



# Renegotiating identity: The cognitive load of evaluating identity and self-presentation after vision loss

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## ARTICLE INFO

### Keywords:

Vision loss  
Disability  
Identity work  
Self-presentation  
Cognitive load

## ABSTRACT

When a person is diagnosed with a condition leading to vision loss, life cannot go on as before. As well as developing new ways to manage their daily activities, people must manage the shock to their identity and decide how they now wish to present themselves. These add to the cognitive load of people with who experience vision loss over and above that of their sighted peers. Our qualitative interview study used a thematic analysis to explore the experiences of people with a condition causing vision loss to understand the work they undertook to integrate this diagnosis into their identity (or not) and to decide how and when to communicate their vision loss to others. People often navigated between identities: their identity prior to the diagnosis, and “the blind person” – an identity forced upon them. Linked to this, but a separate task, was deciding how they wished to present themselves to the world – to fully acknowledge their disabilities, to completely cover them, or to choose a path between these extremes. Self-presentation also depended on the audience (family, friends, colleagues, strangers) and this decision was not a single event: most people faced the necessity of repeating this process many times as their vision fluctuated or circumstances changed, and the cognitive effort this required exacted a toll. We build on the work of the disabled identity, identity continuity and self-presentation theory to describe the experiences of people managing their sense of self when faced with the uncertainty of deteriorating vision and deciding how to present themselves to others. This work requires considerable cognitive effort, adding an additional cognitive penalty of disability to those already coping with the practical difficulties of vision loss.

## 1. Introduction

Vision in some ways defines us. Seeing and being seen is a key form of human connection. From our earliest stages of development, eye contact with a caregiver is fundamental in learning about the world. Sighted babies learn what is important in life when they develop the ability to follow the gaze of a caregiver, and eye contact is considered a necessity for connection in many cultures (Kleinke, 1986).

### 1.1. The cognitive consequences of vision loss

Against this backdrop, the spectre of losing one’s ability to see can be a terrifying one (Enoch et al., 2019). A diagnosis of a condition leading to vision loss often comes as a terrible shock (Ferrey et al., 2022) and it takes some time to come to terms with it (Boagey, Jolly, & Ferrey, 2022).

“Coming to terms with it”, however, is not necessarily an automatic process, or one that occurs without considerable work on the part of the person who has been diagnosed.

In general, living with a visual impairment requires extra effort. The world is largely designed for fully sighted people, and those with a visual impairment must get along with the help of magnifiers, talking clocks, screen readers and so on. Each new technology must be learned and then integrated into the activities of daily living. Coming to terms with a change in circumstances such as a visual impairment also requires cognitive effort on top of all this. This is sometimes tacitly acknowledged, but little previous literature has explored the effort involved in coming to terms with a visual impairment and making decisions around self-presentation from a cognitive perspective. In this paper, we briefly explore two areas described by participants as requiring additional thought and effort: identity work around coming to terms with a

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<https://doi.org/10.1016/j.ssmqr.2023.100372>

Received 20 April 2023; Received in revised form 24 November 2023; Accepted 25 November 2023

Available online 1 December 2023

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disabled identity, and self-presentation work, around managing others' impressions. People with a visual impairment may not think of these tasks in terms of the cognitive effort they require, but they are able to describe the work they do and the cognitive effort undertaken quite clearly.

This is an important concept for sighted people to understand: appreciating the difficulties involved in living with a visual impairment may help them to provide appropriate social support to friends or colleagues, and social support is a predictor of improved of self-esteem in people with a visual impairment (Huurte et al., 1999). By enhancing awareness, it is more likely that people with a visual impairment will be given support, improving their mental health and wellbeing (Augestad, 2017).

### 1.2. Identity in the face of biographical disruption

Similarly to the diagnosis of other chronic illnesses, vision loss can be seen as a biographical disruption (Bury, 1982) in which the "structures of everyday life and the forms of knowledge which underpin them are disrupted" (p 169), requiring a fundamental rethinking of the person's biography and self-concept. After a diagnosis of a condition leading to vision loss, a person's identity must be renegotiated and the new information about current or potential disability somehow integrated. This is a difficult and often ongoing job, and requires considerable cognitive effort on the part of the person who has been given the diagnosis, as part of the process of adapting to the disability (Livneh, 2022).

