



HAL
open science

Psychometric validation of an Assessment Questionnaire on the Perception of and Adaptation to Visual Handicap in Adults (QUEPAHVA)

C. Heren-Le Bastard, A. Bernard, R. Fliss, S. Legouvello, Philippe Allain

► To cite this version:

C. Heren-Le Bastard, A. Bernard, R. Fliss, S. Legouvello, Philippe Allain. Psychometric validation of an Assessment Questionnaire on the Perception of and Adaptation to Visual Handicap in Adults (QUEPAHVA). *Journal Français d'Ophtalmologie*, 2020, 43 (10), pp.e341 - e350. 10.1016/j.jfo.2020.09.001 . hal-03492956

HAL Id: hal-03492956

<https://hal.science/hal-03492956>

Submitted on 15 Dec 2022

HAL is a multi-disciplinary open access archive for the deposit and dissemination of scientific research documents, whether they are published or not. The documents may come from teaching and research institutions in France or abroad, or from public or private research centers.

L'archive ouverte pluridisciplinaire **HAL**, est destinée au dépôt et à la diffusion de documents scientifiques de niveau recherche, publiés ou non, émanant des établissements d'enseignement et de recherche français ou étrangers, des laboratoires publics ou privés.



Distributed under a Creative Commons Attribution - NonCommercial 4.0 International License

Psychometric validation of an Assessment Questionnaire on the Perception of and Adaptation to Visual Handicap in Adults (QUEPAHVA)

Claire Heren-Le Bastard^{a, b*}, Alix Bernard^c, Rafika Fliss^{d, e}, Sabine Legouvello^a, Philippe Allain^{b, d}

^a Centre Régional Basse Vision et Troubles de l'Audition, 4 rue de l'abbé Frémond, 49100 Angers.

^b Laboratoire de Psychologie des Pays de la Loire, LPPL EA 4638, SFR Confluences, UNIV Angers, UNIV Nantes, Maison de la recherche Germaine Tillion, 5 bis Boulevard Lavoisier, 49045 Angers Cedex 01

^c Equipe BePsyLab, Université d'Angers, 5 bis Boulevard Lavoisier, 49045 Angers Cedex 01

^d Département de Neurologie, CHU Angers, 49033 Angers

^e Centre de réadaptation Les Capucins, 49100 Angers.

*Corresponding author e-mail address: claire.lebastard@vyv3.fr

Abstract

Purpose. Handicap evaluation in adults with acquired or progressive congenital visual loss allows for identification of the individual's specific needs and targeted therapy (medical, technical, rehabilitative and psychological). Currently, the subjective dimension of the handicap remains poorly explored in the field of visual loss. Our questionnaire aims to understand the whole of these subjective impacts. It differs from existing quality of life scales in ophthalmology in its approach centered on the process of adaptation, individual resources (technical, cognitive, psychic and environmental), and investigation of the perception of the handicap. The goal of the present study is to validate this questionnaire, which could be used in any adult with a visual handicap, regardless of the extent of the visual loss, its etiology, or the type of treatment or compensatory mechanisms.

Materials and methods. The Assessment Questionnaire on the Perception of and Adaptation to Visual Handicap in Adults (QUEPAHVA) is composed of 28 items relating to perception of the visual impairment, its impact, and adaptive resources. They are divided into 3 sub-categories: Perception of daily life and relationships (10 items), Perception of visual status and compensatory mechanisms (8 items), and Psychological impact of the visual handicap (10 items). The responses are graded on a Likert scale. Factor analysis and verification of psychometric qualities were performed based on the responses of 446 subjects. The discriminatory validity of the NEI-VFQ 25 was proven with 99 subjects. Reliability over time (mean interval between T1 and T2 = 49.43 days) was measured in 31 subjects. Sensitivity to change between pre- and post-management (mean interval between T1 and T2 = 410 days) was tested in 123 subjects.

Results. Internal consistency was very good for the global scale ($\alpha = .90$) as well as for the 3 sub-dimensions ($\alpha = .86$; $\alpha = .79$; $\alpha = .80$). The discriminatory validity was satisfactory ($r = .70$). This result had to be interpreted as a function of the qualitative specificity of the questionnaire. The questionnaire enjoyed good reproducibility over time with regard to its total score and relatively satisfactory reproducibility with regard to its sub-dimensions. Sensitivity to change was very high and accounted for adaptations to the disability over time.

Conclusion. The QUEPAHVA displays good psychometric qualities. It constitutes a new means of evaluation. Its potential applications are many. It permits evaluation of the needs of the individual and adaptation of the protocol of care. Its use in institutions may support a step forward in the science of evaluation and continued improvement in quality of care.

Key words: Handicap, visual impairment, evaluation, process of adaptation, personal resources.

