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Abstract

The objective of this study was to explore the pattern of adaptation in patients who have been diagnosed with visual impairment. Participants ($N = 700$), recruited in the Montreal area (Canada), underwent a structured interview in order to collect information on the duration of the acquired visual impairment and answered the 'Brief Coping', 'Satisfaction with Life Scale' and 'Center for Epidemiologic Studies–Depression Scale' (CES-D). Multivariate analysis of covariance (MANCOVA) revealed that patients who have lived with vision impairment for over 2 years reach significantly higher acceptance and lower denial levels compared to those of patients who had recent vision loss (≤ 2 years). We also found that acceptance was positively correlated with well-being and denial with depression, while acceptance was negatively correlated with depression and, likewise, denial with well-being. Our study results suggest that patients who have been diagnosed with visual impairment engage in an adaptive coping style early in the grief process.

Keywords

Grieving process, visual impairment, acceptance, denial, depression, well-being

Introduction

The traditional five-stage model of grief proposes that people move from denial to acceptance when they are facing a loss (Kübler-Ross, 1970). This theoretical model, inspired by Kübler-Ross's work with terminally ill patients, has been applied to various loss experiences outside its original context, such as the onset of diseases or the end of meaningful relationships. The first stage of this grieving model is the defence mechanism of denial, by which the reality of what is happening is

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denied. The second stage is anger; here, people are emotionally upset and can be angry with themselves or with others. The third stage is bargaining, wherein the individual tries to negotiate a compromise with some form of deity. The fourth stage is depression, with the individual feeling sadness, regret, fear, and uncertainty. Finally, the fifth stage of the model is acceptance, occurring when the individual comes to terms with his or her situation. Kübler-Ross (1970) insisted that the order of the five stages is not chronological and that not everyone will necessarily experience all of these stages since the emotional journey is very individualised.

The grief model has been applied to the case of visual impairment based on the rationale that traumas of vision loss are not fundamentally different from adjusting to any other significant crisis, change, or loss (Giarratana-Oehler, 1976). In fact, visual impairment is a severe chronic health (and functional) loss condition (Schilling & Wahl, 2006), and thus is a significant crisis by definition. For instance, visual impairment has significant negative impacts on a person's quality of life and daily living, much like cancer, constituting one of the most feared health conditions (National Coalition for Vision Health, 2008). It has also been reported that visual impairment can have a greater impact on physical role limitations than several other serious health conditions such as hypertension or diabetes (Lee, Spritzer, & Hays, 1997). Similarly, Stein, Brown, Brown, Hollands, and Sharma (2003) used time-trade-off methods to assess health-related quality of life and showed that age-related macular patients obtained scores comparable to patients having systemic diseases such as stroke and myocardial infarction.

Existing vision rehabilitation services aim to help patients with the adaptation process by offering functional training and psychosocial support (De Boer et al., 2006). The support provided by these services should help patients adapt to their visual impairment and recover a better quality of life. However, it has been estimated that less than 20 percent of adults with vision loss use rehabilitation services (Gresset & Baumgarten, 2002). The low utilisation of rehabilitation services that we see in cases of vision loss might be partly a consequence of some lack of referral from the eye care services to the rehabilitation services (Overbury & Wittich, 2011) but might also be a consequence of individual denial. Indeed, denial is considered to be a barrier to the utilisation of rehabilitation services, while acceptance is the first step towards service utilisation (Pollard, Simpson, Lamoureux, & Keeffe, 2003). Thus, it appears that, at the very least, the first and last stages of the traditional grief model are essential stages to consider, in relation to the decision to seek help from existing services in order to better adapt to vision loss.

In the context of vision loss, denial is defined as a disbelief and refusal to acknowledge the impairment (Tuttle & Tuttle, 2004), while acceptance refers to a full acknowledgement of the vision loss and the subsequent acquirement of new behaviours (Hicks, 1979). Traditionally, acceptance is viewed as the last stage of the grief process for adjustment to loss of sight (Conyers, 1992).

