

# From self-awareness to self-identification with visual impairment: a qualitative study with working age adults at a rehabilitation setting

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## Abstract

**Objective:** To explore the experience of vision loss, focusing on working age patients' self-awareness of impairment and self-identification with the impairment.

**Design:** A cross-sectional and qualitative study, using semi-structured interviews.

**Setting:** A specialized rehabilitation centre and a low vision unit at a public hospital.

**Participants:** A convenience sample of 38 patients between the ages of 20 and 65, with sight loss caused by a serious ophthalmological condition acquired after the age of 18, and doing their rehabilitation.

**Main outcome measures:** A semi-structured interview, addressing three core areas: the emotional impact of vision loss; adjustment; and social support. Interviews were transcribed, coded and analysed by two independent researchers.

**Results:** Seven themes emerged from interviews. Changes in patients' identity, achievement and future life projection arose as being the main transformations caused by vision loss. Self-awareness of impairment appeared associated with the patients' first contact with their loss, while self-identification with the impairment arose connected with the later embodiment process of the vision loss.

**Conclusions:** Patients' self-awareness and self-perceptions of impairment appear to be two important milestones in the adjustment process to vision loss. Their assessment and monitoring over the rehabilitation period might help to promote impairment acceptance and rehabilitation outcomes.

## Keywords

Experience of sight loss, visual impairment, qualitative study, adjustment

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## Introduction

According to the World Health Organization, most of the visually impaired people worldwide are adults and elderly, and live in developed countries.<sup>1</sup> Because of its implications for the subject's activities of daily living and functioning, vision loss has been reported as a potential cause for other individual losses. Stopping work, driving,

reading or writing might be consequences of

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vision loss and often cause an important loss of independence and self-esteem.<sup>2,3</sup> Nevertheless, it is a fact that the experience of vision loss is subjective and may have different meanings for different people. After vision loss people show different kinds of adjustment courses and achieve different levels of rehabilitation outcomes. Thus the personal experience of vision loss has aroused interest in some authors, especially those using qualitative studies.

Loss of independence and mobility, isolation, fear of accidents, depression and the end of life are some of the key themes stressed by adults and elderly who have lost their vision.<sup>4-9</sup> According to these studies, patients expressed great loss caused by vision disease, emphasizing feelings of sadness and of vulnerability. These feelings also appeared to be associated with challenges during the adaptation process, such as how to use assistive devices, especially the white cane.

In terms of social functioning, a study from Wang and Boerner<sup>10</sup> underscored how challenging the re-establishment of relationships after vision loss may be. In this study patients stressed their feeling of being little understood by others and their difficulties due to the lack of visual cues as main relationship-related challenges after vision loss. Concerning the social support some studies have associated an overprotective or a conflictive and controlling social support with worse outcomes during the adjustment process to vision loss.<sup>11,12</sup>

Recent researches have addressed new intrapersonal variables in patients' experience of impairment. Mixed methods studies by Thurston *et al.*<sup>7,13</sup> emphasized patients' experiences of changed perceptions of self as being associated with the adjustment process of transition from sighted to blindness. During this process, patients cope progressively with their vision loss. The impairment is no longer hidden and the white stick and the rehabilitation begin to be accepted. In the same way, Hayeems and colleagues<sup>14</sup> found that subjects who are more identified as being visually impaired were more likely to reveal their disease, to make lifestyle changes, to use assistive devices and, consequently, to be

more autonomous. Although these studies are only with patients with retinitis pigmentosa, they addressed an understudied intrapersonal variable – self-identification with the impairment.

Another interesting intrapersonal variable was addressed by two studies with patients with traumatic brain injury or orthopaedic injuries.<sup>15,16</sup> These studies linked the self-awareness of the impairment with early and late depression. Despite the relevance of this intrapersonal variable, there are no studies on visual impairment that addressed subjects' self-awareness of the impairment. It would be interesting to explore how this variable is related to the adjustment process in visually impaired patients.

Thus, both self-identification with the impairment and self-awareness of impairment appear as new and little studied intrapersonal variables that deserve further research. Therefore, the experience of vision loss is a topic where more research is needed, especially in adults of working age.<sup>17</sup> Practitioners can benefit from this knowledge, especially to promote new target interventions and to prevent patient drop-out in rehabilitation settings.

Our study intends to explore the experience of vision loss on working age adults in a rehabilitation setting, focusing on the patients' self-awareness of the impairment and self-identification with impairment.