1- Introduction

In the adult, acquired or progressive congenital visual diseases leading to visual loss may alter, more or less severely, quality of life and overall well-being. A situation of handicap can thus result. Here, we make a distinction between the concept of visual loss and that of disability as proposed by the WHO (2001). "Loss" is defined as *"any loss of substance or alteration of a psychological, physiologic or anatomic structure or function."* "Disability" is *"a restriction in participation in society resulting from the interaction between a limitation of an activity, due to a health problem, and environmental obstacles."* Analysis of disabilities by the WHO is performed using 4 interdependent components: organic, physiologic and psychological functions, activities/participation, environmental factors, and personal factors. Visual loss may have a number of repercussions, as much for activities of daily living as for the psychic state or social relationships of the individual. The importance of our scale is two-fold. On one hand, it allows for understanding of the total impact of the visual loss, and, on the other hand, it better defines treatment recommendations (medical, technical, rehabilitative or psychological). The evaluation enables a focused approach to the specific needs of the individual. Our questions arose from situations encountered in the center in which we practice. During medical visits, patients were able to express their difficulties in dealing with the consequences of their visual loss and adapt to recommended optical aids or understand their limitations. We thus propose a new tool which, combined with medical and low-vision evaluation data, may be able to guide and direct the care plan. The primary purpose of this article is to summarize the development and validation of this questionnaire.

We will first discuss existing scales. We will then explain how we were led to concentrate our questions on the process of adaptation to the handicap. Then, we will present the method of creation of this questionnaire and demonstrate its psychometric qualities. Finally, we will present possible applications in treatment and institutions.

2- Revue of the literature: existing scales

The first quality of life studies in ophthalmology relied on generic questionnaires unassociated with a particular disease, such as the SF-36 (Stewart and Ware, 1992). These tools did not allow detailed assessment of the impact of visual loss. In the mid 1990's, to address their lack of sensitivity, scales specific to visual loss were elaborated. The most well-known and utilized are the VF-14 (Visual Function Index; Steinberg, 1994) [1] and the NEI-VFQ (National Eye Institute Visual Function Questionnaire, Mangione, 1998) [2]. These two questionnaires, originally in English, were translated into French using the parallel reverse translation method. This technique aims for a word-to-word correspondence between the source and target languages. No cultural adaptations were made for the French versions. The French versions of these two questionnaires were then validated. Two other scales designed for a population of glaucoma patients were created in France, the GlauQOL-36 (Rouland, 2002) [3] and the GlauQOL-17 (Zanlonghi, 2003) [4].

The VF-14 evaluates the functional impact of cataract. It can measure the effect of surgery. While its clinical use has been extended to other visual pathologies, its psychometric properties have only been verified in a population of cataract patients. It is composed of 18 items which describe 14 activities of daily living (reading, seeing obstacles, cooking, driving, leisure activities, manual activities, etc.). Its French-Canadian version has been validated (Gresset, 1997) [5]. The questionnaire limits itself to a functional approach; in other words, it evaluates difficulties in performing a well-defined task. It does not explore behavioral, emotional or psychological dimensions of quality of life.

The NEI-VFQ was proposed to address the lack of questionnaires centered on this medical and functional approach to visual loss. Its applicability covers a larger variety of visual pathologies (AMD, cataract, glaucoma, retinitis pigmentosa, etc.). It includes subjective quality of life dimensions such as mental health. Its original version, consisting of 51 items, is very time-consuming to take. Thus, an abridged version of 25 items was created (NEI-VFQ 25; Mangione, 2001) [6]. This abridged version also displays satisfactory psychometric qualities, and its French version has been validated in a population of glaucoma and ocular hypertension patients (Nordmann, 2004) [7].

The GlauQOL-36 (Rouland, 2002) is composed of 36 items divided into 7 dimensions: activities of daily living, driving, anxiety, self-image, psyche, limitations and management. Its abridged version, the GlauQOL-17 (Zanlonghi, 2003), consists of 17 items.

The literature over time shows a recently increasing desire to broaden the evaluation of the consequences of visual loss beyond the medical and functional realm, in other words, beyond evaluation of abilities and disabilities. Several studies seek to establish links between disease severity and adherence to treatment (Bour, 1993) [8], to evaluate the effects of second-eye cataract surgery (Javitt, 1995) [9], the effects of cataract surgery in elderly subjects (Shuttleworth, 1998) [10], or to measure the effects of low-vision rehabilitation in AMD patients (Scott, 1999) [11]. These studies still are centered around the medical and functional impact of a surgery or treatment. The visual disability remains poorly explored in its subjective dimension.