The concept of biographical disruption focusses on the impact of a sudden disability or illness on identity, and is largely concerned with how individuals adapt to their new circumstances (Livneh, 2022). In contrast, "identity continuity" instead highlights the desire to maintain continuity of identity in the face of a disruption rather than a focus on the loss (Wolfenden & Grace, 2012). This concept is useful in exploring identity after many kinds of loss, not just a physical illness or disability (Papa & Lancaster, 2016) and may help explain why people with a visual impairment may focus on continuing their identity as an independent person after they begin to lose their vision – for example, they may be reluctant to ask for help navigating, identifying others, cooking, and other tasks that represent independence.

Identity does not exist in a vacuum, related only to one's inner self. A person's identity is also determined by societal meanings ascribed to a person's role, including professional roles (with their implications of competence and independence) and social roles (e.g., a parent who can protect their child). Therefore, In responding to the news of a disability, the impact of a person's social sphere cannot be ignored. Identity is affected by social context (Ellemers et al., 2002). A sudden disruption to one's identity in the form of a diagnosis of a disabling disease affects one's identity both directly and through interactions with others.

### 1.3. Self-presentation

Still more effort must be expended on managing others' impressions of oneself, as indicated in reports from our PPI panel. As well as wishing to see themselves as self-reliant and independent, a person is likely to also be concerned about others viewing them in this way. People who are losing their vision refer to wanting to be "seen as independent" and "seen as competent". Losing one's vision can interfere with this, as it can become more difficult to move about independently and perform the activities of daily living (Sanders, 2000). Some people with a visual impairment have difficulties with aspects of personal care and may not be able to evaluate their own appearance very well visually (Weih et al., 2002). As well, people living with a condition causing vision loss are at a double social disadvantage: they may not be able to pick up visual cues that would provide social information about others, but others are able to draw inferences about their disability, depending on how they present themselves (Lamoureux et al., 2004).

Self-presentation (Goffman, 1959) is behaviour undertaken to convey

an image of oneself to others (Baumeister & Hutton, 1987). Although self-presentation is usually automatic, relying on "self-presentation scripts" that are communicated through actions (gestures, tone etc), it becomes more effortful when a person is uncertain about the type of impression that might be created (Schlenker, 2012). A person with a visual impairment may not know the visual impression they are creating (i.e., they may not be completely certain how they look to others), meaning that in many social situations, self-presentation is likely to involve "controlled processes" that require additional cognitive effort.

Why do people work so hard to manage the perception of their disability? A key concept here is the stigma associated with disability (Goffman, 1963) – a noticing of a difference in a social context and subsequent devaluation, or disqualification from full social acceptance, of the stigmatized person based on this. Vision loss is a stigmatized disability. People with a disability are at risk of being confronted with ableism (Hehir, 2007) – discrimination and prejudice against individuals with disabilities. Indeed, the social model of disability postulates that disability is a result of the inaccessibility of society (Winter, 2003) and related to the attitudes and judgements of others, in contrast to the medical model of disability which focuses on impairment. Society often perpetuates ableist norms and ideals, creating an environment where individuals with disabilities are expected to conform to narrow standards of "normalcy." This can lead to immense pressure and anxiety for disabled individuals around how others will respond to them (Hicksted, 2023; Spiegel et al., 2016). They may feel compelled to hide or downplay their disabilities, fearing judgment, exclusion, or pity. The constant need to mask or compensate for their disabilities can be exhausting and detrimental to one's self-esteem and mental well-being.

Vision loss also cannot necessarily be detected from the outside. It is a continuum, as many people with a visual impairment do have some ability to see. Even those who are quite severely visually impaired may not have an obviously disability in some contexts – e.g., they may be able to navigate quite confidently through a familiar place. Therefore, unlike many other disabilities, in some cases people with a visual impairment can choose whether to disclose their disability to others. They may choose to avoid any chance of disability-related stigma (and attempt to maintain identity continuity) by presenting as non-disabled as much as possible. However, in order to obtain help or social support from others, they must explain that they are unable to see. Many people with a visual impairment, therefore, both have some choice in whether to disclose their disability and how much to say (Spiegel et al., 2016), and have the complicated job of making decisions around this choice depending on the outcome they wish to achieve.

Given all this, it is unsurprising that people with a visual impairment might think carefully about how they can manage others' perceptions of them, particularly in cases when their disability is not immediately obvious to the casual observer. People engage in self-presentation management in order to control and monitor the impression others form of them, in an effort to influence the way others perceive them – and via this, the way others respond to and treat them. It can be viewed as a shield against stigma. If a disability is not necessarily immediately visible unless the person with the disability provides cues to it, the best way of avoiding disability-related stigma is to tightly control one's self-presentation by presenting as non-disabled when possible.

