Concept Mapping to Identify Content for a Performance-Based Measure of Low Luminance Vision-Related Activities of Daily Living

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Received: July 3, 2022
Accepted: August 25, 2022
Published: September 27, 2022

Keywords: vision impairment; low luminance; activities of daily living (ADLs); low vision; concept mapping

Citation: Bentley SA, Black AA, Hindmarsh GP, Owsley C, Wood JM. Concept mapping to identify content for a performance-based measure of low luminance vision-related activities of daily living. Transl Vis Sci Technol. 2022;11(9):27, https://doi.org/10.1167/tvst.11.9.27

Purpose: The purpose of this study was to identify low luminance activities of daily living (ADL) relevant to adults with vision impairment using a concept-mapping approach.

Methods: "Group concept mapping" was utilized to identify specific ADLs that persons with vision impairment find challenging under low light conditions. In the first "brainstorming" phase, 24 adults with vision impairment from a range of eye conditions (mean age = 73 years, SD = 14 years) and 26 international low vision experts (mean experience = 22, SD = 11 years) generated statements to the focus prompt, "Thinking as broadly as possible, generate a list of statements detailing specific day-to-day activities a person with vision impairment might find challenging under low light conditions, such as in a poorly lit room or outside at dusk." In the second phase, participants sorted activities by similarity and rated the importance of each activity. Multidimensional scaling and hierarchical cluster analysis were applied to produce concept maps showing clusters of prioritized activities.

Results: One hundred thirteen unique ideas/activities were generated, rated and sorted. Eight clusters were identified (from highest to lowest importance): hazard detection and safety outside; social interactions; navigation; near reading; selfcare and safety at home; distance spotting; searching around the home; and cooking and cleaning.

Conclusions: The conceptual framework and low luminance ADLs identified (the most important being hazard detection and safety outside, and social interactions) provide a basis for developing a performance-based measure of low luminance visual function.

Translational Relevance: A performance-based measure of low luminance vision-related ADLs is required for comprehensively and objectively assessing efficacy of eye treatments and low vision rehabilitation outcomes in adults with vision impairment.

Introduction

Low light levels exacerbate functional performance deficits and are particularly challenging for adults with vision impairment.[1–4] Even in the early stages of eye disease, adults with vision impairment report difficulties with night driving, walking at night, seeing steps, reading under dim illumination, glare, and adapting to changes in illumination.[1,3,5,6] The consequences can be serious, including motor vehicle collisions, particularly involving pedestrians and cyclists,[7,8] falls,[9–12] and emotional distress.[5,13] Measuring these effects has become increasingly important to better understand the problems experienced by adults with vision impairment under low luminance, to design interventions to prevent physical and psychological injury and to develop measures for evaluating and monitoring changes in performance following eye therapies and vision interventions. However, most existing vision-specific patient reported outcome measures (PROMs) and performance-based measures do not specifically consider low luminance conditions.

Only a few self-report questionnaires or PROMs have been designed to measure vision-related function under low luminance, the Low Luminance Questionnaire (LLQ[5]; translated versions, Japanese LLQ[14] and German LLQ-23[13]), Night Vision Questionnaire (NVQ-10),[15] Dark Adaptation Survey (DAS),[16] and Vision Impairment in Low Luminance (VILL) questionnaire,[17] which can provide some personal insights into the challenges faced by people with vision impairment. PROMs are an important tool for understanding the patient perspective in health care, which is a requirement in clinical trials,[18,19] as well as being practical and cost-effective to implement in clinical and research settings. However, PROMs are subjective and may be susceptible to inaccuracies and biases when used as an indicator of functional performance.[20] More objective, direct measures of standardized relevant tasks performed under controlled conditions are also required to understand the consequences of low luminance vision impairment in the real world and to evaluate therapies, particularly in research. Some studies have investigated the performance of a specific activity under low luminance, such as object identification,[21,22] mobility,[23–25] and reading.[26] However, to date, no comprehensive performance-based measure specific to vision-related activities of daily living (ADLs) under low luminance has been developed.