Researchers have adopted several different strategies for assessing responses to loss (Potvin, Lasker, & Toedter, 1989), such as scales to assess grief due to the loss of a significant person (Bourgeois, 2006); however, none of them have been adapted to vision loss. Phenomenology is another common method used to assess adaptation to vision loss (e.g. Lee & Brennan, 2002; Murray, McKay, & Nieuwoudt, 2010; Stanford, Waterman, Russell, & Harper, 2009). Because there is no unique way to face vision loss (Tuttle & Tuttle, 2004), capturing subjective experience becomes relevant to have a better understanding of the individual adaptation under those circumstances. However, if we try to capture more specifically some components of the grieving process, it may be more straightforward to use objective measurements such as scales assessing adaptation. One such objective metric is the Brief COPE (BC; Carver, 1997). BC assesses general coping with daily and major life events, and it has been used in many situations such as chronic illness and

diagnosis of life-threatening illnesses (e.g. Reich, Johnson, Zautra, & Davis, 2006; Yi-Frazier et al., 2010). In it, two of the 14 subscales assess the first and last stages of the grieving process, that is, denial and acceptance, respectively. Denial is conceptualised by the BC as 'refusal to believe that the stressor exists or as trying to act as though the stressor is not real', whereas acceptance is viewed as 'seeing a stressor as real and attempting to deal with the situation'. Since *denial* and *acceptance* in the BC are defined under the same conceptual framework and because the two stages (*denial* and *acceptance*) are conceptually related in the context of a vision loss, it seems logical that the BC could capture these first and last stages of the vision loss grieving process.

Well-being and depression

Grieving is considered a stressful life event that has a severe impact on psychological well-being (Lalitha & Jamuna, 2004). In the context of vision loss, grieving does not differ in terms of consequences. Individuals with visual impairment may experience a degradation of psychological well-being, decreased life satisfaction, and poor adaptation to vision loss (Brennan & Cardinali, 2000; Horowitz & Reinhardt, 1998; Horowitz, Reinhardt, McNerney, & Balistreri, 1994).

Grieving may also involve symptoms of depression (Hensley, 2006; Kendler, Myers, & Zisook, 2008). The diagnosis of a severe chronic health loss condition such as vision loss is often the beginning of emotional and physical losses (Schilling & Wahl, 2006; Strada, 2009). According to Tuttle and Tuttle (2004),

The individual may begin to analyse, one by one, the perceived losses or inability regardless of whether they are realistic or not [...]. Although feelings of distress and doubt are common, in more extreme instances the emotional reactions [to visual impairment] may result in severe depression (p. 55).

In fact, visual impairment has been shown to increase the risk of depression (Desrosiers et al., 2009; Renaud et al., 2010). The rate of depressive disorders among elderly adults with advanced macular degeneration (32.5%) is approximately twice as high as that found in the general community-dwelling elderly population (Brody et al., 2001). In some cases, the disability represents such an un-adjustable state that one must try to deny it (Wright, 1974).

Thus, one may adapt to visual impairment in several ways. Adaptation to vision loss, in terms of coping strategies (i.e. acceptance and denial) and psychological outcomes (i.e. well-being and depression), may be a function of the duration of vision loss. In the past 6 years, two longitudinal studies have attempted to understand how psychological adaptation to vision loss changes over time (Schilling & Wahl, 2006; Schilling, Wahl, Horowitz, Reinhardt, & Boerner, 2011). In one case, psychological adaptation to age-related macular degeneration (AMD) was studied in terms of subjective well-being (i.e. positive and negative affects; Schilling & Wahl, 2006). In Schilling and Wahl's study, 90 seniors with AMD were followed for a 1-year period, during which five measurement points of affective well-being (measured by the Positive and Negative Affect Schedules [PANAS]; Watson, Clark, & Tellegen, 1988) were conducted at 3-month intervals. Their results indicated that positive affect tends to decline in the initial phase of the disease, slow down with temporal distance to the outbreak, and finally level off. In contrast, there was no trend of mean-level change for negative affect. More recently, Schilling and colleagues (2011) conducted a 1-year follow-up study among 451 AMD patients to establish the adaptation dynamics of chronic functional impairment. Their results suggested that perceived functional vision losses mediated the effects of vision loss on psychological well-being (measured by the Adaptation to Age-Related Vision Loss Scale [AVL]; Horowitz & Reinhardt, 1998). One explanation the authors offered for

these findings was that the early phases of vision impairment demoralise individuals in terms of psychological attitudes. However, as their experience of visual impairment continues, individuals get used to their condition and are then able to keep these attitudes differentiated from the functional consequences of vision loss. Thus, the findings of these two studies suggest that the time elapsed after a person has received a diagnosis is an important factor influencing adaptation to vision loss. However, the term 'adaptation' may be embodied in a broader definition involving acceptance, denial, depression, and well-being. Thus, in contrast to previous studies, we used scales designed to assess those particular constructs. Moreover, because the two longitudinal studies described above were conducted within a relatively short period of time (i.e. 1 year), it is difficult to establish the relationship between the duration of vision loss and the way one is coping with this loss. The use of a cross-sectional design is thus better suited to capture how people adapt as a function of duration of vision loss.