Therefore, once diagnosed, a person with a visual impairment is plunged into a constant inner negotiation about who to tell, how much to tell and when to tell. Remaining silent about their vision loss allows the assumption of "normality" or non-disability, as long as all cues that might indicate disability are tightly controlled. Similarly to people with other illnesses and disabilities, people may become experts at "reading cues about how much to tell and when to tell it" (Charmaz, 2002) (p 317) – with the added complication, of course, that they may not be able to see the facial expressions and bodily cues that can convey this information.

The aim of this qualitative study was to examine several aspects of the additional cognitive load associated with vision loss, over and above

learning to navigate, use low-vision aids and so on. It explores the interplay between negotiating one’s own identity after being diagnosed with a condition leading to vision loss and determining how to present oneself to others. Participants described undertaking both of these tasks, generally over a period of time. This involved a lot of work, particularly since the ground often shifted due to changes in vision, in health or in other aspects of their lives, such as employment.

2. Materials and methods

2.1. Sample and recruitment

This study was approved by the Health Regulatory Authority (18/SW/0124) and adhered to the Declaration of Helsinki. We used a variety of recruitment methods: patients were identified by the eye hospital or volunteered after hearing about the study from a charity or group, or by snowballing through existing contacts. Eighteen participants with a diagnosis of eye disease (Table 1) were recruited, provided with an introductory letter and a participant information sheet, and interviewed in person or by telephone. Consent forms were returned by post when interviews took place by telephone. Participants were encouraged to ask questions about the study and all interviews were arranged at a time and location (in the case of in-person interviews) of their choosing. We

sought a maximum variation purposive sample in order to capture a wide range of experiences. Demographic data are presented in Table 1.

2.2. Interviews and data analysis

Interviews were conducted by an experienced interviewer (AF) between July 2018 and February 2020. Participants gave informed written consent prior to the interview. A semi-structured topic guide was used which included an initial open-ended section in which the participant explained their experiences of vision loss and its effects in their own words. Semi-structured prompts were then used to elicit information on the impact of vision loss on a person’s life, relationships and ways in which they interacted with others. Participants were asked about the effect of their diagnosis, both on life in general and on their mental and psychological health. They were also asked to discuss their strategies for coping with their vision loss. They were not specifically asked about their own identity or self-presentation; these topics emerged as participants discussed their experiences. Interviews generally lasted between 60 and 120 min and continued until participants felt they had fully explored the topic. All interviews were audio-taped and transcribed verbatim from the encrypted recordings by professional transcribers and checked by the researchers. Final transcripts were uploaded to NVivo 12 (QSR International, USA). Pseudonyms were assigned to all participants to ensure confidentiality and anonymity.

Thematic data analysis (Braun and Clarke, 2006) took an inductive approach informed by grounded theory methodology. Using inductive methods allowed us to remain rooted in the data(Charmaz, 2002). Constant comparison was used to locate relationships between concepts and themes across interviews (Glaser & Strauss, 1967) related to the experience of integrating the new information about the diagnosis into a person’s identity and their experiences of deciding how to present themselves to others. After several close readings of each transcript, data were assigned to categories using the NVivo ‘node’ function by AF, based on interpretation of the interview transcripts. Using constant comparison, a coding framework of emergent themes was developed. Broad themes were identified related to coded segments of data on topics related to discussions of identity, decisions about who to tell about their vision loss and the work involved in both renegotiating their identity in the light of the diagnosis and explaining their disability to others. Themes were then checked and illustrated using the stories participants told about the work involved in coming to terms with their visual impairment and deciding how to present themselves.

2.3. Author positionality

The researchers are not visually impaired. [Author 1] is a cognitive psychologist by background working in an interdisciplinary setting, with an ongoing interest in mental health and novel ways to improve wellbeing. She has no background in vision loss but extensive experience in mental health and wellbeing, as well as the effects of increased cognitive load.

[Author 2] is a health service researcher with a background in medical studies and medical sociology with a particular interest in the management of long-term conditions from the perspective of patients and health professionals. Although she has no experience of vision loss she has extensive experience of research into person centred care, patient and public involvement and a patient’s response to illness, diagnosis and the treatment journey.

[Author 3] specialises in visual impairment and is qualified and has practiced in low vision care for >20 years. This work was inspired by patient reports during the low vision work to [Author 3] and a desire to improve the care being provided. By performing the study and providing evidence base for the additional cognitive load of visual impairment (VI) we can raise the profile amongst practitioners working with people who are VI. Regular focus groups were undertaken with VI patients throughout this work to inform the work and also confirm the findings

Table 1  
Patient Demographic data.

