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The Eye Sensation Scale: An Ophthalmic Pain Severity Measure

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ABSTRACT

Purpose. The aim was to develop a single-item, categorical ophthalmic pain severity scale.

Methods. Focus groups were held with people who had experienced ophthalmic pain. Participants described their ophthalmic pain experiences with reference to level of severity, and commented on proposed pain scale designs. Thematic analysis of transcripts, and participants' category choices and scale preferences, were used to determine the number of response categories and labels chosen for the instrument. The final instrument was evaluated using a mail-out questionnaire.

Results. Five ophthalmic pain domains were identified: intensity; nature (including subdomains: physical sensation, temporal patterning, simile/metaphor); physical effects; emotional effects; and behavioral effects. The most frequent descriptors were physical sensation (n = 160), behavioral effects (n = 87), and physical effects (n = 68). Participants preferred a five-category scale. The higher frequency severity descriptors used by the participants formed the basis for the category labels for the instrument ("extreme," "severe," "moderate," "mild," "none"). Notably, many participants rejected the word "pain" in favor of "discomfort" or "light sensitivity." Participants commonly linked severity and nature descriptors; however, the same nature descriptor (e.g., "ache" or "scratching") did not confer the same pain severity between participants.

Conclusions. A five-category scale was chosen for assessing the severity of ophthalmic sensations: the Eye Sensation Scale. The scale involves rating the severity of the ophthalmic sensation that is most important to the patient and provides the opportunity to describe other attributes or effects of the sensation. Evaluation indicated the adequacy of the final instrument.
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Key Words: scale development, pain measurement, focus groups, qualitative research, corneal transplantation, outcome assessment, patient-centered outcomes

Our overarching aim was to design an instrument to measure general ophthalmic pain severity, which would also be suitable for our specific research purpose of assessing pain relief outcomes of corneal transplantation. Corneal transplantation for pain relief is important as indicated by the Australian Corneal Graft Registry in which 73% of the corneal grafts registered were performed to improve vision, and 19% to relieve eye pain.[1] Improvement in vision as a corneal graft outcome is effectively assessed using the standard clinical measures of visual performance,[2–4] but ophthalmic pain relief had not been formally assessed using an eye-specific instrument.

Many different types of scales have been developed to measure pain, including visual analogue scales and various categorical scales using faces, numbers, or verbal categorical descriptors.[5–8] However, no pain scale specific to ophthalmic pain has been developed and validated using focus groups and Rasch analysis. The majority of previous investigators have used general pain scales to measure pain after ophthalmic procedures or the impact of treatments for ophthalmic pain.[9–21] The only designated ophthalmic pain scale is the two-item pain subscale of the National Eye Institute Visual Function Questionnaire-25.[22,23] However, the National Eye Institute Visual Function Questionnaire pain scale has not been developed with any statistical validity e.g., factorial validity; it has poor psychometric properties,[22–27] and does not hold up under Rasch analysis.[28, 29] Ideally, an instrument should be developed and validated on ophthalmic patients to ensure optimal specificity

and sensitivity to change in ophthalmic pain. Good psychometric properties including valid interval scoring are also important. Therefore, we set out to develop such an instrument.

It was envisaged that this instrument would be administered in the clinical setting by eye care practitioners and was developed for use both in research and as a clinical tool for measuring ophthalmic pain. Because of the time constraints of the clinical setting the instrument had to be brief and relatively easy to administer. We used focus groups to explore how ophthalmic pain was described by those who had or were experiencing ophthalmic pain. Our specific goal was to develop a scale of pain severity, and we therefore sought information on the appropriate number of scale categories and their descriptors, as well as how ophthalmic pain was described more generally, from these discussions. We used this qualitative data to ensure incorporation of all important features of ophthalmic pain that needed to be considered in order to be able to design an instrument that could adequately measure ophthalmic pain severity.

METHODS

Setting

The focus groups were held in the conference room of the ophthalmology service of Flinders Medical Centre (The Flinders Eye Centre), Adelaide, South Australia.

Ethical Approval

Ethical approval for this study was gained from the Flinders Clinical Research Committee before commencement. Detailed study information was given to potential participants before gaining written consent from those who wished to be involved. This study adhered to the tenets of the Declaration of Helsinki.