3- A new scale taking personal resources into account

Our study aims to pick up where these works left off and add to them. However, we differ from them on several points. First, we wish to create a tool which might be used in any individuals with visual loss, regardless of the severity of their disease (from mild to blind), etiology (progressive congenital or acquired), or the type of compensatory technique (glasses, loupes, filters) or treatment (medication, surgery). In addition, while our initial idea was to develop a quality of life scale, our thinking on the subject eventually led us to address the perception of the handicap resulting from the visual loss and the process of adaptation. The statute of 2005 defines the concept of handicap as *“any limitation of activity or restriction from participation in social life experienced by a person in his or her environment due to a substantial, permanent or definitive alteration in one or more physical, sensory, mental, cognitive or psychic functions, a multiple disability or an incapacitating health problem.”* Our scale does not restrict itself to limitations, losses or inabilities, but it also addresses adaptations, resources, rehabilitation and change. Sacks (1995) [12] speaks of *“the ability of the organism to create organization and a new order that responds to the specific change in these devices and needs.”* For us, it is a question of identifying where the person is in this new organization. This approach, thus far absent in existing questionnaires, includes all the resources (technical, cognitive, psychic and environmental) put to use or not to compensate for the handicap. Also explored are the concepts of the individual's awareness and perception of his or her visual loss. The questionnaire is constructed so as to position the individual as the actor in his or her situation. Sacks (1995) insists on the value of studying *“the internal worlds that patients create under the pressure of their disease.”* These adaptive abilities should be taken into account and supported by caregivers. The questionnaire enables taking stock of these elements.

Our study references the model of Process of Production of the Handicap (PPH; Fougeyrollas, 1998 [13]), which breaks away from the biomedical model, then the individual model. This model combines environmental factors and personal factors. PPH consists of *“a model explaining the causes and consequences of disease, trauma and other conditions to the integrity and/or development of the person.”* Through our questionnaire, our desire is to facilitate a better understanding of the situation surrounding the visual handicap and thus identify the issues, both singular and collective, at play. The PPH model illustrates *“the interactive relationship between the deficits, disabilities and environmental obstacles and defines the situations of the handicap as the result of this interaction”* [14].

Through this multidimensional approach to visual handicap , we can obtain a snapshot of the movements operating between these various dimensions, knowing that they are in perpetual motion and interacting with each other. We share the notion that *“the handicap does not necessarily present as a permanent, static reality for every person.”* Our questionnaire may come to reflect this change through multiple re-administrations over time.

4- Materials and methods

4-1 Development of the questionnaire

Our approach is centered on the patient’s point of view. To this end, we performed over fifty semi-directed interviews with users, taking notes to record their experience. We were careful not to convey our expertise or represent ourselves as caregivers. All the concerns expressed by the patients were analyzed and organized into detailed areas. This content analysis allowed us to extract a number of elements from the conversations, such as difficulties encountered, impact on general life, experiences with technical and optical aids, the search for ways and means, loss of autonomy, effects on mood, consequences on social activity, lack of understanding on the part of friends and family, and withdrawal into oneself. Resulting from this was a process of editing the items. The semantics were analyzed, and redundant questions were discarded. This first version of the questionnaire was discussed with a committee of experts. Ophthalmologists, technicians, opticians, occupational therapists, psychologists and a social worker weighed in on finalizing the form of the questionnaire. This meeting of the professional minds was very productive and gave life to the common desire to put the patient first. Then, to test the tool, a pre-test was performed with 49 subjects. From their remarks and reactions, we made semantic-type changes. We finally chose 28 items. To limit defensive reactions and facilitate completion of the questionnaire, the items were organized as follows: The first questions are of a general nature and approach the visual loss in a concrete, functional manner. For example: *“Do the optical aids you are using help? Have you been able to continue the majority of your activities?”* Items referencing attitudes and more personal dimensions are found at the end of the questionnaire: *“Do you have self-confidence? Do you feel that you are managing the emotional consequences of your visual problems as well as possible?”*

This is a self-administered questionnaire. The individual assesses and evaluates his or her own perception of events. The responses are organized into a 5-point Likert scale: no, a little, moderate, a lot, totally. After these various developmental steps, we obtained the version of the questionnaire which was used in the scientific validation protocol.

4-2 Population

The study population was composed of 446 visually impaired adults over 20 years of age (170 men, 276 women). The mean age of the subjects was 66.8 years (standard deviation = 17.3 years; range 19-97 years). The subjects included in the study had progressive congenital or acquired visual loss ranging from mild to blindness (WHO criteria; see figure 1), treated or not with optical and/or technical aids. Excluded from the study were individuals with cognitive difficulties and/or severe psychiatric disease, with legal guardians. The demographic characteristics of the population are described in table 1.

4-4 Procedure

Subjects were recruited over a period of 51 months between January 2013 and June 2017. The questionnaire was administered upon admission and discharge from the Service. Upon treatment, the

anonymous data of the participants was recorded, and the study was declared to the National Committee on Data Rights. The study adhered to the ethical principals applicable to medical research involving human beings (World Medical Association Declaration of Helsinki, June 1964). The research protocol was carried out with participation of the physician coordinator of the service, guarantor of the patient's care pathway.

5- Results

5-1 Content validity

In parallel with the quantitative steps, we took qualitative steps to verify content validity. This step relied on the reaction of the subjects to answering the questionnaire (lack of understanding, free association of ideas), giving us an idea of how the questionnaire would be received. In addition, we asked some of them about the relevance of the questionnaire. We also relied on the expert committee solicited during the formative stage of the questionnaire. This process of co-construction and co-development encouraged synergy between the subjects, professionals and researchers and placed the study into a systematic dynamic.