## Methods

To perform this research, an exploratory and cross-sectional design using qualitative methods was adopted.

Adult patients were recruited from two specialized centres: a rehabilitation centre for visually impaired people and a low vision unit at a public hospital. Inclusion criteria were: between ages 20 and 65; having lost vision after the age of 18; vision loss due to an acquired ophthalmological disease or trauma; and in a rehabilitation setting. The following patients were excluded: under age 20, or above age 65; with a serious congenital ophthalmological condition; HIV positive; and with any confirmed neurological

and cognitive impairment. Patients with different types of visual impairment (severe low vision and blindness) were considered. The criteria to classify the type of impairment were based on medical reports and according to the World Health Organization's classification for low vision and blindness.<sup>18</sup> Patients at different stages of rehabilitation were selected: patients who were in the first three months of their rehabilitation and patients who were more advanced (more than three months) in their rehabilitation. In both centres, rehabilitation includes integrated multidisciplinary services such as: mobility and orientation; psychological support; Braille; adapted computer technologies; and educational support. In the rehabilitation centre patients also have physical education and art therapy. In the low vision unit, patients are followed by a physician specialized in low vision. The rehabilitation turnaround time is between four and six months, depending on the patient's needs. Ethical procedures were adopted following the institutional protocol, and using an informed consent form.

### *Data collection*

Our data were collected through an assessment protocol composed of two interviews for each patient lasting between 45 and 60 minutes. This protocol was designed to collect the maximum data about their experiences. A second interview facilitates a patient's reports about their feelings and attributions to vision loss. The process of selecting and inviting patients to participate in our study was performed in partnership with the centre practitioners. Then they were directly invited to be interviewed. A total of 50 patients were invited and 38 accepted or fulfilled all inclusion criteria.

Qualitative data were collected using a semi-structured interview, which was conducted through open-ended questions. These questions were designed to address patients' experience of sight loss, including patients' self-awareness of the impairment and self-identification with the impairment. Thus, three core areas were

addressed: the emotional impact of vision loss; the adjustment process to vision loss; and the perceived social support. The questions were created to be bias free, to allow for any kind of narrative about each theme and to facilitate the fluency of participants' narratives about their experiences (see Appendix 1). All interviews were conducted and audio-recorded by the same researcher (HS) who had no previous relationship with the participants. This researcher was supervised during the whole study by another researcher (RAO).

The interviews continued being conducted even after researchers felt saturation had been reached, in order to get the maximum variation of sample's characteristics. A total of 87 interviews were conducted for all 38 participants ( $n=38$ ). As can be seen in Table 1, the mean participants' age was 42 ( $SD=14.5$ ) and 18 were women. Most of them (65.8%) were blind and the remaining patients had severe low vision. The main aetiology of the impairment was glaucoma ( $n=13$ ). Patients who lost their vision faster ( $n=17$ ) or progressively ( $n=21$ ) were assessed. Rehabilitation time varied between 1 and 12 months.

### *Data analysis*

After the interviews were recorded, they were transcribed verbatim. Then they were analysed using the Thematic and Categorical Analysis proposed by Bardin.<sup>19</sup> In this method, an induced analysis modality with an open coding technique was adopted,<sup>20,21</sup> because we did not have any previous ideas or conceptualizations about the subjects. The content analysis was conducted by following these steps: transcriptions were read at least twice, line by line to infer global and specific meanings and structure; each narrative's specific meanings that generated open codes (semantic criteria) were identified and labelled; codes were gathered by sharing common themes; themes were reanalysed and reviewed in order to be labelled and regrouped in thematic categories; thematic categories were validated by returning to the data through the