Participants

Participants for the focus groups were purposively sampled from The Flinders Eye Centre. Eligibility criteria included experience of ophthalmic pain (past or current), 18 years of age or over, English conversational skills sufficient for free participation in the focus group discussions, and sufficient cognitive function for informed consent. Ophthalmologists and clinic staff ascertained eligible participants from the Flinders Eye Centre patient population. The focus group participants were from a wide range of socioeconomic and ethnic backgrounds, and lived within a 50-km radius of the Flinders Eye Centre.

The age and gender characteristics of the participants, and the eye conditions causing ophthalmic pain, were representative of Flinders Eye Centre adult patients who had experienced ophthalmic pain, including corneal graft candidates and recipients (Table 1). Among participants, the most common cause of ophthalmic pain was either recurrent corneal erosions or rejection of a corneal graft. The types of eye conditions causing ophthalmic pain experienced by participants included typical pain indications for corneal graft surgery.[1]

Recruitment

Eligible patients were screened in a brief telephone interview, and those who were willing to be involved in the focus group discussions were appointed to a session. Aiming for six to eight participants per group, 23 patients were approached with 15 agreeing to participate (65%). This resulted in four to six participants per group, a number at the lower end of what is considered satisfactory for focus groups participation.[30] A follow-up letter, study information sheet, consent form, and demographic form were sent to each participant before their focus group. Participants were asked to bring the completed forms to their focus group session.

TABLE 1.
Participant characteristics and eye conditions causing ophthalmic pain

Focus group	Total n (male)	Mean age (SD)	Age range	Eye condition causing ophthalmic pain (no. participants)
One	6 (2)	59 (12.5)	42–79	Recurrent corneal erosion (2) Dendritic ulcers (1) Conjunctival intraepithelial neoplasia and keratitis with subsequent evisceration (1) Superior limbic keratitis (1) Rejection of corneal graft (1)
Two	4 (3)	64 (11.1)	49–75	Herpetic keratitis (2) Rejection of corneal graft (1) Recurrent corneal erosion (1)
Three	5 (3)	51 (15.3)	24–66	Rejection of corneal graft (2) Recurrent corneal erosion (3)
Overall	15 (8)	57 (13.2)	24–79	Recurrent corneal erosion (6) Rejection of corneal graft (4) Herpetic keratitis (2) Dendritic ulcers (1) Conjunctival intra-epithelial neoplasia and keratitis with subsequent evisceration (1) Superior limbic keratitis (1)

Each participant was offered a small monetary gift to assist with traveling or parking expenses.

Data Collection

Focus groups are a standard methodological approach for identifying questionnaire content directly from the target population. They have the advantages of providing richness of data and enhancing recall through participant interaction with minimal facilitator influence. Three 1- to 2-hour focus group sessions were held over a period of 3 months. These sessions were audio-recorded, and verbatim person-specific transcriptions were produced and independently reviewed by two researchers after each session. Subsequent focus group protocols were modified to explore important emergent themes and issues. Data collection ceased when no new themes or issues were evident and content saturation was thought to have occurred. The final instrument was evaluated using a mail-out questionnaire to all focus group participants in which they were asked the following questions: 1. In your opinion, does the severity scale of the Eye Sensation Scale, with its choices of "extreme," "severe," "moderate," "mild," or "none" allow you to adequately describe the intensity or severity of the eye pain/sensations you have experienced? (*yes/no—if "no," please explain*); 2. Do you think that the Eye Sensation Scale, as it currently exists, allows you to adequately describe the pain/sensation you have experienced? (*yes/no—if "no," please explain*).

Focus Group Protocols and Topics

The focus groups were facilitated by Lynda Caudle who has had previous experience in conducting focus groups. A high degree of participation was encouraged from all focus group members. The focus group protocol proceeded from general unguided query about the eye pain participants had experienced, to issues, and exercises specific to development of the eye pain scale. Moderator bias was managed by following recommended focus group moderation techniques, i.e., minimize moderator interaction with focus group participants by encouraging participants to interact with each other, and by responding to participants in an impartial way only when necessary to encourage participation and further clarification/description.[30]

The preferred category descriptors and the number of nonredundant response categories required to adequately capture participants' ophthalmic pain experience were explored using different methods as described in Fig. 1. Prototype pain severity scales were designed based on previously published scales and data were collected in the focus groups.[8, 31–34] A verbal rating scale (a set of categories with named descriptors) was selected as these types of scales are easy for a majority of people to use.[35–37] Given that previous research has shown that scales with many (e.g., 7 to 10) categories suffer from underutilized or overlapping response categories,[38–40] we conjectured that four or five categories would be sufficient for ophthalmic pain measurement and initially trialled prototypes of this size. Examples of the pain severity scales used to assess scale response patterns and preferences used in the last focus group are shown in Fig. 2.