Study purpose

The aim of this study was to explore the pattern of adaptation to visual impairment in terms of denial, acceptance, well-being, and depression, among patients with varying lengths of time since diagnosis. The following hypotheses were tested:

Hypothesis 1: Acceptance will be more commonly reported by patients who have had their diagnosis for a longer time than by patients who have received their diagnosis more recently.

Hypothesis 2: Patients who have received their diagnosis more recently will report greater denial than patients who have lived with their visual impairment for a longer time.

Hypothesis 3: Patients who have lived with their visual impairment for a longer time will report greater well-being than the other patients (i.e. those with recent diagnoses).

Hypothesis 4: Patients who have lived with their visual impairment for a longer time will report less depression than those who have received their diagnosis more recently.

Hypothesis 5: Denial will be positively related to depression and negatively related to well-being.

Hypothesis 6: Acceptance will be positively related to well-being and negatively related to depression.

Methodology

Sample

The data in this study were drawn from a database produced by the Montreal Barriers Study, between January 2007 and October 2010. A total of 700 patients with best-corrected visual acuity worse than 20/70 or with a visual field $<60^\circ$ in their best eye were recruited at the time of their appointment from four ophthalmology departments in Montreal, Quebec (Sir Mortimer B. Davis Jewish General Hospital, Royal Victoria Hospital, Hôpital Notre Dame, and Hôpital Maisonneuve-Rosemont). The study protocol followed the tenets of the Declaration of Helsinki. Ethics approval was obtained from the Institutional Review Boards of the four hospitals as well as the Research Ethics Committee of the Center for Interdisciplinary Research in Rehabilitation of Greater Montreal. Study participants gave their written consent after having the purpose and procedure of the study explained to them by one of the nine research assistants involved in the study. Questionnaires were answered via in-person interviews with a research assistant. Participants

ranged from 26 to 100 years in age, with the majority over the age of 60 ($M = 74.26$, $SD = 13.56$). The male and female proportions were 44 and 55 percent, respectively. The majority of participants were diagnosed with macular degeneration (52%), followed by glaucoma (19%) and diabetic retinopathy (15%). The severity of visual impairment was proportionally distributed within the sample (38% mild impairment, 32% moderate impairment, 30% severe impairment).

Procedure

Participants were approached in the waiting room by a research assistant and informed about the opportunity to participate in a survey while waiting to be called into their ophthalmologist's examining room. An interview was conducted to collect demographic information (Table 1). Interviews lasted 30 min on average. All participants answered questions in the same order: general demographics, coping strategies (BC; Carver, 1997), depressive symptoms (the CES-D–Short Form; Radloff, 1977), and well-being (Satisfaction with Life Scale; Diener, Emmons, Larsen, & Griffin, 1985). This structure of questioning was decided in order to make participants feel comfortable by answering more general questions before moving into potentially more sensitive questions.

The BC (Carver, 1997) is a short version of the COPE inventory (Carver, Scheier, & Weintraub, 1989), which itself has proven useful in health-related research. This questionnaire comprises 14 subscales, each consisting of two items, and determines the frequency with which people utilise various coping mechanisms. Using a 4-point scale (1 = *I usually don't do this at all* to 4 = *I usually do this a lot*), participants responded to questions about how they cope when they are facing a stressful event. Although participants answered the entire BC questionnaire, only the subscales of denial and acceptance are presented in detail here. Items of the acceptance subscale ($\alpha = .57$) are 'I accept the reality of the fact that it happened' (Item 1) and 'I learn to live with it' (Item 2). Items of the denial subscale ($\alpha = .54$) are 'I say to myself "this isn't real"' (Item 1) and 'I refuse to believe that it has happened' (Item 2).

The CES-D–Short Form (Radloff, 1977) is a short 10-item self-report scale designed to measure depressive symptomatology in the subject's past week. Scores range from 0 (*never*) to 3 (*most of the time*), with higher scores indicating greater depressive symptoms. An example of an item is 'I was bothered by things that usually don't bother me.'