5-2 Correlation analysis

A correlation analysis was performed to detect links between the various items on the questionnaire, so as to identify redundant items and/or factors of poor descriptive value. The correlation network obtained is shown in figure 2.

The items appear to be well correlated, and we note the absence of negative correlations. However, we see that items 12 and 16 are very far from the center of the network. These involve intervention by a third party either upon "request" (item 12) or by the possibility of "speaking about the visual disability" (item 16). This distance indicates a resistance to asking for help and to daring to express specific needs. From a clinical point of view, we feel that it is worthwhile keeping them in the final version of the questionnaire. These items reference the visually disabled individual's attitude toward the interviewer.

5-3 Exploratory factor analysis

An exploratory factor analysis (EFA based on Pearson correlations) was felt preferable to a principal component analysis, in accordance with the recommendations of Brown (2006) [15].

As suggested by various authors (Hinkin, 1998 [16]; Boynton & Greenhalgh, 2004 [17]; Tsang, Royse, & Terkawi, 2017 [18]), a verification of the number of possible factors with our data was also performed, notably including Horn's parallel analysis (Garrido, Abad, & Ponsoda, 2013 [19]). These analyses revealed 3 factors around which the 28 items were distributed. With their own values greater than 1, all 3 were able to be retained (Kaiser, 1960 [20]).

5-4 Item response theory (IRT) approach:

Following the item response theory (Embretson & Reise, 2000 [21]), particularly the Rasch model (Laveault & Grégoire, 2002 [22]), we proceeded with optimization of the scoring of items and verification of the unidimensionality of the variables vis a vis the adjustment indices. The results are presented in table 2.

The final version of the questionnaire is presented in table 3. It consists of 3 dimensions which we named as follows, as a function of the items associated with them: (1) Perception of daily life and relationships (10 items), (2) Perception of the visual handicap and compensatory mechanisms (8 items),

(3) Psychological impact of the visual handicap (10 items). The questionnaire is scored using the following calculation: no (1 point), a little (2 points), moderate (3 points), a lot (4 points) and totally (5 points). The total score is out of 140 points, and the sub-dimensions account for 50, 40 and 50 points respectively. Consequently, the higher the total or sub-dimensional score, the better the adaptation to the handicap.

5-5 Reliability of the scale

5-5-1 Internal consistency of the global scale

The calculated alpha coefficient for the global questionnaire was $\alpha = 0.90$. This coefficient corresponds to the criteria for acceptance of a questionnaire (Cronbach, 1951).

5-5-2 Internal consistency by factor

To verify the clinical consistency of the 3 factors determined on EFA, we verified good internal consistency of each of the 3 sub-scales of our questionnaire.

The results show excellent consistency for all 3 factors, with coefficients of $\alpha = 0.86$ for factor 1, $\alpha = 0.79$ for factor 2, and $\alpha = 0.80$ for factor 3. The results suggest good unity between questions belonging to the same factor.

5-6 External validity

In our population, 99 subjects were given the NEI-VFQ 25. To verify external validity of the questionnaire, we looked at the correlation matrix of the NEI-VFQ 25 using a parametric method (Pearson correlations) with corrections of the results by the Bonferroni correction method.

The results obtained demonstrate acceptable correlation between the questionnaire's total score and that of the NEI-VFQ 25. With an $r = 0.70$ ($p < .0001$), the discriminating validity is acceptable. The results obtained may be explained by the fact that our scale measures quite different aspects from those in the NEI-VFQ 25, thus the complementary nature of the two tools. The NEI-VFQ 25 provides the status of where difficulties are encountered in the daily performance of certain tasks (16 of the 25 items) and briefly touches on behavioral and emotional reactions (9 of the 25 items). However, it does not elicit information on rehabilitation and compensatory strategies used or not to get around the stated difficulties. In contrast, the QUEPAHVA goes beyond observation of handicap and abilities. It reports the resources, strategies and abilities contributing to adaptation to the handicap.

5-7 Reproducibility

We also tested reliability over time. The responses for a same individual were checked upon several administrations of the questionnaire, under identical experimental conditions. We studied the difference between scores obtained after a time interval between T1 and T2 (mean interval between T1 and T2 49.43 days) on a sample of 31 subjects. We obtained the following results: **Factor 1:** $t(30) = -0.54$; $p = 0.58 > .05$ **Factor 2:** $t(30) = 0.37$; $p = 0.70 > .05$ **Factor 3:** $t(30) = 0.70$; $p = 0.48 < .05$ **Total:** $t(30) = 0.65$; $p = 0.51 < .05$

For factors 1 (Perception of daily life and relationships) and 2 (Perception of the visual handicap and compensatory mechanisms), the difference between the two administrations of the questionnaire was not significant. With regard to factor 3 (Psychological impact of the visual handicap), the difference between T1 and T2 was significant.