Age	Frequency
<39 years	3
40–59 years	6
>60 years	9
<b>Gender</b>	
Female	9
Male	9
<b>Condition</b>	
Diabetic retinopathy	1
Ushers Syndrome Type 2	2
Stargardt Disease	2
Macular degeneration	2
Central vein occlusion	1
Choroideremia	1
Retinitis pigmentosa	8
Degenerative myopia & glaucoma	1
<b>Interview Type</b>	
In person	11
Telephone	7
<b>Living status</b>	
Alone	9
With others	7
Not Known	2

with the participants before publication, so that PPI was embedded in the heart of this work.

### 3. Findings

Questions of identity came to the fore, with many participants struggling with whether they identified as a “blind person”. Intertwined with this was the question of whether they wished to be seen as a “blind person” by others – and whether this changed depending on the social roles (family, friends, work colleagues) or context in question. Both of these elements exemplified the additional cognitive load placed on people who had experienced vision loss.

Three major themes spoke to the difficult and complicated business of renegotiating both a person’s identity and the image they present to the world, and the additional cognitive load this adds (see Fig. 1). These themes included “Identity after diagnosis”, “Self-presentation” and “Effort and cognitive penalty”. Participants described the work they undertook both to integrate the diagnosis into their identity and to decide how much to explain to others. This was complicated by the trajectory of a person’s vision loss. Deterioration in vision could be quite sudden or very slow, and this also affected disclosing vision loss to others and incorporating visual disability into one’s identity. Participants experienced these factors, as well as other requirements like relearning to navigate, learning to use low-vision technology etc, as additional cognitive “work” that was not required of their sighted peers.

#### 3.1. Identity after diagnosis

Being diagnosed with a condition leading to vision loss generally came as a shock (Ferrey et al., 2022) and it often took some time to come to terms with the diagnosis and all its implications. These implications included medical questions, concerns about the heritability of the disorder and decisions around whether and how to use low vision aids to cope with the activities of daily living. However, there were also pressing questions around continuity of identity, and how to integrate this new information.

Receiving a diagnosis could suddenly bring into focus months or years of difficulties that may not have been fully realised – “I didn’t have any feeling at that point that anything was wrong ... but in hindsight, yeah, there were probably some early clues there” (Luisa). It is possible to be disabled without recognising this oneself (Grue, 2016), and among our participants there was a feeling that perhaps they should have known earlier that something was wrong. In some cases, clues that were noticed were discounted because they did not want to think that their vision might not be as sharp as it once was. Participants described coping with difficulties using work-around strategies (such as always holidaying at a familiar resort) or not realising that certain problems were a result of vision loss, such as having difficulties navigating in dimly-lit environments. All of this coping involved additional effort, although it was not always noticed if changes in vision occurred slowly.

Several participants described being labelled “clumsy” as a child, only later realising that these accidents could be attributed to poor vision. Similarly, Deborah had “always had bad night vision. And it’s always just been a bit of a joke, really.” For these people, something that may have been a bit of a joke (clumsiness, losing things or poor night vision) was suddenly revealed as a harbinger of a potentially severe disability and a threat to their entire way of life. Understandably, this was difficult to come to terms with. Traits that seemed benign or even charming were now signs of current or impending disability.

Each person then had to find a way to fit this new diagnosis into the way they saw themselves and incorporate it into their identity. This brought to the fore participants’ often unexamined pre-existing beliefs about disability – that it precludes independence, opens the door to stigma and makes a person “less than” (Garthwaite, 2015) – a “spoiled identity” (Goffman, 1963). The instinctive rejection of the “blind identity” expressed by some of the participants and the equating of vision loss with losing one’s independence appeared to be linked to internalised negative beliefs about disability (Martz, 2004). For example, Jamie “did not want to be defined by it [his genetic condition]” while Christos explicitly described himself as being between two identities – his “normal self” and his “disabled identity”.

*“At the moment I kind of feel like I’m in between two identities, if that makes sense ... On the one hand, I’m [Christos] the normal outgoing guy. And the other, the other side is this guy who’s losing his vision, you know, and doesn’t hear very well.”*

Christos thus distanced himself verbally from his own disabled identity. He characterised his “disabled identity” by what it cannot do (see or hear well), but contrasted this identity with his identity as a “normal outgoing guy” – i.e., not stigmatized or “other”. It is not the difficulties with seeing or hearing alone that made the disabled identity seem so far from the “normal” to Christos – it was the accompanying stigma, whether related to self-stigmatisation or stigma from others.