**Table 1.** Characterization of the sample

Variable	N	Valid %
Age ( $M = 42.7/SD = 14.5/Min: 20; Max: 64$ )		
20–40 years	18	47.4%
41–65 years	20	52.6%
Gender		
Male	20	52.6%
Female	18	47.4%
Education level		
Up to 9 years	28	73.7%
>9 years	10	26.3%
Age at vision loss ( $M = 39.2/SD = 14/Min: 18; Max: 64$ )		
18–40 years	21	55.3%
41–65 years	17	44.7%
Type of acquired visual impairment		
Blindness	25	65.8%
Severe low vision	13	34.2%
Main pathology causing vision loss		
Glaucoma	13	34.2%
Retinitis pigmentosa	7	18.4%
Retinopathy	7	18.4%
Physical trauma	3	7.9%
Cataracts	2	5.2%
Others	6	15.7%
Time between first diagnosis and vision loss – evolution (years) ( $M = 7.3/SD = 8.4/Min: 0; Max: 34$ )		
0–3 years (fast)	17	44.7%
>3 years (progressive)	21	55.3%
Time between vision loss and interviews (years) ( $M = 3.3/SD = 2.9/Min: 1; Max: 16$ )		
0–2 years	20	52.6%
>2 years	18	47.4%
Rehabilitation time (months) ( $M = 4/SD = 3/Min: 1; Max: 12$ )		
0–3 months	19	50%
>3 months	19	50%

patients' direct quotations. This procedure was performed by two researchers (HS, RAO) who had an exhaustive discussion and reflexion about each meaning and defined criteria for each categorization during all the analysis steps. There was a high consensus between researchers, and disagreements were solved by returning to the transcripts.

## Results

The three core categories addressed by the interviews generated six themes, each one with specific subthemes extracted from patient verbalizations. As can be seen in Figure 1, the three themes related to the category 'Emotional impact of vision loss' allowed the patients' self-awareness of impairment to be obtained. The two themes that emerged from the category 'Adjustment to vision loss' enabled the exploration of the patients' self-identification with visual impairment. Perceived social support generated themes related to its attributions and its relations with the recovery process. In addition to these categories, patients also approached another one related to their perceptions of well-being.

### *Self-awareness of the visual impairment*

***Patients more aware of their impairment.*** A large number of patients ( $n = 26$ ) showed emotional responsiveness to vision loss and greater self-awareness of their impairment. These patients verbalized the following feelings associated with becoming impaired: sadness, depression, anguish, anxiety, shock, non-acceptance of the impairment, anger and thoughts of death. All of them also acknowledged some implications of vision loss on their lives. They reported changes in the inner and relational world, such as in basic skills, identity/personality, psychological well-being, academic or professional achievement, and social and affective life. Some of the changes pointed out by the patients were stopping doing daily life activities and working; giving up on some future life