Analyses

The focus group transcripts were reviewed independently by two researchers and all comments relating to ophthalmic pain were

Focus Group 1 "What words best describe the eye pain you have experienced?" Rank these descriptors from worst to least." "How many discernable levels of eye pain are there, or how many levels of should be included on a pain scale to adequately describe all the levels you have experienced?"
Focus Group 2 "What words best describe the eye pain you have experienced?" Participants were then given a series of untitled scales and were asked to mark the pain they had experienced on each scale in turn, beginning with a two-response category scale ("No pain" and "Worst pain imaginable"), increasing successively by one response category to a five-response category scale ("No pain" and four levels of pain up to the "Worst pain imaginable"). Finally, participants were asked to choose the scale that best described the pain they had experienced, and give reasons for their choice.
Focus Group 3 Participants were given three scales with differing numbers of response categories (either four or five) and differing category descriptors (See Figure 2). Participants were then asked to examine each scale in succession and mark the pain they had experienced. Finally, participants were asked to choose the scale that best described the eye pain they had experienced and give reasons for their choice.

FIGURE 1.
Different protocols for discussing pain scales in successive focus groups.

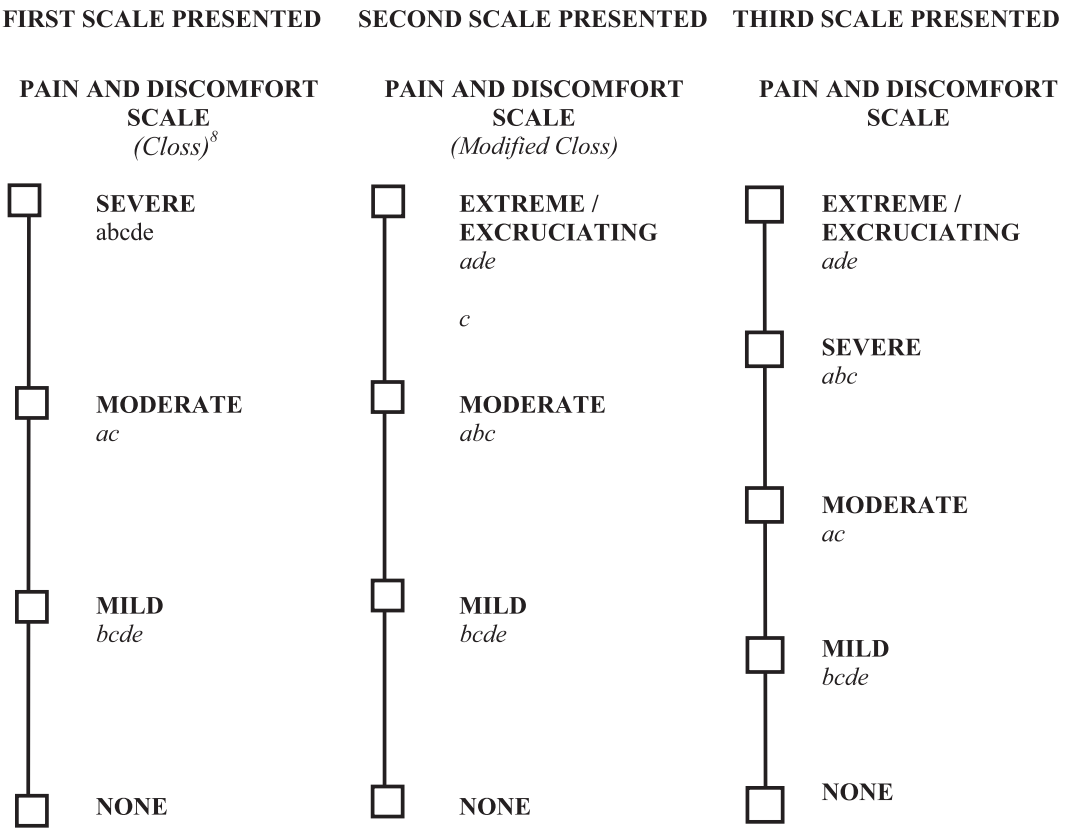


FIGURE 2.
Use of successive scales response categories in focus group 3. Italicized letter designates participant response category choices.