Patients also sometimes specified the terminology they felt best described them, perhaps describing their current identity more specifically. The word “blind” was often a focus of this careful use of language. For example, Luisa said, “I’m not hundred percent blind. But sometimes I don’t see as quick as a normal person.” Similarly, when Deborah’s primary-aged child asked “Oh, are you blind, or something?” she responded “Don’t say that to people, you know?.. ‘I know I can’t see very well in the dark, but that’s it – I just can’t see very well in the dark, really.’” Clara had not registered as sight impaired “because I’m not really totally ... I mean, I can’t see well, but I can see.” Specifying the nature of their impairment distanced Luisa, Deborah and Clara from including themselves in the catchall label of “blind”. To describe themselves as blind or visually impaired felt wrong and untruthful – in conflict with their identity.

Those who felt more confident in their identity, including their disability, seemed to wrestle less with these concerns. “At the end of the day, if you don’t like me for me, and what I’ve got, then it’s your problem.” (Nathan). This may be partially due to the benefit of having to spend less time and cognitive effort on coming to terms with one’s identity (see section 3.3).

#### 3.2. Self-presentation

Regardless of whether a person with a visual impairment identified as disabled or not, the reality of a visual impairment was that they needed to modify some aspects of their lives to compensate for the lost vision. This often affected how they presented themselves to others. For example, they sometimes needed to ask for help from others more than they would previously have done, or explain actions such as avoiding travelling at night. Needless to say, all this explaining and asking added to the mental burden associated with vision loss.

Depending on the eye condition, vision loss could be quite gradual and is not always obvious, even to a person’s family and close friends.

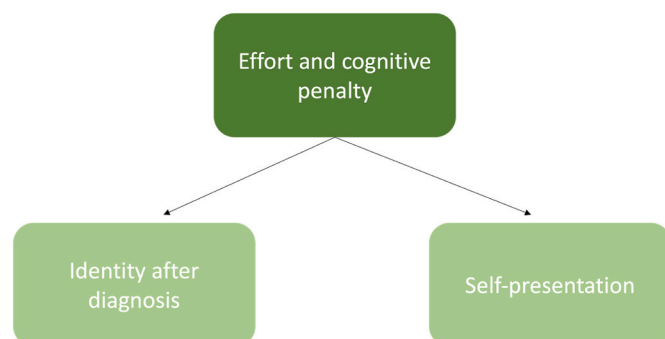


Fig. 1. Graphical representation of themes.



Nathan's colleagues said, 'well, I had no idea' ... 'I never would have guessed' when he told them about his diagnosis. Michelle referred to vision loss as an "invisible illness" – "people don't see it, people don't know." Vision loss could be particularly invisible to strangers. Therefore, in many cases the person with a visual impairment has a *choice* about what and how much to disclose. Separately to any inner work done to integrate their disability into their identity -but perhaps hinging on it - people must make decisions around who to tell about their impairments, how much to tell them and when to explain.

Thinking about who to tell about the diagnosis (family, friends, acquaintances, love interests, work colleagues?) and how to present themselves could preoccupy people who were newly diagnosed or who found their condition was deteriorating. "I try and minimise the number of people that know about the condition anyway, I don't think it's particularly ... relevant to my relationships with people at work, etc" (Jamie). Several people also mentioned that they did not wish to lose their independence ("I don't want any help ... I can do this on my own" [Nathan]) or perception of independence to others.

In order to manage the perceptions of others, our participants carefully chose how to explain their difficulties or use of aids such as special glasses. When asked about her glasses, Michelle only admits to having an "eye condition" or "problems with her eyesight". Margaret, who worked as a teacher, made a game of having students help her keep track of the glasses she was always losing – and the students never realised that Margaret could not see the glasses at all as her vision had deteriorated so much.

Avoiding disability-related stigma or pity were key motives for aiming to present to others as non-disabled. Brenda said, "there's a huge fear, blindness and all that comes with it, people really fear ... you sense their fear and anxiety." Jamie "didn't want to be treated differently as a result" of disclosing his deteriorating vision. Nathan explained that he once felt that telling people about his disability "can scare someone away ... it could put pressure on the relationship." Indeed, Goffman (Goffman, 1963) and others (e.g., Pryor et al., 2012) have explored the phenomenon of "stigma by association", in which people who are closely associated with stigmatized individuals are also discredited. Christos described himself as "devalued" in his relationships because he needs "more help than a lot of people". In the context of a romantic relationship, he described this as "emasculating".