The development of a performance-based measure should commence with consideration of which content, or, in this case, activities, should be included. Content can be informed by evidence in the literature and, more importantly, by stakeholders (patients, clinicians, and researchers). Typically, input from stakeholders might be obtained from qualitative methods, such as interviews, focus groups, surveys, Delphi, and nominal group techniques. “Group concept mapping” is a robust integrative mixed method that goes beyond these approaches by combining qualitative and quantitative techniques to produce concept maps and data displays, resulting in comprehensive visual representations of key ideas/activities, their importance, and their inter-relationships.[27,28] Although this method has been used extensively in health research, the approach is novel in vision research, where it has been applied to perspectives on in-home monitoring of older adults with vision impairment,[29] quality in cataract care,[30] and the impact of vision impairment on the lives of young adults.[31]

This study aimed to identify contemporary low luminance ADLs relevant to adults with vision impairment using a concept mapping approach as the basis for the development of a low luminance vision-related performance-based measure.

Methods

Participants

Two groups were invited to participate in the study: patients with vision impairment and expert low vision professionals knowledgeable about the effects of vision impairment. A convenience sample of patients with vision impairment was recruited from the Queensland University of Technology Optometry Low Vision Clinic. To be eligible, patients were required to have best corrected visual acuity in the range 6/12 (20/40) to 1/60 (20/1200) caused by any diagnosed eye disease. Purposive and snowball sampling were used, through pre-existing relationships with the research team, to recruit national and international expert low vision professionals who had extensive research or clinical experience. Demographic and other data collected for the patient group included age, sex, and primary eye condition, and for the low vision professional group included country of practice and years of experience.

The study was approved by the Queensland University of Technology Human Research Ethics Committee and adhered to the tenets of the Declaration of Helsinki. Informed consent was obtained prior to participation.

Group Concept Mapping Data Collection and Item Structuring

Group concept mapping was conducted using, The Concept System “groupwisdom” (Build 2021.24.01, Ithaca, NY; https://groupwisdom.com/). In brief, group concept mapping involves several phases. In the first “brainstorming” phase, participants generate short statements in response to a “focus prompt” or question, until saturation of the topic is reached. In the second phase (“item structuring”), statements are sorted by participants into groups of similar statements and then the statements are rated by importance. In the third analysis phase, statistical analyses are applied to construct maps displaying the relationships between clusters of data.

In the first phase of this study (“brainstorming”), participants were asked to respond to the focus prompt (via mail, telephone, or the “groupwisdom” web-based application): “Thinking as broadly as possible, generate a list of statements detailing specific day-to-day activities a person with vision impairment might find challenging under low light conditions, such as in a poorly lit room or outside at dusk.” Statements were collated for the entire group in the web-based application and reviewed for clarity and duplication to generate a list of unique statements using the terminology of the participants as much as possible. Additionally, the researchers (authors S.B., J.W., and A.B.) checked to ensure that the main categories of activities included in existing low luminance PROMs reported in the literature (mobility, driving, adjustment to lighting conditions, reading, and faces)[5,13,15,16] were covered by the statements generated.

In the second phase ("item structuring"), the unique statements generated in the first phase were sorted into groups of similar statements. This was completed on a separate occasion, when unique statements of activities were presented back to participants (in randomized order) and participants asked to sort activities by their similarity (either in an in-person session with the support of a sighted assistant for participants with vision impairment or via the web-based application) and rate the importance of each activity on a five-level scale (where 1 = not important and 5 = very important).

Statistical Analysis

Descriptive statistics were calculated for participant characteristics. The group concept mapping analysis was conducted using The Concept System groupwisdom (Build 2021.24.01, Ithaca, NY; https://groupwisdom.com/), where multidimensional scaling and hierarchical cluster analysis were applied to the data to produce graphical representations of major ideas or clusters and possible connections, which depict the composite thinking of the participants. Multidimensional scaling positions the statements on a map where those statements that have been frequently sorted together in the same group are positioned close to each other. Goodness-of-fit was determined by the stress value (the better the fit, the lower the stress value; <0.35 considered favorable, indicating adequately represented item structuring).[27] Hierarchical cluster analysis then aggregates the statements into clusters on the basis of inter-statement distances. Maps with 4 to 10 clusters were produced and compared for both groups combined and each group separately. Three of the researchers (authors S.B., J.W., and A.B.) examined each map to select the configuration that made the most conceptual sense (i.e. that neither resulted in loss of relevant concepts due to too few clusters, nor resulted in difficult interpretation due to overlapping concepts across clusters). Each cluster in the selected final map was named by the researchers to best reflect its content. The average importance rating for each statement and cluster was also calculated. The Pearson correlation coefficient was used to determine the association between ratings for low vision professionals and patients and Welch's t-test to compare group differences (two-tailed; $P < 0.05$ considered statistically significant).