The *Satisfaction with Life Scale* (Diener et al., 1985) is a 5-item questionnaire measuring subjective well-being, which is described as 'the personal ability to enjoy oneself and one's own life' (Koivumaa-Honkanen et al., 2001: 38). Using a 7-point Likert-type scale, ranging from 1 (*strongly disagree*) to 7 (*strongly agree*), patients are asked to indicate the degree of agreement or disagreement with each item. An example of an item is 'so far I have gotten the important things I want in life'.

Analyses

To test Hypotheses 1, 2, 3 and 4, results were analysed using between-group multivariate analysis of covariance (MANCOVA). This analysis allowed us to test how depression, well-being, and the use of acceptance and denial as coping strategies employed in the grieving process differ across groups of patients with varying time since diagnosis. Participants were categorised based on the duration of their vision loss. For the purpose of this study, we dichotomised the duration of vision loss by ascertaining the median and interquartile ranges of this variable. Four duration categories (interquartiles) were defined: Category 1: 0–2 years, Category 2: >2–5 years, Category 3: >5–12 years, and Category 4: more than 12 years. Separate analyses of covariance (ANCOVAs) on each

Table 1. Descriptive information for sample characteristics ($N = 700$)

Variable	M (SD)	%
Age	74.26 (13.56)	
Gender female		55
Race (white)		87
Current employment		
Working		8
Retired		77
Not working		15
Education		
Primary		16
Secondary		50
Post-secondary		34
Present annual income		
<10,000		6
10,000–14,999		11
15,000–19,999		9
20,000–29,999		12
30,000–39,999		8
40,000–49,999		5
50,000–59,999		3
60,000–69,999		2
70,000 or more		2
No income		6
Third party		10
Don't know		2
Did not specify		24
Marital status		
Married		48
Widowed		31
Single/divorced		21
Type of visual impairment		
Macular degeneration		52
Glaucoma		19
Diabetic retinopathy		15
Retinal detachment (all types)		4
Retinitis pigmentosa		1
Anterior segment/cornea		3
Posterior segment (all other retinal problems)		4
Other		1
Unknown		1
Severity of visual impairment		
Mild impairment (70–200+)		38
Moderate impairment (200–400+)		32
Severe impairment (400 or worse)		30

of the dependent variables were then performed. Finally, significant univariate ANCOVAs were identified with a *Helmert* contrast that compared each of the duration categories to the mean effect of all subsequent categories. For all analyses, age, gender, ethnicity, current employment, level of education, present annual income, marital status, type of visual impairment, and severity of visual impairment were controlled for. Table 1 presents descriptive information for sample characteristics (covariates). Table 2 presents the mean acceptance, denial, well-being, and depression as a function of duration of vision loss.

In order to test the expected associations between the two coping strategies (acceptance and denial) and the psychological outcomes (well-being and depression; Hypotheses 5 and 6), Spearman's rho correlations were calculated. Table 3 presents the intercorrelations among all measures.

Results

Acceptance, denial, well-being, and depression as a function of duration of vision loss

We found a significant effect of duration categories on acceptance, denial, well-being, and depression, $\Theta = 0.04$, $F(4, 430) = 3.75$, $p = .005$.

Acceptance. Duration of vision loss had a significant effect on acceptance, $F(3, 441) = 2.64$, $p = .049$, *partial* $\eta^2 = .02$. *Helmert* contrasts revealed that acceptance was significantly lower among patients in Category 1 (0–2 years; $M = 3.26$) compared to patients in Categories 2, 3, and 4

Table 2. Mean acceptance, denial, well-being, and depression as a function of duration of vision loss (SE in parentheses)^a

Duration of vision loss	0–2 years	>2–5 years	>5–12 years	>12 years
1. Acceptance	3.26 (0.82)	3.48 (0.71)	3.51 (0.76)	3.46 (0.72)
2. Denial	1.69 (0.96)	1.53 (0.83)	1.38 (0.71)	1.39 (0.72)
3. Well-being	5.05 (1.32)	5.04 (1.27)	5.09 (1.30)	4.98 (1.40)
4. Depression	0.81 (0.64)	0.73 (0.56)	0.76 (0.61)	0.77 (0.62)

^aAcceptance and denial measured on a 1–4 scale, with a higher score indicating a higher score for acceptance and denial; well-being measured on a 1–7 scale, with a higher score indicating a higher score for well-being; and depression measured on a 0–3 scale, with a higher score indicating a higher score for depressive symptoms.