Thus, the questionnaire shows relatively satisfactory reproducibility depending on the factor. These results may vary slightly due to testing conditions.

5-8 Sensitivity to change

A variance analysis (ANOVA) was performed with the goal of showing sensitivity to change. This involves the ability of the questionnaire to show a change in status between two administrations over time and to objectify perceptible changes, spontaneous or not (Lepège, 2001) [23]. The evaluation of sensitivity of change of the QUEPAHVA was performed by calculating the variations in scores between the results obtained pre and post care program (mean time interval between pre and post was 410 days) in 123 subjects. We obtained the following results: **Factor 1:** $F(1,328) = 16947$; $p < .001$; **Factor 2:** $F(1,328) = 2050$; $p < .001$; **Factor 3:** $F(1,328) = 3718$; $p < .001$; **Total :** $F(1,328) = 573$; $p < .001$. For all the factors as well as the total scale, the difference between pre ($\mu = 80.5 \pm 1.2$) and post ($\mu = 98.8 \pm 0.99$) care program was highly significant. The questionnaire's sensitivity to change is high. The questionnaire can thus show fine changes and movements which may occur over time.

6- Discussion

The process of scientific validation carried out has allowed us to demonstrate and prove the value, both clinical and statistical, of the questionnaire. We may now add this new specific measurement tool to the field of visual handicap and present its various applications.

6-1- Psychometric qualities of the scale

Factorial analysis allows us to observe a factorial structure in 3 sub-dimensions. We note that only 3 items of the 28 could be statistically associated with 2 factors. For the remainder of the 25 other items, they are statistically associated with one factor. This illustrates the existence of a clear distinction between the sub-scales. Their pertinence is also obvious from a clinical point of view.

Content validity was discussed in a committee of experts in the field of visualhandicap . Analysis of internal consistency of the global scale and its sub-scales demonstrates alpha coefficients ranging from 0.79 to 0.90. These results reflect good reliability of the questionnaire. Discriminatory validity was tested. An acceptable positive correlation of 0.70 with the chosen reference tool (NEI-VFQ 25) was observed. The questionnaire shows relative reproducibility over time depending on the factor. These results are related to less than favorable experimental conditions. This may be explained by the long time between T1 and T2 (49.43 days). The literature recommends an interval between T1 and T2 of 15 days, an interval which we could not achieve due to the internal logistics of the Service. The factor related to the psychological dimension was found to be even more sensitive to progression and changes over time. In order to retest the reliability of the questionnaire, the protocol should be reproduced with a more relevant interval between T1 and T2. These results may be showing a certain sensitivity of the scale to change. This was demonstrated under specific experimental conditions and is very high. The scale meets the criteria for scientific validation.

6-2 Perspectives and applications

Our study serves, through new elements, to enhance our understanding of visualhandicap . Beyond this theoretical value, it also promises clinical and institutional value.

Evaluation of individual needs

The Law of June 30, 1975 (integration of disabled individuals) and the Law of January 2, 2002 (defining social and medico-social action) reaffirm the principle of the central place of the individual within the system of support and care. Thus, the Law of 2002 art. 7 insures the rights of the user, with,

inter alia, “individualized management and support designed to promote his or her development, autonomy and inclusion, adapted to his or her needs, respecting his or her informed consent, which must be expressly sought when the individual is able to express his or her wishes and participate in the decision.” ANESM (National Agency for Evaluation and Quality of Facilities and Social and Medico-social Services, 2008) publishes new preferred professional practice patterns regarding “personal conditions and personalized support” [24] as well as “practices of cooperation and coordination of the care plan of the disabled individual” [25]. Our study clearly lends itself to the current legal and legislative context. These texts now set the standard for care facilities. Their recommendations are clear: to incorporate the needs, expectations and desires of the individual, with the goal of co-designing a personalized plan for the individual’s way of life. Within this context, our scale constitutes a good evaluation tool.

Therapeutic evaluation

On the side of the individual, the questionnaire favors his or her self-description and personal read on the life experience. This more or less comfortable subjective exercise may promote a certain, more detached perspective. The self-evaluation of feelings, perceptions, abilities and resources is an integral part of the work of psychic development and self-knowledge. Getting a handle on the individual’s perception of him- or herself is interesting from a diagnostic point of view, but the goal can also be an explanation and adjustment of negative self-perceptions that the individual may harbor.

Thus, the use of our scale in therapeutic evaluation should also be developed. This subjective, individualized evaluation, at a given time, enables the individual to realize, with help from a professional, where he or she is in his or her perception and understanding of the visual handicap and the available means and strategies put in place. The scale may constitute a common support between the individual and the caregiver, encouraging change. The idea is to support the individual in the understanding of his or her visual handicap so as to develop and/or reinforce adaptations and adjustments (technical, cognitive, psychic, behavioral, rehabilitative, etc.) which might help in the management of the experienced consequences. This therapeutic evaluation consists of “transforming the psychological work-up into a brief therapeutic intervention” (Finn, 2016 [26], Chudzik, 2014 [27]). It proposes the use of testing tools “to help individuals to better understand themselves and find solutions to their problems that still exist. Its main purpose is to facilitate positive change in the individual.” This brief technique clearly fits into the time frame of a care plan on the short and medium terms. We find our approach to be collaborative.