Results

Participant Characteristics

In the first data collection "brainstorming" phase, participants were 24 adult patients with vision impairment from a range of eye conditions (mean age = 73 years, SD = 14 years; 46% women; 55% with age-related macular degeneration, 29% with inherited retinal degeneration, 8% with glaucoma, and 8% with other conditions) and 26 expert low vision professionals (mean experience = 22 years, SD = 11 years) from the United States, Australia, the United Kingdom,

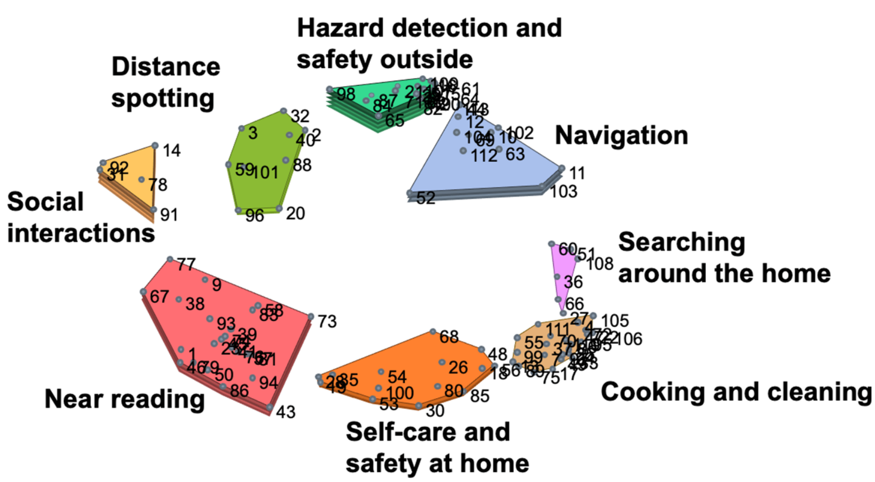

Figure 1. Concept map of activities a person with vision impairment might find difficult under low luminance. Each numbered dot represents a unique activity statement; each bounded area represents a cluster of similar activities. The theme of each cluster has been named. Clusters with more layers were rated more important by participants. Similar clusters are located close to each other.

Table. Clusters and Sample Statements/Activities[a] with Average Importance Ratings[b]