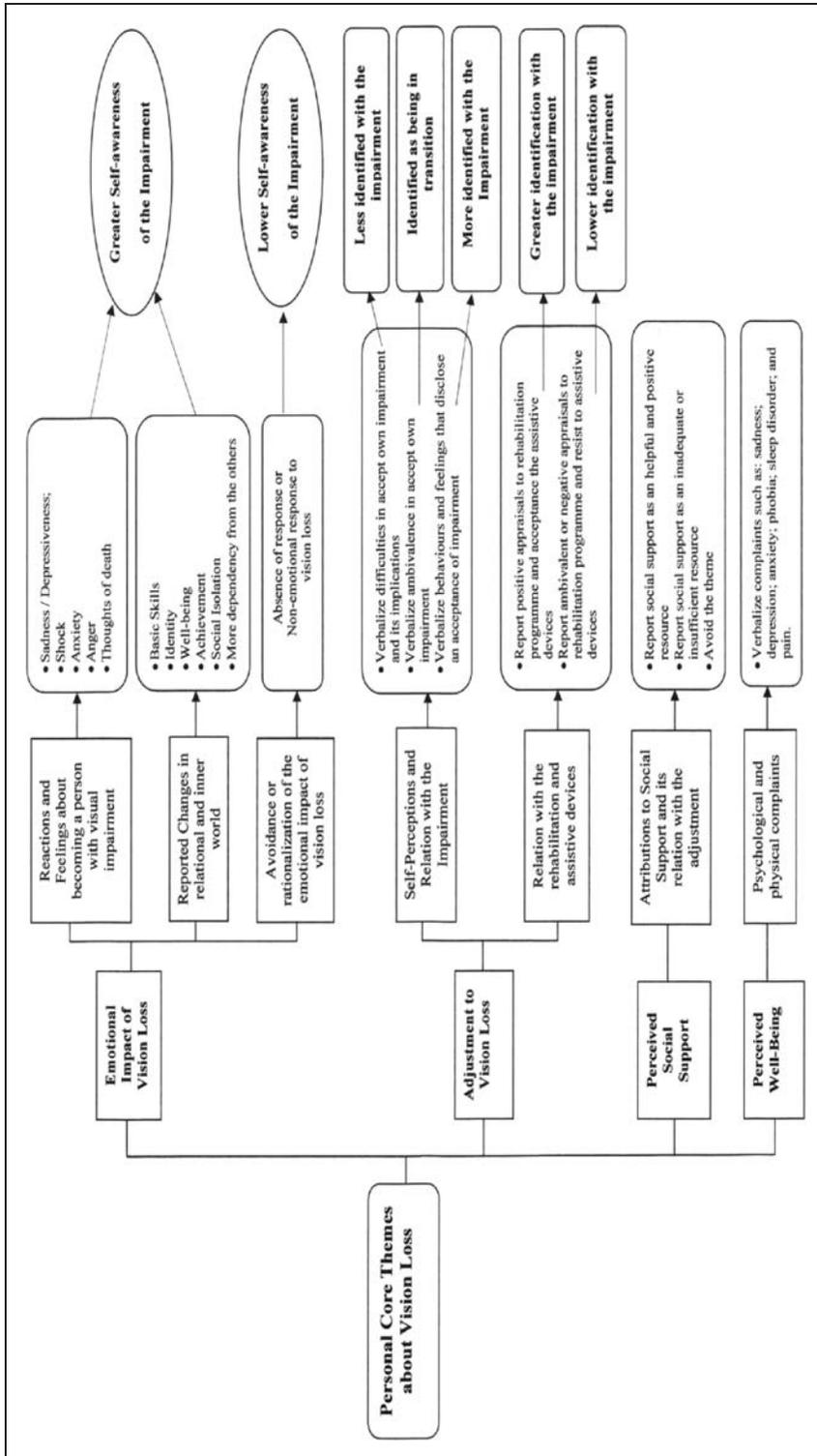


Figure 1. Categories, themes and subthemes that emerged from interviews.

plans; being a more dependent person; being more isolated from the others; being abandoned by others; and losing friends and trust in others.

*It was something that disturbed me very much! I was shocked and down and lost a lot of weight ... up to 59 kg! I was very depressed... I didn't want to live anymore... I felt very sad. (Participant 19) The hardest part was having to stop working ... I lost my job and stopped doing many things such as driving, reading, walking alone ... I became sadder... before the loss I was happier and more satisfied with my life. (Participant 39)*

*Others told me that I wasn't the same person ... I was happier ... today I'm feeling sad... I isolated myself at home, because I lost my interest in everything! Moreover, nobody understands me! Few people want to accept a blind person and have her as a friend! On the other hand, it's very hard to depend so much on others! (Participant 32)*

**Patients less aware of their impairment.** Other patients ( $n=12$ ) showed a non-emotional response or an absence of response to vision loss, and a lower self-awareness of their impairment. Most of these patients devaluated or refused the emotional impact of vision loss, and did not report any change in their lives caused by vision loss. Frequently, they changed the theme to other matters not related to vision loss. In the few cases of some responsiveness to vision loss patients rationalized the theme and devaluated any major limitation related to the impairment.

*I loved working in my farm, because I had an active life, but today I'm not a poor little thing... Things happen and we have to deal with it! Life goes on. (Participant 30)*

*I had no problem with it! I know, some people feel down ... but you don't know me! I never back down in my life! (Participant 10)*

*I know there are some things that I cannot do, but it's temporary! I know I will see again soon!*

*No, I never felt sad or depressed with this! I'm very strong, and I know it will change! (Participant 24)*

**Self-identification with the visual impairment**  
**Patients more identified with their impairment.** Twelve patients exhibited narratives about themselves and their vision loss where they appeared to be identified with their impairment. In these cases, the impairment was addressed as being part of them, the rehabilitation and the assistive devices were appraised as being helpful and positive resources. The white cane was frequently addressed as part of the new lifestyle and a useful device to begin to walk alone again. In some situations they also showed they had future plans associated with the rehabilitation work, such as to return to work.

*Before rehabilitation I hid my problem and hid myself... I was isolated... Today I found a new life... I have new friends... I take better care of myself! The stick has helped me so much; I can walk alone to many places where I couldn't before. The rehabilitation has helped me so much. I adore my teachers! They have been so understanding with me! I never thought I would find a place like this centre!... I'm discovering new skills in me. I'm planning on returning to school. (Participant 35)*

**Patients identified as being in transition.** The majority of our patients ( $n=20$ ) presented an ambivalence narrative about themselves, their impairment and about the rehabilitation progresses. Even if they are partially resistant to some assistive devices and lifestyle changes, feeling ambivalent about the white stick and the rehabilitation's value, these patients already have some identification with their impairment. Therefore, there is already a partial acceptance of their condition and the related adaptive aids. In these cases patients appeared to be in transition between being identified as a person without visual impairment and a visually impaired person.