identified and examined for dominant themes. Identified comments about ophthalmic pain were then coded according to these themes, and were analyzed further for any subdomains or divergent themes.

Relative frequencies of the broad domains and subdomains were then produced. In this way, the participants' experience of ophthalmic pain, and more importantly, the way they tended to describe their ophthalmic pain was captured, with the salient features identified. This also provided a vignette of how each participant conceptualized their own ophthalmic pain. Discourse analytic features of the participants' descriptions were also examined, revealing frequent use of similes or metaphors, "negative" descriptions or what the pain was not, and the use of external criteria or standards.

Participant responses to the focus group exercises, such as ordering of descriptors according to increasing severity of ophthalmic pain, and participant response patterns and scale preferences were used to assess the optimal number of nonredundant response categories and preferred category descriptors for the final instrument.

RESULTS

Descriptions of ophthalmic pain from the focus group data suggested five broad descriptive domains of intensity, nature (including subdomains of physical sensation, temporal patterning, and simile/metaphor subdomains), and physical, emotional, and behavioral effects. As the participants were asked to describe their ophthalmic pain without further specification in the main, the relative frequencies of the descriptors and domains indicated their relative importance. Physical sensation descriptors were the most frequently mentioned aspect of ophthalmic pain (n = 160). When the simile/metaphor nature subdomain descriptors (n = 44) and the temporal patterning descriptors (n = 22) were added to the physical sensation descriptors, the nature domain became by far the most prominent domain with 220 nature references (Table 2). Behavioral effects of pain were the next most frequently mentioned aspect (n = 87), followed by the severity descriptors (n = 75), and the physical effects of pain (n = 68) (Tables 3 and 4). Emotional effects were the least mentioned descriptors with 23 references. As can be seen from the relative frequencies, participants tended to describe the nature of their pain, and how the pain affected their lives (behavioral effects). Severity descriptors tended to not be used when describing ophthalmic pain, unless specifically requested.

The high frequency of the use of alternate words to "pain" such as "uncomfortable" and "discomfort" indicated that the scale should not be referred to, or titled, simply as a "pain scale," but should be more properly titled a "Pain and Discomfort Scale" to reflect the importance of these alternate words in describing ophthalmic pain. This was further supported by several participants (both men and women) who repeatedly explained that the painful sensation they had experienced in their eyes was "not pain," but rather "discomfort." These participants viewed "pain" as distinct from ophthalmic painful sensations, in that they regarded "pain" as the painful sensation they experienced when "hitting their thumb with a hammer," "cutting themselves," or other types of somatic pain that they described as sharp, immediate, and intense. These participants used these examples to explain that they would not refer to their ophthalmic sensations as "pain," but rather as "dis-

TABLE 2.
Ophthalmic pain nature descriptor frequencies within physical sensation, temporal patterning, and simile/metaphor subdomains

	Pain nature descriptor frequencies
Physical sensation	
Aching	22
Grittiness	22
Sharp	12
Dull ache	9
Irritation	9
Light sensitivity	7
Head-aching	6
Stinging	5
Raw	5
Scratchy/scratchiness	5
Niggling	5
Aware of the area	5
Pulsating	5
Throbbing	4
Itch/itching	4
Bruised	4
Deep	3
Stitch	3
Severe ache	2
Uncomfortable ache	2
Slight ache	2
Dull pain	2
Nagging	2
Abrasive	2
Rough	2
Inhumane	1
Burning	1
Unpleasant	1
Gritty irritation	1
Penetrating	1
Heavy	1
Absorbing	1
"Full on"	1
Throbbing ache	1
Aggravation	1
Grates	1
Total number of descriptors	160
Temporal patterning	
Constant/continuous	16
Intermittent	3
Persistent	2
Perpetual	1
Total number of descriptors	22
Simile/metaphor	
Like sand or grit in your eye	15
Like there's something/foreign material in your eye	12
Like dust or hair/eyelash in your eye	5
Like a knife in your eye	4
Like salt and pepper in your eye	2
Like gravel or pebble in your eye	2
Like shampoo in your eye	2
Like pressing your thumb on the table and just leaving it there until it hurts	1
Mind boggling	1
Total number of descriptors	44