Repeated experience of disability-related stigma could lead to a reluctance to ask for help, or conversely to a strong desire to disclose their disability to others to dispel "worse" assumptions. For example, Lee worried that people would think he was drunk or "odd" if he did not explain his sight impairment: "people don't automatically assume that, okay, that person who's being a bit unusual, he's probably sight impaired ... they think, he's odd, I think I'll give him a wide berth." People with a disability are well aware that ableism is rife and these concerns likely underlie much of the preoccupation with self-presentation and decisions around disclosing a visual impairment to others.

Conversely, however, those who finally integrated the threat to their identity and were willing to disclose their status as a partially-sighted person to others found that others were quite often supportive. Nathan said, "Kept it quite bottled up to myself for probably a lot of my teenage years, until I was into my twenties, where then I started to open up a bit more. Started to explain a bit more what, what I've got .... And then I think that opened the door to sort of more support, me branching out to get more support."

Even the term "blind" was embraced and proudly displayed by some who had integrated their vision loss into their identity. Colin said, "When I'm out doing ... my long distance sort of walks and so on, the easy way out for me was – on the back of my rucksack, in sort of quite large, fluorescent letters, was to put the two words 'blind walker', on the back." Colin found this identified him to other road users, improved safety, and fit with his perception of himself. "I'm blind, and that works for me." Here again, once a decision had been made about self-

presentation (often as a consequence of having also resolved some questions around identity [section 3.1]), releasing a person from rumination on these topics and freeing up cognitive resources.

### 3.3. Effort and cognitive penalty

The twin processes of renegotiating one's identity and renegotiating one's social presentation required a lot of time, thought and energy. This extra effort was not required prior to the vision loss and was performed in addition to managing the usual activities of daily living, work and leisure activities with low vision. Furthermore, every time a person's impairment fluctuated, further work was required to assess how this change might affect identity, and how they should now present themselves to others.

Disclosing a condition to others also took a toll, on top of the work involved in just having a visual impairment. Lee explained:

So it is just ... a case of constantly having to learn a new way of doing things and constantly having to sort of adjust ... having to explain the situation to strangers who, you know, will come out with things like [um] 'You don't look blind' or 'You don't look severely sight impaired' and, and that feeling of actually having to explain myself to other people.

Concealing a visual impairment also required a considerable amount of work.

Jamie described "doing a scope" of a room alone before meeting others there, to check for steps or other hazards so others would not see him stumble. As above, Margaret misdirected her class by "losing" the glasses she could not see. Leslie collected gadgets and tools (talking tape measures, bits of wood of known lengths) and counted steps in a new location so he would know how to get out again.

Decisions about disclosure at work could be even more fraught (Spiegel et al., 2016; Tomas et al., 2022), as in this arena stigma could affect a person's livelihood. At work, Jamie put on a 'game face' and covered his disability:

*'I'm doing reasonably well at my job. I don't - yeah, I just don't want anyone to, to have any caveat with their opinion for me, I want it to be based on my personality and my performance. Rather than 'oh, he's doing really well for someone who's dealing with stuff outside of work' (Jamie)*

Although Jamie wished to be assessed similarly to his colleagues, the additional cognitive load placed on him by checking for hazards and covering his disability in work situations actually meant he was working much harder than a fully sighted person during every interaction (Charmaz, 2002).

Other work done by people with a visual impairment involved explaining away any mishaps or "odd" behaviour as being related to something other than a visual impairment. This constant monitoring, explaining and excuse-making exerted a considerable cognitive penalty on the person with a visual disability. For example, Nathan described making excuses for any mishaps: 'I walked into lamp posts, you know - I used to do that all the time, you know?' "oh, I was miles away, didn't see that". Deborah used her wine consumption as an excuse for having knocked her wine glass over when in fact she had not seen the glass.

Living with vision loss could add to a person's cognitive load even when they were alone. Jamie described not wanting to drift off into thought, lest he begin ruminating on how his vision loss has affected his life.