No.	Statement	Total no. Statements in Cluster	Average Importance Rating for Both Patients and Professionals ($n = 23$)	Average Importance Rating for Professionals ($n = 12$)	Average Importance Rating for Patients ($n = 11$)
	Cluster 1: Hazard Detection and Safety Outside	*20*	*3.92*	*3.87*	*3.99*
61	Seeing cars when crossing the street		4.83	4.67	5.00
113	Crossing the road		4.74	4.58	4.91
107	Avoiding obstacles on a footpath/sidewalk		4.48	4.50	4.45
34	Identifying curbs		4.43	4.42	4.45
109	Seeing cars without headlights on		4.39	4.25	4.55
62	Judging depth of objects/obstacles		4.35	4.08	4.64
21	Detecting pedestrians or cyclists		4.30	4.08	4.55
82	Walking on uneven surfaces		4.09	4.17	4.00
15	Avoiding cracks on a footpath/sidewalk		4.04	3.75	4.36
71	Seeing dark colored cars		3.96	3.67	4.27
5	Adapting to changes in light levels		3.87	3.83	3.91
64	Seeing low hanging tree branches		3.87	3.75	4.00
29	Identifying landmarks to aid navigation		3.78	3.67	3.91
	Cluster 2: Social Interactions	*5*	*3.60*	*3.43*	*3.78*
92	Recognizing faces		4.09	3.83	4.36
14	Finding other people		4.00	3.83	4.18
31	Recognizing facial expressions		3.78	3.58	4.00
	Cluster 3: Navigation	*11*	*3.49*	*3.67*	*3.29*
44	Moving around outdoors		4.17	4.25	4.09
102	Walking up/down stairs		4.09	4.33	3.82
12	Navigating dark hallways		3.78	3.58	4.00
	Cluster 4: Near Reading	*23*	*3.46*	*3.45*	*3.47*
46	Reading medicine labels		4.61	4.75	4.45
1	Reading texts on a mobile phone/cell phone		3.96	3.92	4.00
43	Using a computer		3.96	4.08	3.82
93	Reading labels in supermarkets		3.83	3.83	3.82
41	Writing		3.83	3.33	4.36
73	Identifying money		3.83	4.00	3.64
	Cluster 5: Self-Care and Safety at Home	*14*	*3.43*	*3.60*	*3.24*
30	Measuring medicine		4.52	4.83	4.18
35	Checking food expiry dates		4.09	4.08	4.09
100	Managing diabetes medication		3.91	4.83	2.91
48	Identifying whether food has gone off		3.87	4.08	3.64
56	Checking whether the gas is on using the cooktop		3.83	4.42	3.18
	Cluster 6: Distance Spotting	*9*	*3.33*	*3.15*	*3.53*
32	Identifying the correct public restroom/toilet		4.09	3.83	4.36
3	Finding places and people in crowded areas		3.83	3.50	4.18
2	Reading bus numbers		3.59	3.45	3.73
	Cluster 7: Searching Around the Home	*6*	*3.20*	*3.32*	*3.06*
27	Using controls on stove/cooktop		4.13	4.25	4.00
36	Finding things dropped on floor		3.61	3.25	4.00
66	Inserting a key into a lock		3.48	3.58	3.36
	Cluster 8: Cooking and Cleaning	*25*	*3.11*	*3.08*	*3.14*
24	Cutting food		3.83	3.75	3.91
33	Pouring a drink into a cup		3.83	3.92	3.73
13	Finding food in a cupboard		3.57	3.50	3.64

[a]Clusters based on sorting by low vision professionals. Sample statements/activities are those ranked in the top 30% (out of 113) for importance, having an average rating >3.75. For less important clusters, 1 or 2 sample statements with average ratings <3.75 are given to convey the theme of the cluster.

[b]Importance rated on a 5-level scale, where 1 = not important and 5 = very important.

Canada, and Germany. In the second "item structuring" phase, 10 patients completed the sorting of statements into groups and 11 completed the rating of statements for importance. For the professional group, 12 completed the sorting task and the rating task.

Concept Maps and Importance Ratings

In the first phase, 173 statements were generated by both the low vision professionals and patients in response to the focus prompt. Following removal of duplicate ideas and refinement, 113 unique statements

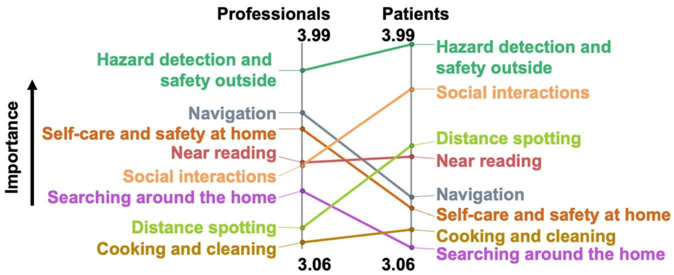

Figure 2. Relationship between expert low vision professional (*n* = 12) and low vision patient (*n* = 11) mean importance ratings by cluster (rating scale 1 to 5, where 1 = unimportant and 5 = very important).