The support of individuals living with a sensory loss begins at the time of the evaluation, with the method by which the individual is evaluated and positioned within this approach. One must remain vigilant to incorporate the individual into the interpretation of the data collected in the evaluation.

This evaluation may be performed at different times in order to assess potential change, or lack thereof, in the individual’s progress, or to evaluate the effects of a treatment.

Evaluation of the perception of the visual disability and quality of life

Taking into consideration the subjective experiences of the visual defect and its impact on the individual’s life goes back to the concept of quality of life. Campbell (1976) [28], followed by Andrews (1980) [29], address this concept around the subject of satisfaction in various areas of living, through “a cognitive view and judgement of the individual’s experience of well-being.” This satisfaction is also related to individual needs (Maslow’s hierarchy of needs [30], 1943) and desires (Corten et al, 1997 [31]). The WHO (1994) defines this concept as “an individual’s perception of his or her place in existence, within the context of the culture and value system within which he or she lives, in relation to his or her goals, expectations, norms and concerns.” Nordenfelt (1994) [32] evaluates all of these perceptions, sensations, emotions, and ideas of the individual, as well as all of his or her actions, activities and successes, and the events and actions which affect the individual. Our scale is based in these approaches and fits well into current trends in organized public health (WHO, regional health agencies, etc.).

Evaluation within the context of a care protocol

The results obtained with our questionnaire may be combined with those obtained from objective medical and paramedical evaluations (orthoptic, low vision, occupational therapy). It thus constitutes a complementary, ancillary index in the overall understanding of the individual. Our questionnaire is easy to use. It may be of assistance to the professional who can use it as a framework for the interview process. The layout of the questionnaire also allows the professional, depending on specialty (physician, technician, psychologist, optician, etc.) and/or the patient's problems, to more specifically explore one of the factors.

In order to measure the effects of a care protocol, the questionnaire may be administered pre and post care program. Its use is efficacious on our Service, where it plays an integral part in our practice. We use it pre and post rehabilitation. Its use may be extended to any type of surgical procedure or treatment which may affect vision (for example, after intravitreal anti-VEGF injections for exudative AMD).

Improving quality of care

In order to measure the effects of a care plan, our study scale can be used before and after. This feedback also may help an institution assess a proposed support measure. With a view toward continued improvement, we have begun to put this step in place.

Conclusion

The QUEPAHVA has been validated by this study and shows good psychometric qualities. It is a simple tool which can be used quickly. It can measure, with relevance and finesse, the situation surrounding a visual handicap at a given time, as well as the effects of a care program, and it can help direct management. It brings new elements of understanding to the table for the ophthalmology clinic.

Disclosures

The authors have no conflicts of interest to declare.

Acknowledgements

This research received a clinical research grant from the Future Foundation.