*I like to be here (in the rehabilitation) ... I've learned a lot of new things that help me ... I returned to doing many things ... However ... I still have problems with the cane, because it draws attention and people say: 'look at the blind!' I know I am blind, but it's still hard to hear it! (Participant 2)*

**Patients identified as being a person without visual impairment.** Other patients ( $n=6$ ) said that they did not need or did not like the assistive devices, refusing help, resisting rehabilitation, acknowledging the white stick as a bad or a useless thing, and in some cases, referred to themselves as being sighted. In these cases, the rehabilitation was frequently felt to be an inadequate resource that is not helpful for their individual needs. These verbalizations indicate that these patients do not identify themselves as impaired and keep identifying themselves as sighted:

*I'm very well ... I don't have any problem with it ... I know there are people that are traumatized, but you don't know me, I'm strong!! ... I don't use the stick because I have my wife ... she helps me ... I think that maybe rehabilitation is being too long for me ... I have to work ... I've been thinking about quitting! (Participant 8: <3 months of rehabilitation)*

**Perceived social support.** Fifteen patients thought of their social support as being a good and helpful resource. These patients valued the role that their friends or family have in their adaptation and recovery.

*When I went blind the world broke down ... It was a big shock ... I was very lost because it was unexpected and I'd never thought that it could happen to me and I still do not understand ... However, today I feel better ... thanks to my family ... my husband! They have been the main reason for my staying here. (Participant 32)*

Other patients ( $n=21$ ) reported inadequate or insufficient social support. These patients referred to a lack or an absence of support from their family or friends, frequently verbalizing feelings of loneliness and abandonment.

*They try to help me but they don't understand me ... they still believe that I can do many things that I can't ... however, they have improved lately! (Participant 25)*

*After I became blind, nobody cared about me ... People must think I have a contagious problem or that I'll be a lot of work and trouble for them! (Participant 13)*

**Problems in well-being.** A large proportion of our patients ( $n=25$ ) also verbalized current problems in well-being through physical and/or psychological complaints. The most mentioned complaints were mood changes (depressive and sadness), sleep disturbance, and anxiety and somatic complaints:

*I'm feeling very sad ... I cannot sleep and I'm less motivated to do anything. I'm feeling bad with this! (Participant 16)*

**Experience of vision loss in different groups of patients.** As can be seen in Table 2, results point to higher occurrence of patients who are more identified with visual impairment in the group of those who have been at rehabilitation for longer. In terms of the type of impairment, the data show no relevant differences between the two groups (Table 3).

## Discussion

Our study retrieved a set of themes on the experience of vision loss which are, apparently, similar to those that emerged from previous qualitative studies.<sup>4-7</sup> Verbalizations such as the depressive reactions, feelings of loneliness, changes in basic skills and autonomy, and

**Table 2.** Frequency of emerged themes by two phases of the rehabilitation

	Rehabilitation time	
	0–3 months (n = 19)	>3 months (n = 19)
Experience of vision loss		
Self-awareness of the impairment		
More aware	13 (68.4%)	13 (68.4%)
Less aware	6 (31.6%)	6 (31.6%)
Self-identification with the impairment		
As sighted	4 (21.1%)	2 (10.5%)
As in transition	11 (57.9%)	9 (47.4%)
As visually impaired	4 (21.1%)	8 (42.1%)
Perceived social support		
As a good resource	7 (36.8%)	8 (42.1%)
As inadequate or insufficient	11 (57.9%)	10 (52.6%)
Perceived well-being		
Report problems/complaints	11 (57.9%)	13 (68.4%)
Did not report problems/complaints	8 (42.1%)	6 (31.6%)

some difficulties with rehabilitation, were the most similar findings in comparison with studies with older adults.<sup>5,6,8,9</sup> However, the themes from our qualitative data contain mostly a set of verbalizations associated with characteristic issues of working age patients. For this reason, our patients' narratives reflected different approaches to vision loss implications when compared to older adults in a similar condition. In terms of the emotional and personal impact of vision loss, patients were more focused on losses in their professional course and achievements, on changes in their identity and/or in their marital life. In general, the depressive feelings were associated with these life transformations. The emotional impact of vision loss in our sample appears associated with two main losses: who the subject was/is (the identity); and who the subject will be (the future projection). In the sense used by Damasio,<sup>22</sup> these transformations caused by vision loss could indicate a potential