Whenever "ache"/"aching" was used alone it was classified as a nature descriptor rather than a "pain" substitute. Whenever severity descriptors were associated with "ache"/"aching" these were also counted in the severity descriptor frequencies.

"Light sensitivity" listed under physical sensations refers to light sensitivity synonymous with pain, rather than being an effect of pain as listed in Table 4.

comfort." For example, one participant persisted in talking about his pain as a discomfort even though he was taking Panadeine Forte [paracetamol (Acetaminophen) 500 mg, codeine 30 mg] for pain relief. He repeatedly referred to this pain as "not pain" but a "major discomfort." As a consequence of these explanations of ophthalmic pain, the scales presented to participants in focus group 3 (Fig. 2) were titled "Pain and Discomfort Scale" to encompass these findings and avoid participants not using the scale because they did not regard their sensation as pain.

It was also evident from the focus group dialogues, that participants tended to describe the pain (if experiencing more than one type concomitantly) or aspects of their pain that bothered them the most, whether it be how their pain felt (nature), how it affected themselves and their lives (physical and behavioral effects) or how they felt about their pain (emotional effects). The participants also tended to describe their pain at its worst intensity, and did not tend to talk about how it increased/decreased, unless specifically asked to talk about how the pain developed or behaved over time.

Apparent gender differences in the description of ophthalmic pain included the pain comparatives used to illustrate their pain. For instance, several women compared the ophthalmic pain they had experienced to being worse or not as bad as the pain of childbirth, whereas men used pain comparatives such as "hitting their thumb with a hammer," breaking bones or dislocating joints, or cutting themselves. Further exploration of gender differences in the description of ophthalmic pain were not explored as participant numbers were not considered sufficient.

Subjective and cultural elements also seemed to be operating in participants' descriptions of their ophthalmic pain. Participants, both men and women, tended to "talk down" the severity of their pain, even though it was evident that their pain was significant, i.e., taking Panadeine Forte for pain relief, or not being able to move about or open their eyes because of their pain. Several of these participants referenced what they appeared to view as generally held cultural norms when talking about their pain, such as "You have to just put up with it, don't you?"

Thematic Analysis of Severity Domain Descriptors

The descriptors used to indicate severity of ophthalmic pain are shown in Table 3. The frequencies of alternate words to "pain",

TABLE 3.
Ophthalmic pain severity descriptors frequencies, including other alternate descriptors to "pain"

Severity descriptors		Totals
Extreme		
Extreme pain	12	
Extremely uncomfortable	1	13
Very		
Painful	5	
Uncomfortable	2	
Sore	2	9
Severe		
Pain	6	
Ache	2	
Discomfort	1	9
Excruciating pain	7	7
Intense pain	6	6
Moderate pain	3	3
Mild		
Pain	1	
Discomfort	2	3
Major discomfort	2	2
Really painful	2	2
A lot of pain	2	2
Quite painful	2	2
Not minor/mild pain	2	2
Uncomfortable ache	2	2
Slight ache	2	2
A little		
Pain	1	
Discomfort	1	2
Very severe pain	1	1
Very serious pain	1	1
A pain worse than childbirth	1	1
Extremely severe pain	1	1
A bit of pain	1	1
Really bad pain	1	1
Bad pain	1	1
Bloody uncomfortable	1	1
Not real good	1	1
Total number of descriptors	75	
Words other than "pain" used alone to indicate pain severity:		
Uncomfortable	24	
Discomfort	19	
Sore/soreness	5	
Total number of descriptors	48	

such as "uncomfortable," "discomfort," "sore," or "soreness" are indicated separately if not used together with a severity descriptor. Higher frequency severity descriptors included "extreme", "very," "severe," "excruciating," "intense," "moderate," and "mild," and these were considered as candidates for the category labels of the final scale.