References

- [1] Steinberg EP, Tielsch JM, Schein OD, Javitt JC, Sharkey P, Cassard SD, Legro MW, Diener-West M, Bass EB, Damiano AM, et al. The VF-14. An index of functional impairment in patients with cataract. *Archives of Ophthalmology* 1994 May;112(5):630 8.
- [2] Mangione CM, Lee PP, Pitts J, Gutierrez P, Berry S, Hays RD. Psychometric properties of the National Eye Institute Visual Function Questionnaire (NEI-VFQ). *Archives of Ophthalmology* 1998;116(11):496 504.
- [3] Rouland JF, Denis P, Bechetoille A et al. Création d'un questionnaire spécifique évaluant la qualité de vie chez les patients glaucomateux : générations des items. *Journal français d'ophtalmologie* 2002 ;25:85 94.
- [4] Zanlonghi X, Arnould B, Béchetoille A, Beaudoin C, Bron A, Denis P, et al. Glaucome et qualité de vie. *Journal français d'ophtalmologie* 2003 26 (HS2):39 44.
- [5] Gresset J, Boisjoly H, Nguyen T, Boutin J, Charest M. Validation of French-language versions of the Visual Functioning Index (VF-14) and the Cataract Symptom Score. *Canadian journal of ophthalmology Journal canadien d'ophtalmologie* 1997;32(1):31 7.
- [6] Mangione CM, Lee PP, Gutierrez PR, Spritzer K, Berry S, Hays RD. Development of the 25-item National Eye Institute Visual Function Questionnaire. *Archives of Ophthalmology* 2001;119(7):1050 8.
- [7] Nordmann JP, Viala M, Sullivan K, Arnould B, Berdeaux G. Psychometric validation of the National Eye Institute Visual Function Questionnaire – 25 (NEI VFQ-25) French version : in a population of patients treated for ocular hypertension and glaucoma. *Pharmacoeconomics* 2004;22(3):197 206.
- [8] Bour T, Blanchard F, Segal A. Therapeutic observance and life of patients with primary open-angle glaucoma. Apropos of 341 cases in the department of Marne. *Journal Français d'Ophtalmologie* 1993;16(6-7):380 391.
- [9] Javitt JC, Steinberg EP, Sharkey P, Schein OD, Tielsch JM, Diener M, et al. Cataract surgery in one eye or both. A billion dollar per year issue. *Ophthalmology* 1995;102(11):1583 1592; discussion1592-1583.80.
- [10] Shuttleworth, Luhishi, Harrad. Do patients with age related maculopathy and cataract benefit from cataract surgery? . *British Journal of Ophthalmology* 1998;82:611 616.
- [11] Scott IU, Smiddy WE, Schiffman J, Feuer WJ, Pappas CJ. Quality of life of low-vision patients and the impact of low-vision services. *American Journal of Ophthalmology* 1999;128(1):54 62
- [12] Sacks O. Un anthropologue sur mars, sept histoires paradoxales. *Seuil*, 1995;p.18 22
- [13] Fougeyrollas P, Cloutier R, Bergeron H, Côté J, St-Michel G. Classification québécoise : processus de production du handicap. Québec, Réseau international sur le processus de production du handicap 1998.
- [14] Fougeyrollas P. Séminaire du Réseau partenarial francophone pour la formation et la recherche sur la CIF et le PPH. Paris, 2 décembre 2005.
- [15] Brown T.A. *Confirmatory Factor Analysis for Applied Research*. New-York: The Guilford Press;2006.
- [16] Hinkin T.R. A brief tutorial on the development of measures for use in survey questionnaires. *Organ Res Methods* 1998; 104 21.
- [17] Boynton P. M, Greenhalgh T. Selecting, designing, and developing your questionnaire. *British Medical Journal* 2004;328(7451):1312 1315.
- [18] Tsang S, Royse C, Terkawi A. Guidelines for developing, translating, and validating a questionnaire in perioperative and pain medicine. *Saudi Journal of Anaesthesia* 2007,11(Suppl 1):80 89.
- [19] Garrido L. E, Abad F. J, Ponsoda V. A new look at Horn's parallel analysis with ordinal variables. *Psychological Methods* 2013;18(4):454 474.
- [20] Kaiser H.F. The Application of Electronic Computers to Factor Analysis. *J Educational and Psychological Measurement* 1960;20(1):141 151.
- [21] Embretson S.E, Reise S.P. *Item Response Theory for Psychologists*. Mahwah, N.J: Lawrence Erlbaum Associates 2000.

- [22] Laveault D, Grégoire J. Introduction aux théories des tests en sciences humaines. Paris : De Boeck; 2002.
- [23] Lepage A., Coste J. Mesure de la santé perceptuelle et de la qualité de vie : méthodes et applications, Editions ESTEM; 2001.
- [24] ANESM. Les attentes de la personne et le projet personnalisé d'accompagnement. 1^{er} décembre 2008.
- [25] ANESM. Les pratiques de coopération et de coordination du parcours de la personne en situation de handicap. 6 avril 2018.
- [26] Finn E. L'évaluation thérapeutique. Théorie et techniques, Dunod; 2016.
- [27] Chudzick L. Les différentes étapes de l'Évaluation thérapeutique. Le Journal des psychologues vol. 323, no. 10, 2014, p. 28 31.
- [28] Campbell A, Converse P, Rodgers W. The Quality of American Life: Perceptions, Evaluations, and Satisfaction. Russell Sage Foundation; 1976.
- [29] Andrews F. M, McKennell A. C. Measures of self-reported well-being: their affective, cognitive and other components. Social Indicators Research, 8,1980;127 155.
- [30] Maslow A. A Theory of Human Motivation. Psychological Review, vol. 50, n° 4;juillet 1943, 6.
- [31] Corten Ph, Mercier C. Subjective Quality of Life Assessment. The Quavisub: content, validity, utility. International Report NATO Collaborative Research Grant n° 910084 Pattern of Quality of Life among People with Disabilities, Brussels; 1997.
- [32] Nordenfelt L. Concepts and Measurement of Quality of Life in Health Care. Philosophy and Medicine, n°47, Kluwer Academic Publishers; 1994.

Figures and tables

Table 1. Demographic characteristics: types of disease.

Figure 1. Demographic characteristics: degree of visual impairment (n = 446).

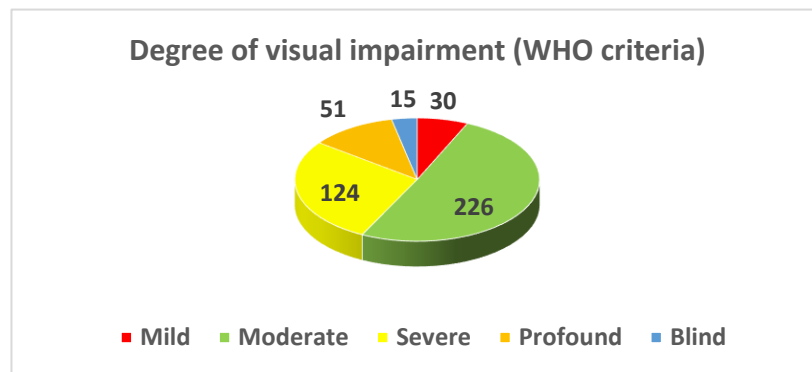
Figure 2. Network of correlations between the 28 items on the questionnaire. The items are found in Appendix 1.