Table 3. Spearman's rho correlations and descriptive statistics: acceptance, denial, well-being, and depression

	<i>M</i>	<i>SD</i>	1	2	3	4
1. Acceptance	3.32	0.80	–			
2. Denial	1.53	0.82	–.29*	–		
3. Well-being	5.00	1.32	.16*	–.16*	–	
4. Depression	0.79	0.61	–.20*	.30*	–.46*	–

M = mean; *SD* = standard deviation.

*Correlation is significant at the .01 level (two-tailed).

(over 2 years; $M = 3,48$, $t(3) = -0.23$, $p = .006$ (two-tailed), $r = .13$); however, acceptance did not differ significantly between any other categories (Figure 1). These findings support Hypothesis 1.

Denial. The analysis indicated that duration also had a significant effect on denial, $F(3, 441) = 3.60$, $p = .01$, $partial \eta^2 = .02$. *Helmert* contrasts revealed that denial was significantly higher among patients in Category 1 (0–2 years; $M = 1.69$) compared to patients in subsequent categories (over 2 years; $M = 1.43$, $t(3) = 0.27$, $p = .003$ (two-tailed), $r = .15$). However, denial did not differ between patients in any other categories (Figure 2). These findings provide support for Hypothesis 2.

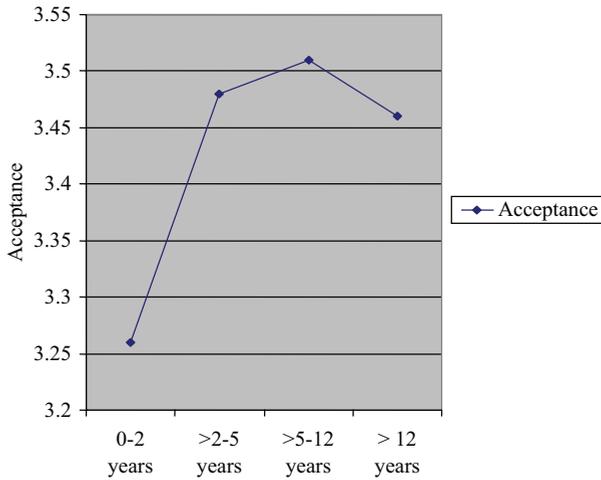


Figure 1. Acceptance as a function of duration of vision loss.

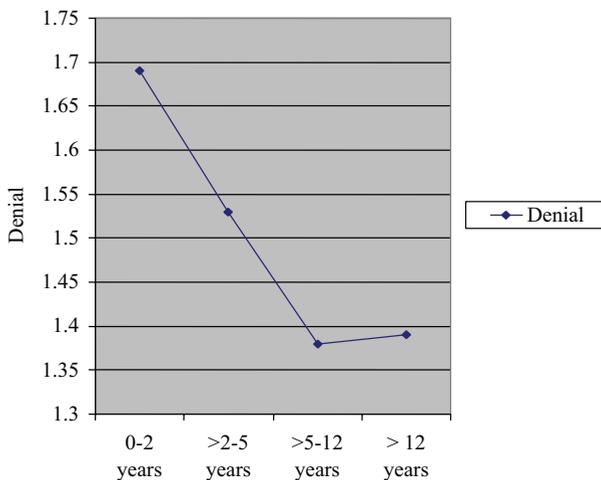


Figure 2. Denial as a function of duration of vision loss.

Well-being and depression. There was no significant main effect of duration of vision loss on well-being, $F(3, 441) = 0.07, p = .98$, or depression, $F(3, 441) = 0.35, p = .79$. These findings do not support Hypotheses 3 and 4 and will be addressed in the 'Discussion'.

Associations between acceptance, denial, well-being, and depression

As expected, there were significant effects of both acceptance and denial on well-being and depression. Acceptance was associated with positive psychological consequences (i.e. negatively correlated with depression, $r = -.20, p < .01$, but positively correlated with well-being, $r = .16, p < .01$), whereas denial was associated with negative psychological outcomes (i.e. positively related to depression, $r = .30, p < .01$, but negatively correlated with well-being, $r = -.16, p < .01$). These findings provide support for Hypotheses 5 and 6 (Table 3).