or activities were presented to participants for sorting and rating. Multidimensional scaling of the 113 statements had the best fit, as indicated by the lowest stress value, for the sorting completed by the low vision professionals (stress value = 0.21, $n = 12$), compared with patients (stress value = 0.30, $n = 10$), and both groups combined (stress value = 0.23, $n = 22$); cluster maps were compared for the sorting completed by each group and by both groups combined. As expected, based on the stress value, cluster maps arising from the sorting completed by low vision professionals were conceptually clearer (i.e. there was a clearer theme to the activities grouped in each cluster) than the maps arising from the sorting completed by either the patients or by both groups combined. An 8-cluster map comprising the 113 activity statements generated by both patients and professionals, based on the sorting by low vision professionals, was selected as the one making most conceptual sense (Fig. 1). The 8 clusters, from highest to lowest average importance rating, were: hazard detection and safety outside; social interactions; navigation; near reading; selfcare and safety at home; distance spotting; searching around the home; and cooking and cleaning. The Table gives the number of statements in each cluster, average importance rating (completed by 23 professionals and patients combined) and sample statements (including those ranked in the top 30% for importance [rating >3.75]) to convey the theme of each cluster.

The relative importance of clusters for each participant group is shown in Figure 2. Overall, there was a moderately strong correlation between patient and low vision professional ratings for importance of clusters of activities ($r = 0.49$). Hazard detection and safety outside was rated the most important cluster by both the low vision professionals and patients. Although patients rated social interactions and distance spotting as being more important, and navigation and self-care and safety at home less important compared with low vision professionals, the differences were small and not significant ($P > 0.05$).

Discussion

In this study, 8 clusters or groups of vision-related activities related to challenges under low luminance were identified by both expert low vision professionals and patients with vision impairment (from highest to lowest importance ratings): hazard detection and safety outside; social interactions; navigation; near reading; selfcare and safety at home; distance spotting; searching around the home; and cooking and cleaning. The clusters that included the most activity statements were hazard detection and safety outside, near reading, and cooking and cleaning. Many of the clusters and individual activity statements rated most highly for importance seem to be those that might pose greater risk to personal safety. Clusters with lower importance ratings (searching around the home and cooking and cleaning), comprise household activities where lighting can usually be increased. Although low vision professionals and patients differed slightly in their perceived relative importance of the clusters of activity statements, any differences were not significant.

The hazard detection and safety outside and navigation clusters were rated as highly important and were located next to each other on the cluster map, indicating a close relationship, as expected. Several activities within these clusters related to crossing the road, driving (either as a driver or passenger), and walking around the environment (mobility). This is consistent with the literature (where these activities are frequently reported as challenging for adults with vision impairment), and the focus of low luminance PROMs.[5,8,13,15,16] These activities are not easily standardized and could present safety issues in a set of tasks that might be included in a performance-based measure. An option for both crossing the road and driving could be a carefully designed computer-based "hazard perception test" (HPT).[32,33] HPTs typically involve real video or static images that require the viewer to identify a range of potential hazards or traffic conflicts (e.g. cars and pedestrians). To date, no studies have investigated performance on HPTs simulating mesopic or night-time conditions. However, performance on daytime HPTs has been associated with crash risk and on-road driving performance.[34–36] Although HPTs have been mostly used to evaluate driving, there are a few studies that have used HPTs to investigate the ability to cross the road safely during the daytime.[33,37,38] With regard to walking around the environment, a number of standardized, relatively safe and compact laboratory courses, typically seeded with hazards simulating the real world, have been designed to evaluate mobility performance under a range of luminance levels,[23,24,26,39–41] and could incorporate many of the activities identified in this study. An additional activity in the hazard detection and safety outside cluster that warrants specific consideration for inclusion in a comprehensive performance-based measure is adapting to changes in light levels. To date, adaptation to light levels has been limited to a few performance-based mobility[41–43] and driving studies[41–46] investigating glare disability, in spite of it being such a frequently reported problem for patients with vision impairment.[3,5,16,17,47]