Table 2. Structure with all items of the questionnaire.

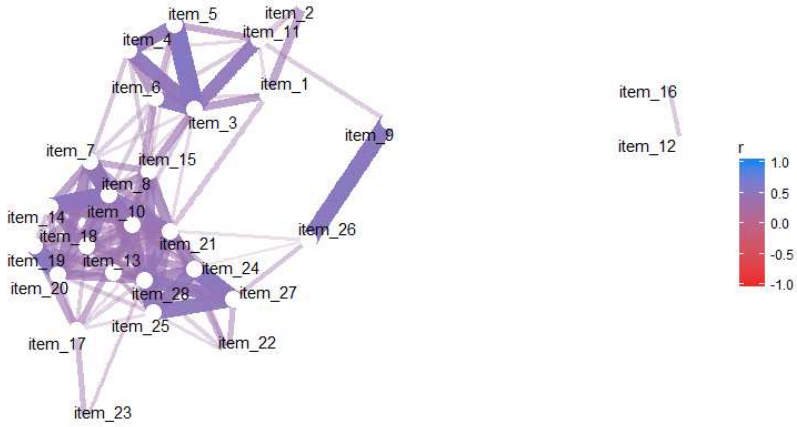
Table 3. Final structure of the questionnaire: 3 factors, 28 items.

Degree of visual Impairment

Mild	30
Moderate	226
Severe	124
Profound	51
Blind	15



Correlations between DV items



*Nb : **Positive correlations** are shown in blue and **negative correlations** in red. The intensity and width of the lines are proportional to the **correlation coefficients**. To the right of the **correlation network**, the color legend shows the **correlation coefficients** and their corresponding colors.*

Condition	Number of subjects	Condition	Number of subjects
AMD	170	Traumatic	21
Retinitis pigmentosa	67	Multiple sclerosis	8
Glaucoma	48	Atrophy	11
High myopia	49	Diabetic retinopathy	12
Usher syndrome	6	Congenital	32
Neuropathy	23	Idiopathic	9

Variable	Factor1	Factor2	Factor3	Uniqueness
q1	0,12	0,52	0,30	0,63
q2	-0,13	0,54	0,22	0,64
q3	0,29	0,77	0,06	0,31
q4	0,34	0,61	-0,04	0,51
q5	0,19	0,67	-0,05	0,51
q6	0,38	0,58	-0,03	0,52
q7	0,69	0,22	0,07	0,48
q8	0,76	0,16	0,11	0,39
q9	0,04	0,38	0,44	0,66
q10	0,60	0,23	0,28	0,51
q11	0,02	0,69	0,16	0,50
q12	-0,27	0,41	0,37	0,63
q13	0,43	-0,01	0,42	0,64
q14	0,69	0,03	0,10	0,51
q15	0,50	0,33	0,32	0,59
q16	0,03	0,23	0,53	0,67
q17	0,30	0,24	0,42	0,68
q18	0,58	0,07	0,28	0,58
q19	0,51	0,09	0,33	0,63
q20	0,60	0,04	0,30	0,55
q21	0,53	0,19	0,43	0,50
q22	0,21	0,05	0,53	0,67
q23	0,13	-0,14	0,48	0,73
q24	0,35	0,02	0,59	0,53
q25	0,33	0,07	0,61	0,51
q26	0,10	-0,29	0,46	0,70
q27	0,25	-0,02	0,69	0,46
q28	0,50	0,01	0,54	0,47

Note: In red, the items unassociated with any of the 3 factors.

Factor 1 Perception of daily life and relationships (10 items)	Factor 2 Perception of visual status and compensatory mechanisms (8 items)	Factor 3 Psychological effects of the visual handicap(10 items)
7- Activities of daily living 8- Autonomy 10- Ability to perform a task 13- Comfort in social situations 14- Feeling of independence 15- Ability to adapt 18- Feeling of security outdoors 19- Participation in family life 20- Participation in social life 21- Problem solving	1- Awareness of visual difficulties 2 – Identification of functional consequences 3- Awareness of compensatory mechanisms 4- Use of optical aids 5- Use of technical aids 6- Investment in/use of remaining visual abilities 11- Development of non-visual compensatory mechanisms 12- Request for assistance	9- Desire to do things 16- Communication about visual disability 17- Feeling of security at home 22- Dealing with onlookers 23- Family's and friends' understanding of the situation 24- Self-confidence 25- Emotional adjustment to visual disability 26- Future plans 27- Self-image 28- Sense of well-being