Discussion

The Montreal Barriers Study was conducted in the ophthalmology departments of four hospitals situated in Montréal, Québec, Canada. Using a substantial sample of 700 participants from the resulting database, the present study sought to enhance the understanding of the grieving process and, more specifically, the stages of acceptance and denial in people with a visual impairment. MANCOVA and contrast analysis were used to circumscribe the length of time in which acceptance and denial are meant to occur. Our analysis revealed that early in the process of vision loss (i.e. 0–2 years), individuals manifest lower acceptance and higher denial than do patients who have lived with their impairment for a longer period of time (over 2 years). These findings suggest that acceptance and denial co-occur in the grief process of vision loss. Moreover, they suggest that patients will engage in an adaptative coping style quite early in the grief process of vision loss.

An additional aim of the study was to examine how well-being and depression change as a function of duration of vision loss. Despite the fact that coping strategies (i.e. acceptance and denial) were associated with well-being and depression as we expected, our findings suggest that the duration of vision loss does not influence levels of well-being and depression. Thus, these results do not support Hypotheses 3 or 4. One explanation for these findings may be pre-existing personal factors (e.g. resilience) or the presence of comorbid factors. In fact, comorbid health conditions, negative life events, and past history of depression represent potential risk factors for depression (Blazer, 2002).

Our findings suggest that adaptation to visual impairment differs as a function of duration of vision loss. As mentioned earlier, denial is known to be a barrier to the use of rehabilitation services (Pollard et al., 2003). Furthermore, it seems that most patients reach some degree of readiness for engaging in a rehabilitation process 2 years after their diagnosis of visual impairment, a finding which should be taken into consideration.

Even if denial and acceptance seem to be essential stages that patients have to reach in order to better adapt to vision loss, other models have been proposed in the context of adaptation to visual impairment. For example, Dodds (1989) has proposed the self-efficacy model, according to which one will adjust positively to visual handicap by acquiring realistic expectancies about one's future competencies. Thus, according to this model, a sense of competence is essential for successful rehabilitation. Similarly, the lifespan theory of control (Heckhausen & Schulz, 1995) has been applied to the area of vision loss (Boerner, Brennan, Horowitz, & Reinhardt, 2009). In accordance with this theory, one may adapt to acquired disabilities in old age (such as visual impairment), by either shaping one's environment to fit one's particular needs and

developmental potential (i.e. primary control strategy), or by making cognitive changes within oneself (i.e. secondary control strategy: goals and interpretations). Other theoretical models suggest that adjusting to visual impairment requires a cognitive shift (e.g. Zaborowski, 1997). More precisely, adjustment to vision loss may be achieved when a cognitive shift in personal identity occurs, that is, an individual self-identifies as a visually impaired person (Hayeems, Geller, & Faden, 2005).

Limitations and further research

Although our cross-sectional study was well suited to explore the pattern of adaptation to visual impairment with a large sample of participants, several important limitations should be noted that were inherent in the Montreal Barriers Study database. First, causal relationships cannot be inferred. The strength of the respective linkages among intra-individual changes in the acceptance, denial, well-being, and depression variables remains a question to be studied in more depth. Future longitudinal studies are needed to investigate the natural life history of patients with a visual impairment progressing through the course of the disease.

The second limitation of this study results from the use of short subscales in the original database, each consisting of two items, to assess the stage of denial and acceptance in the grieving process. Replication of our study with the use of more elaborate and adapted instruments that assess grieving stages (for examples of grief scales, see Bourgeois, 2006; Futterman, Holland, Brown, Thompson, & Gallagher-Thompson, 2010) may provide further insights. Ideally, future studies would gain from the use of more extensive measures of psychological adaptation to visual impairment (i.e. anxiety, social isolation, social functioning). In fact, the present study does not offer information about how people with visual impairment may concretely use their coping strategies in their daily life and how these strategies might be observed by practitioners.

The issue of comorbidity is omitted in this study, and this may constitute a final limitation. It has been illustrated that various other health conditions, such as atherosclerosis or diabetes, can significantly affect the quality of life of an individual with vision loss (Steinman & Allen, 2012). Thus, the presence of other health conditions can potentially influence quality of life independent of vision loss effects. Thus, future studies should assess a broader range of health conditions, not only those related to visual impairment, in order to control for the external biases they may introduce.

In short, because vision loss involves serious consequences, both physically and psychologically, it is important to pursue research in this area in order to develop a more complete and clearer understanding of the grieving process that is specific to this unique kind of loss.

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Declaration of conflicting interests

The authors declare that they do not have any conflict of interest.

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