A decision to tell others about their condition often came as somewhat of a relief – removing some of the need to do the work of covering the disability (see section 3.2). Leslie called it "owning up" to people that he had the problem. When he started to have trouble in social situations – e.g., not recognising people in the pub - he felt it was better to explain than to face the social awkwardness that ensued when people did not realise that he had a problem. He characterised the response as "generous" – people began to introduce themselves if he did not recognise their voice and to guide him to a seat. Clara felt the same way –

"I have had to say to people, 'well, I know your voice - ... but I can't actually see your face'". Although explaining about a visual impairment could be difficult and forever removed the option of presenting oneself as non-disabled, it did remove the burden of constantly covering and devoting extensive cognitive resources to avoiding any reference to one's disability.

#### 4. Discussion

Being given a diagnosis leading to vision loss has many consequences. Some may be expected, such as difficulties moving around in low-light conditions or reading small print – "taken for granted tasks ... are disrupted such that everyday life becomes problematic" (Green et al., 2002)(pp 258–259). However, participants described two additional consequences: the need to re-evaluate or renegotiate their identity in light of their disability, and the constant decisions around how much of their disability to demonstrate or explain to others. Both of these processes require thought and processing on the part of the person who has been given the diagnosis. This mental effort is added to the additional work a visual impairment already requires, such as learning to use assistive technologies, developing methods such as counting steps to aid navigation, and coping with sometimes rapidly changing visual abilities. Thus, there is a large "cognitive penalty of disability" linked to vision loss.

Participants described the consequences of this major life change. Whether characterised as a "biological disruption" (Bury, 1982), a turning point, or an "epiphany" that requires "some kind of rebirth" (Frank, 1993) into a new identity, implicit in all of these descriptions is the effort required to "normalise in the face of disruption" (Bury, 1982). However, the interviews with our participants serve to draw out two specific pieces of work they had to undertake after being diagnosed with a visual impairment: identity work – renegotiating their identity to include this new diagnosis; and self-presentation work – managing the impression they convey of themselves to others. Self-presentation is particularly relevant to vision loss as many of these participants could often "pass" as non-disabled. However, generally this is not automatic and requires considerable effort on the part of the person with a visual impairment to cover anything that might indicate that they are unable to see clearly.

Describing the onset of an illness or disability as a biographical disruption tends to conceptualise it as a sort of roadbump or turning point in the path of life which a person must come to terms with, then move past into a new identity or way of being. This disruption changes everything and the after is not the same as the before. This quite linear approach did not match the experiences described by the participants in this study. Adapting to vision loss is not a linear process or a trajectory for most people, and complete adaptation may take some time, and may not ever be completely achieved (Powdthavee, 2009). It also takes effort – this is something people mull over and consider at length, and over sometimes quite extended periods of time. A complicating factor for people with a visual impairment is the progressive or sometimes fluctuating nature of the impairment. Disease progression varies considerably, a fact that patients wished they had been told at the time of diagnosis (Ferrey et al., 2022). Vision can remain stable for years, then suddenly deteriorate, and there is no way to tell what an individual patient's trajectory will be. This additional ambiguity adds to the difficulty of integrating this disability into one's identity. Similarly to chronic illnesses (Larsson & Grassman, 2012), in people with a visual impairment, losses and deteriorations may occur repeatedly over the lifespan, leading to multiple disruptions to identity and, crucially, to being forced yet again to integrate this new disability into one's identity. Although people may be aware that additional vision loss is a possibility, when it happens it is an unexpected and unpleasant surprise (Larsson & Grassman, 2012) that kicks off an additional process of renegotiation.

People can therefore be faced with an iterative process of coming to terms with a diagnosis, working through the impact on identity and self-

perception, and deciding how much to tell family, friends and colleagues – and then repeating the process again every time vision changes or deteriorates. Each additional life change (such as a new job) requires addressing these areas again. Rather than a turning point in the road, this is more like picking your way through a bog, where the ground is not solid and forward momentum is difficult because the ground may shift suddenly under your feet. The constant decisions and consideration of what every change means is exhausting and requires considerable cognitive effort.

Yoshida's metaphor of a "pendulum of self" (Yoshida, 1993), describing the process undertaken by those who have acquired disabilities, may better fit the experience of people with a visual impairment. She describes this reconstruction of self after becoming disabled as a pendulum which swings back and forth between disabled and non-disabled aspects of self. This better describes the ongoing nature of renegotiating one's identity after a diagnosis, and the clear impact of the change on one's self and identity. It is not a linear process or a trajectory for most people. A person may feel off-balance in their efforts to ensure identity continuity as the pendulum sweeps back and forth.