**Table 3.** Frequency of emerged themes by type of visual impairment

	Type of acquired visual impairment	
	Blindness (n = 25)	Low vision (n = 13)
Experience of vision loss		
Self-awareness of the impairment		
More aware	17 (68%)	11 (84.6%)
Less aware	8 (32%)	2 (15.4%)
Self-identification with the impairment		
As sighted	3 (12%)	3 (23.1%)
As in transition	14 (56%)	6 (46.2%)
As visually impaired	8 (32%)	4 (30.7%)
Perceived social support		
As a good resource	10 (40%)	5 (38.5%)
As inadequate or insufficient	13 (52%)	8 (61.5%)
Perceived well-being		
Report problems/complaints	15 (60%)	9 (69.2%)
Did not report problems/complaints	10 (40%)	4 (30.8%)

change in the subjects' autobiographical self, both in terms of their body and global image, and in the future projection of this image. Furthermore, other authors have also found changes in subjects' spatial and temporal senses and their relation with objects after vision loss.<sup>23–26</sup>

In terms of the adjustment process, our sample also focused on different themes of the recovery process in comparison with the older adults previously studied. Most of rehabilitation goals were not only focused on recovery of basic skills and autonomy, but also on the acquisition of new skills to allow a return to work and to realize new projects for future life.

Because of the significant life changes caused by vision loss, this experience appeared to be potentially hard to overcome and to accept. At first, each of our patients facing loss of vision coped by accepting more or less their own

reality, and reacted according to their acceptance. This meant that patients with different self-awarenesses of the impairment were found. After this first confrontation with impairment, patients reported an adjustment process in which they made efforts to embody the impairment and reach a more or less adaptive course. Thus, the three types of identification that seemed to be associated in our sample with the embodiment of the visual impairment is part of the adjustment process. In terms of the influence of the rehabilitation and the type of visual impairment, the results suggest a positive interference of the rehabilitation in the adjustment process and no influence of the type of impairment.

These findings suggest a model for the adjustment process to vision loss, in which the self-awareness of impairment and the self-identification with the impairment appear to be important milestones of the evolutionary process of adaptation (Figure 2). In this model the self-awareness of impairment initiates the adjustment

process through the patients' confrontation with their new condition. A lower awareness will make the patient more susceptible to be less identified with his or her visual impairment, whereas a greater identification with the impairment will be more likely to occur after a greater awareness of the impairment is achieved. In other words, the impairment's embodiment appears to be influenced by how much the patient is aware of his or her situation. Rehabilitation provides a positive interference in this process because it facilitates the patient's self-awareness and embodiment progress.

A part of this theoretical framework is supported by other qualitative studies,<sup>7,13</sup> especially that of Hayeems *et al.*<sup>14</sup> Like this study, our findings stress the importance of a patients' self-perception and self-identification with the impairment in the adjustment process. Moreover, Hayeems also proposes that the self-identification might be associated with rehabilitation outcomes. However, our model goes further in terms of the beginning of the