The second most important cluster comprised the fewest activity statements, mostly related to identifying faces and facial expressions. Diverse approaches have been used in previous studies to measure the ability of persons with vision impairment to identify faces and facial expressions, several that could be included as a low luminance performance-based measure, each with advantages and disadvantages. Some studies have simply used printed or projected famous faces.[48,49] However, even famous faces might not be familiar to everyone. Other studies have either used faces that were photographed for the purpose of the study,[50–52] or faces from validated standardized databases (originally assembled to investigate prosopagnosia).[53–55] Regardless, it is challenging to standardize images of faces with respect to features, such as expression, head posture, hair, etc. Facial expressions used are typically neutral, sad, anger, fear, happy, surprise, and disgust, as these are consistently found within most cultures.[56] For face recognition, matching and odd-one-out methods have been used to evaluate performance (with several trials to account for variability in faces and guessing), and for facial expressions, simple naming has been used.[49,51,52,57] Even so, no studies have assessed the effect of low luminance on face perception in adults with vision impairment.

The near reading cluster in this study comprised a large number of activity statements, mostly related to reading small text, such as medicine labels, mobile phone texts, computer use, shopping labels, food/ingredient labels, books, menus, and brochures, as well as writing and identifying money. Some of these are more likely to be undertaken in low luminance than others (e.g. reading a book in bed or a menu in a dimly lit restaurant). Most are easily replicated and standardized, and, indeed, many have been included as part of performance-based measures designed for photopic conditions,[48,58,59] as well as low luminance PROMs.[5,13,15,17] Similarly, many of the activities in the distance spotting cluster could be easily replicated and standardized (e.g. identifying the correct public restroom, reading bus numbers, and road signs).

Three clusters, self-care and safety at home, searching around the home, and cooking and cleaning, were positioned close to each other on the cluster map, and therefore closely related, as the named themes suggest. Indeed, some of the activities could easily belong in one cluster or the other (e.g. finding/cleaning spills, and using controls on the stove/cooktop). However, given the large number of activities in these clusters and that the 8-cluster map made most conceptual sense for all other clusters, these were not combined. Activities in the self-care and safety at home cluster were mostly related to managing medications, checking that foods are safe for consumption, and safe use of appliances (e.g. checking the gas on the stove/cooktop). Relatively few activities were in the searching around the home cluster and included finding things dropped on a floor and inserting a key into a lock. Although cooking and cleaning comprised the largest number of activities and was of some importance, it was rated least important compared with all other clusters. Although some of the activities in these 3 clusters are less likely to occur in low luminance (and hence not commonly included in low luminance visual function research to date), are impractical or unsafe to include in a performance-based measure (e.g. cutting of food, and making a cup of tea/coffee). To be comprehensive, a few could be considered for inclusion in a low luminance performance-based measure and have been used previously (e.g. finding food in a cupboard and inserting a key into a lock[5,58–60]).

The strengths of this study were use of group concept mapping and inclusion of both expert low vision professionals and patient stakeholder groups. In contrast, existing low luminance PROMS were developed using parts of other PROMS in the literature,[15,16] or focus groups and interviews with predominantly patients with macular degeneration.[5,17] However, there were some limitations. Although participants were asked to generate a list of "…activities a person with vision impairment might find challenging under low light conditions, such as in a poorly lit room or outside at dusk," several of the activities reported are not usually performed under low luminance conditions. However, for the purpose of designing a low luminance performance-based measure, having a wide range of potential tasks from which to select is useful at this stage. In addition, a smaller number of participants went on to complete the sorting and rating components of the study. Understandably, participants with vision impairment found it challenging to sort the large number of statements into groups of similar activities, even with assistance, producing less consistent sorting of similar activities compared with the low vision professionals. Therefore, the clusters were based on the sorting completed by the professional group. Perhaps having a larger number of participants with vision impairment involved in sorting may have resulted in an equal or better goodness-of-fit compared to the low vision professionals.

In conclusion, this study has defined a conceptual framework using the group concept mapping approach and identified activities that present challenges under low luminance for patients with vision impairment. The most important activities were related to hazard detection, and safety outside and social interactions. These findings can inform the design of a performance-based measure of low luminance visual function.

Acknowledgments

Supported by a Queensland University of Technology "Institute for Biomedical and Health Innovation Ideas Grant."

Disclosure: **S.A. Bentley**, None; **A.A. Black**, None; **G.P. Hindmarsh**, None; **C. Owsley**, None; **J.M. Wood**, None

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