female		5/7 (41.7% / 58.3%)
Visual field loss		
Side	Right	6 (50%)
	Left	6 (50%)
Size	Half	6 (50%)
	Quarter	5 (41.7%)
	Other	1 (8.3%)
Visual neglect		n=1 (8.3%)
Time since stroke (months) **(and since visual field loss occurred)**		Median: 9 Range: 6-24
Most common other stroke effects		
	Memory	6 (50%)
	Lower limb / mobility	6 (50%)
	Upper limb	5 (41.7%)
	Cognition	3 (25%)
	Psychological	2 (16.7%)
Living situation		
	Alone	3 (25%)
	With family	4 (33.3%)
	With spouse	5 (41.7%)

Table 2 Framework categories developed during analysis

Framework Categories
1. How vision has changed
2. Emotional impact
3. Changes in personal relationships
4. Interaction between vision and other post-stroke impairments
5. Effect on daily activities
6. Dealing with and managing visual problems
7. Goals
8. Thoughts on the training and study

Figures

Figure 1: Visual field loss in stroke survivor's daily life: conflict between perception, experience and knowledge

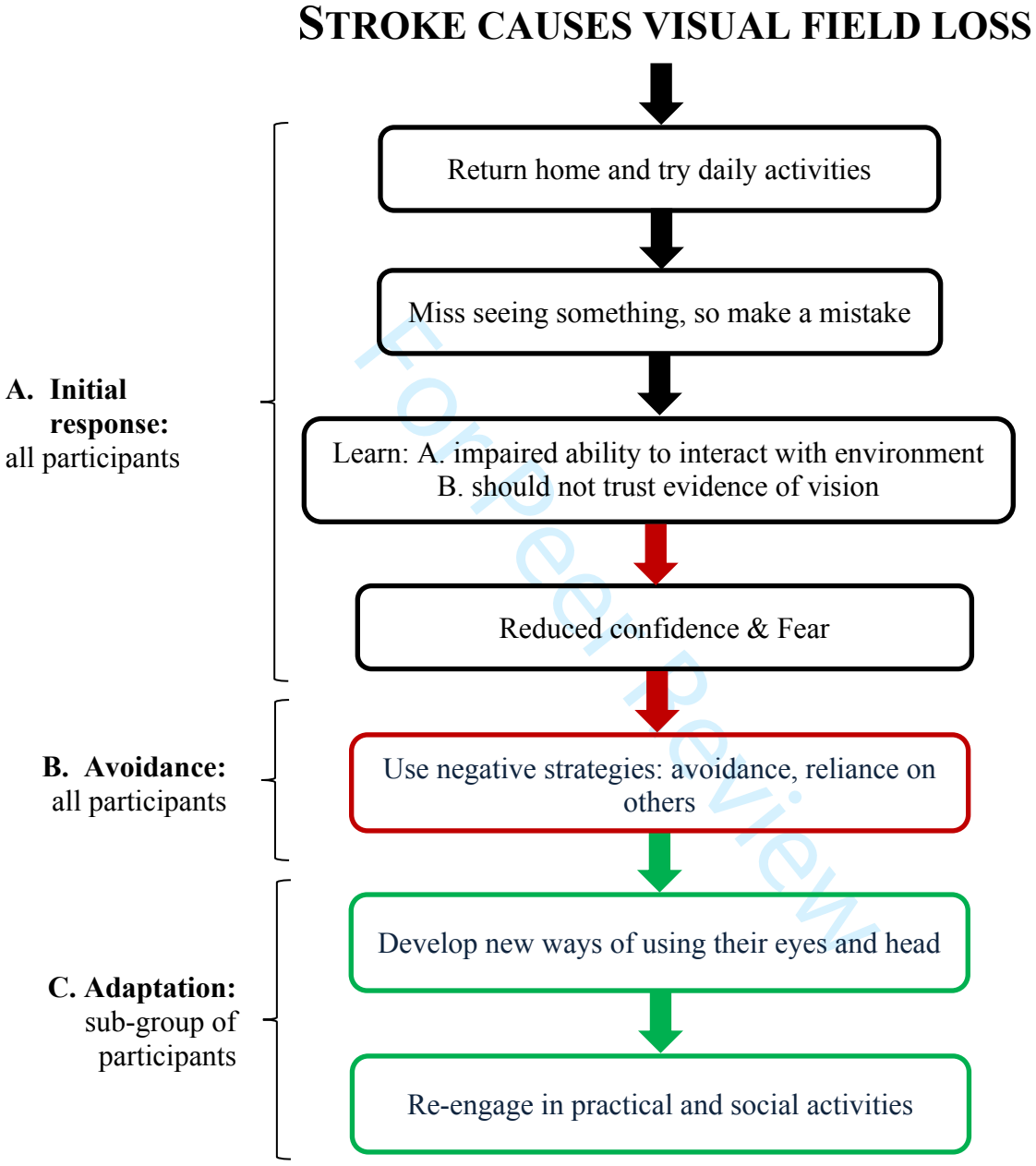


Key

VFL: visual field loss

Figure 2

Figure 2: Avoidance and adaptation responses to visual field loss



Title: Supplementary Material 1

Description: Interview prompt sheet questions

- Tell me about your stroke(s)
- How were you first aware of problems with your vision?
- What difficulties have you experienced because of your vision?
- What has helped you with your vision problems and difficulties?
- What aspects of your daily life, that have been affected by your visual problems, would you most like to improve?
- Is there anything else you would like to tell me that we haven't already covered?

Title: Supplementary Material 2

Description: Full list of identified categories and codes

Category	Included Codes
How vision has changed	1. describing their visual loss 2. vision not an instinctive action 3. lack of awareness or understanding 4. vision as a presenting symptom
Emotional Impact	1. fear / anxiety / worry 2. confidence 3. independence / burden 4. frustration 5. embarrassment 6. resentment / hatred 7. remembrance / loss (of their previous life) 8. denial 9. depression 10. self-image and self-worth 11. positive emotional responses 12. other emotional
Changes in personal relationships	1. impact on family relationships (incl role) 2. dependency on and impact on others 3. impact on social situations 4. how others treat them or see them now
Interaction between vision and other post-stroke impairments	1. vision and physical impairments 2. vision and cognition 3. vision and language 4. vision and fatigue (or struggle) 5. the impact of vision on stroke rehab 6. the impact of stroke impairments on vision rehab 7. other interactions
Impact on daily activities	1. overall or general impact 2. reading 3. driving 4. everyday activities 5. mobility in the house 6. bumps and falls 7. outdoor mobility / getting out of the house

	8. work & return to work 9. leisure & social activities 10. doing things themselves 11. other impact
Living with and managing visual problems	1. change over time 2. vision-related management strategies 3. other self-management and coping strategies 4. internal and personal factors affecting management 5. external factors affecting management 6. support from family, friend s and others 7. assessment and management services 8. provision of information 9. wider service needs and support 10. other
Goals	1. improvement in their vision 2. driving 3. reading 4. returning to work 5. improved confidence 6. independence / doing things unaided 7. family role 8. other
Thoughts on the training and study	1. knowledge expectations & opinions 2. attitude to the study or training 3. barriers 4. facilitators