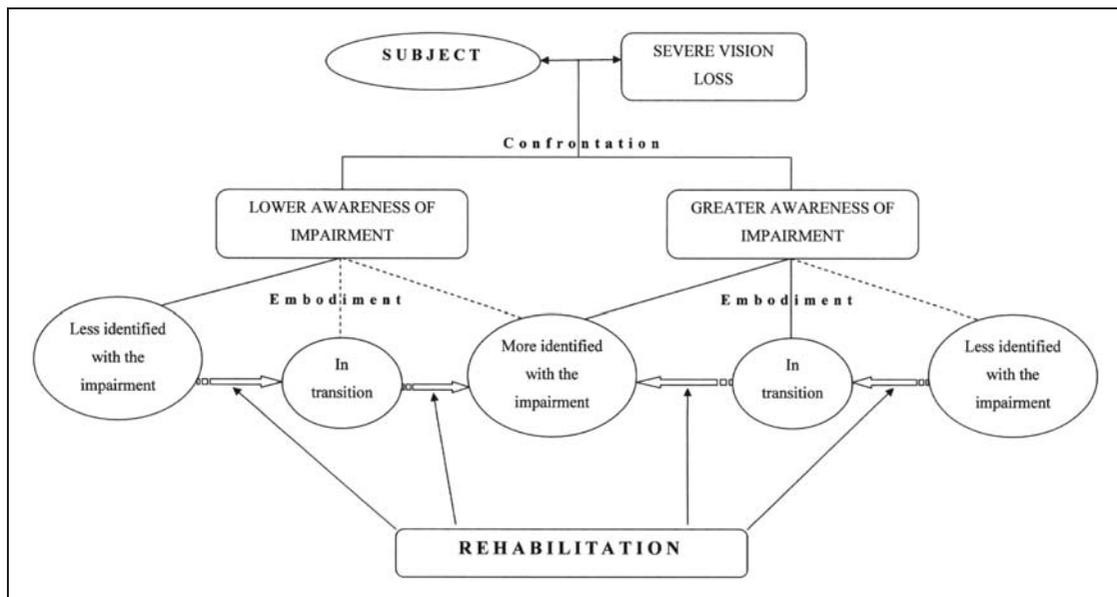


Figure 2. Model of the adjustment to vision loss. — Less likely to occur.

adjustment process, because we explored which intrapersonal variables could be behind the embodiment process.

Consistent with previous studies, our results also showed other variables that seem to influence how patients' experience their vision loss: the quality of patients' perceived social support<sup>12</sup> and well-being.<sup>27</sup> The only reason for these variables not appearing in our model is that we do not know their relation with patients' self-awareness and self-identification. We just know that some previous studies found an association between these variables and patients' levels of emotional distress, well-being and outcomes.<sup>27-29</sup>

In terms of clinical practice, these findings bring some innovative cues for the assessment and intervention work. During the follow-up of these patients, an assessment protocol that includes monitoring of their self-awareness and self-identification will help to identify the phase of the adjustment they are in. This information is helpful in understanding certain patients' reactions and behaviours, such as why the patient is refusing rehabilitation, an assistive device or a specialized aid; why the patient is conflicted with peers or with practitioners; or why the patient's expectations do not match his or her reality. A good diagnosis of the intrinsic causes of a patient's behaviour during the rehabilitation process will be valuable both for individual intervention plans and for more effective psychotherapeutic work.

Although our study supports some previous findings from the literature and presents a model for the adjustment process, some limitations need to be acknowledged. First, even though our sample size is big enough for a qualitative study, it is a selected sample composed only of patients who are going through rehabilitation.

Second, despite the fact that patients at the beginning of their rehabilitation were included in our sample, the effect of the rehabilitation was not completely controlled. Therefore, it would be interesting for future research to compare patients who have not started their

rehabilitation with those who are doing it, in terms of the vision loss experience.

Third, the interviews were only semi-structured. Even though the interviews were conducted with a view to being bias free, three core areas were predefined to be addressed. Thus, interviews tended to be steered to these areas which could have biased the results.

Fourth, because this was a cross-sectional study rather than a longitudinal study, the evolution of patients' adjustment to vision loss over time was not assessed. It would be interesting to perform this in future studies.

Finally, our proposed model cannot be generalized to other samples and only reveals the experiences of vision loss of our studied patients. It indicated only relevant clues to take into account in clinical practice and future research.

### Clinical messages

- The experience of vision loss in adults of working age appears to be related to changes in the patient's identity, achievement and future life projection.
- To assess self-awareness of impairment and self-identification with the impairment it might help to identify the patient's adjustment course, behaviours and reactions over the rehabilitation period.

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## Appendix I – Core questions for patient interviews

1. Beginning of the interview:
  - a. I would like to know more about you, your history, what's happened with you, your feelings, how did you come here?
2. The emotional impact of vision loss
  - a. What's happened with you? How did you know that you were having problems with your vision?
  - b. How did you react to your vision loss? Which thoughts occurred to you? How did you deal with it?
  - c. Did the vision loss lead to any significant change in you and your life? Was there a life or a person before and another after the vision loss? If so, what changed?
3. Adjustment to vision loss
  - a. How did you come here (to rehabilitation)?

- b. How are you doing your rehabilitation? Has it been helpful? Have you had some particular problems with any area? What do you think about the stick?
  - c. What personal aims do you have in the rehabilitation?
- 4. Relation with the social support
    - a. How did your family and friends react to your vision loss?
    - b. Have you had some significant support from your family, friends, or others?

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