Separately, of course, each additional loss may influence the way in which it is possible for a person to present themselves to the world. There is a clear interplay between identity, stigma and ableism – people must be comfortable in their own disabled identity in order to "disclose" it to others, and self-acceptance is key (Brown & Leigh, 2018). Work around impression management (Leary & Kowalski, 1990) explores the ways in which individuals actively shape and control the perceptions others have of them. According to Leary and Kowalski (1990), impression management involves both conscious and unconscious efforts to control how one is perceived, aiming to create a favorable impression and maintain social acceptance. By adopting specific behaviors, appearances, and communication strategies, individuals seek to shape others' impressions, manage their own self-image, and align with social norms and expectations. Impression management can have significant implications for personal relationships, social integration, and success in various domains (Schlenker, 1980).

The mental calculus involved in decisions around who to disclose a condition to is already considerable, and the additional work of impression management adds to this burden. People may wish to tell some (e.g., close friends) and hide vision loss from others (e.g., work colleagues) in order to manage others' impressions of them as a competent and independent person. Indeed, there is some evidence that people will avoid using low-vision services that might help them considerably because of concerns about self-presentation (Spafford et al., 2009). A deterioration in vision may take away some of these choices. However, once information is disclosed it cannot be taken back.

This is key to recognise in professional and social settings. By requiring the visually impaired individual to educate others and make these decisions, the burden of vision impairment on the individual is increased. Workplaces need to incorporate additional training and accessibility practices to reduce the risks of disclosure and the need for such decision making. For example, it is helpful for managers and colleagues to understand that vision is not "all or nothing" and that people can vary in how their vision loss presents – they may be able to read (using some remaining central vision) but find it difficult to navigate new environments, or they may be able to navigate using remaining peripheral vision but not recognise faces. It is also important to understand that the trajectory of vision loss can vary, and to provide time and space (as well as additional adjustments such as screen readers) if vision deteriorates. However, as our work shows, not everyone with a visual impairment wishes to disclose this to others, and it is important to be sensitive to this. Providing practical support where needed (e.g., guidance in unfamiliar or dimly-lit environments) in a way that does not foreground the disability would be ideal.

Understanding the social model of disability may lead organisations, social groups, friends and families to be more supportive, thereby reducing the risks of disclosure and decreasing the cognitive burden

decision-making around disclosure of the visual impairment. Social support is key, and it can be helpful for family, friends and colleagues to understand the large volume of extra work undertaken by a person with a visual impairment on a daily basis and provide emotional and practical support with this where possible. Healthcare professionals must be aware that patients are dealing with more than just the physical effects of visual impairment, as there are many secondary impacts such as those outlined here. This provides an argument for better mental health support services for people with visual impairments, which are currently severely lacking. However, even expressing understanding of the mental strain caused by a visual impairment can be helpful.

#### 4.1. Limitations

Although our study included in-depth interviews with participants who varied in age, condition and lifestyle (see Table 1), we had a poor representation of participants from ethnic minorities. However, we spoke to people of a wide range of ages and diagnoses. Participants described their experiences as they remembered and interpreted them, but it was clear that some peoples' identities were currently in flux as they worked through the problem of their own identity and how to present themselves to others. Future work could focus on the ways in which people with a visual impairment reveal or conceal stigmatized identities.

#### 4.2. Conclusion

Being diagnosed with a condition leading to vision loss is a very stressful life event (Ferrey et al., 2022). However, the full implications of such a diagnosis only becomes fully evident months or years after the initial shock. Our participants described the additional work and cognitive effort associated with the diagnosis of a vision loss, such as learning to use low vision aids, sticking to familiar locations and working out how to avoid travelling at night. However, they also described two additional layers of work they had to undertake: renegotiating their identity (often multiple times) in the face of disability, and deciding who to tell about their disability. The latter involved multiple decisions about self-presentation and much effort related to either disclosing or hiding their visual impairment. This qualitative study outlines the cognitive penalty exacted by living with a visual impairment and the strategies people use to manage their lives in the face of this. A wider shift to the social model of disability with accessibility built in would help to reduce this additional load.

#### Funding

This study was supported by a grant from Oxfordshire Health Services Research Committee (OHSRC) grant number 1379. This work was also supported by the NIHR Oxford Biomedical Research Centre. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health. The sponsor and funding organization had no role in the design or conduct of this research.

#### CRedit authorship contribution statement

**Anne E. Ferrey:** Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Writing – original draft. **Lucy Moore:** Writing – review & editing. **Jasleen K. Jolly:** Conceptualization, Funding acquisition, Investigation, Methodology, Project administration, Writing – review & editing.

#### Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

#### Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.ssmqr.2023.100372>.

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