Thematic Analysis of Domains Other Than Severity

The descriptors participants used for the nature, (including physical sensation and temporal patterning), and the physical,

TABLE 4.
Ophthalmic pain physical, emotional, and behavioral effects descriptor frequencies

	Pain nature descriptor frequencies
Physical effects	
Light sensitivity/photophobia	15
Watering/watery eyes	10
Unable to open your eyes	9
Fatigue/tiredness/feeling "flat"	8
Increase in pain tolerance	7
Eye sight affected	5
Physically unwell	4
Red/pink eyes	4
Headache or migraine	2
Too painful to cry	2
Decrease in pain tolerance	1
Facial swelling	1
Total number of descriptors	68
Emotional effects	
Depression	4
Frustration	4
Hyped up/tense	3
Worry	3
Think you are going mad/insane	2
Miserable	2
Annoying	2
Hate it	1
Terrible	1
Short-tempered	1
Total number of descriptors	23
Behavioral effects	
Photophobia evasion	13
Rest—sit down/lie down/sleep	10
Close my eyes	9
Bear or work through it	7
Unable to live with it	5
Counter-irritation—(banging/hitting head/rubbing)	5
Unable to think, concentrate or focus	5
Takes over your whole life/absorbing	4
Cannot get away from it	3
Unable to rest	3
Try to be positive	3
Learn to live with	3
Apply pressure	2
Apply cold	2
Try not to move	2
Uncoordinated movements	2
Cannot cry	2
Cannot converse	1
Destroys your quality of life	1
Wanted to take my eye out	1
Cannot get rid of it	1
Try not to get worried/stressed	1
Unable to be positive	1
Unable to drive	1
Total number of descriptors	87

emotional, and behavioral effects of ophthalmic pain are shown in Tables 2 and 4. Analysis of the nature descriptors indicated that participants most commonly described the nature of their painful experience in terms of its physical sensation and temporal patterning. Corresponding subdomains were therefore created, including a further subdomain of simile and metaphor, given the frequency with which participants used these to describe the nature of their pain. The physical sensation of pain was by far the most frequently mentioned aspect of the nature of their pain (n = 204), including the simile/metaphor subdomain, and comparatively, temporal patterning was rarely mentioned (n = 22) (Table 2).

It was also evident that some participants had experienced concomitant pain of differing nature and/or severity, i.e., such as brief periods of sharp, stabbing pain against a background of continuous pain of a different nature and severity, such as a dull generalized ache or "gritty/sand-in-your-eye" sensations. This has implications for how patients should be instructed to make pain ratings and this was taken into account in the design of the final instrument.

Light sensitivity was often experienced concomitantly with pain, and participants variously described this as a type of pain and/or a cause or exacerbation of pain, as well as a physical or behavioral effect of pain. Several participants talked about light sensitivity as a significant problem which they hoped could be alleviated. Certainly for some subjects, photophobia was seen to be indistinguishable from pain. We reflected this in the scales piloted in focus group 3 by requesting assessment of not simply "pain" or "discomfort" but "eye sensations." The title of the finalized scale was also changed to reflect this and became the "Eye Sensation Scale."

With respect to the effects of pain, participants mentioned behavioral effects more frequently (n = 87), than physical (n = 68) and emotional effects (n = 23) (Table 4). These behavioral effects included references to what they did to alleviate pain, coping behaviors, what they could not do because of their pain, and what they were still able to do despite their pain.

Category Response Analyses Using Various Scales

The response category choices and scale preferences of participants in focus group 3 are shown for three successively presented scales (Fig. 2). The category selections of participants C and B across the successive scales indicated that an intermediate category of "severe" should exist between "extreme/excruciating" and "moderate."

Response category choices between the four-category scales and the five-category scale confirmed the adequacy of the lower scale categories from "none" to "moderate." As can be seen, participants A and C continued to choose "moderate" rather than moving up to "severe" thereby providing evidence for stability of this descriptor within the scale structure. Likewise, participants B, C, D, and E also remained with the descriptor "mild" across the successive scales, suggesting the adequacy of category levels from "none" to "moderate."

The third scale presented with five categories ranging from "none" to "extreme/excruciating" was preferred by all the participants and participant choices showed good utilization of all the categories with no apparent redundancy.

The Final Eye Sensation Scale

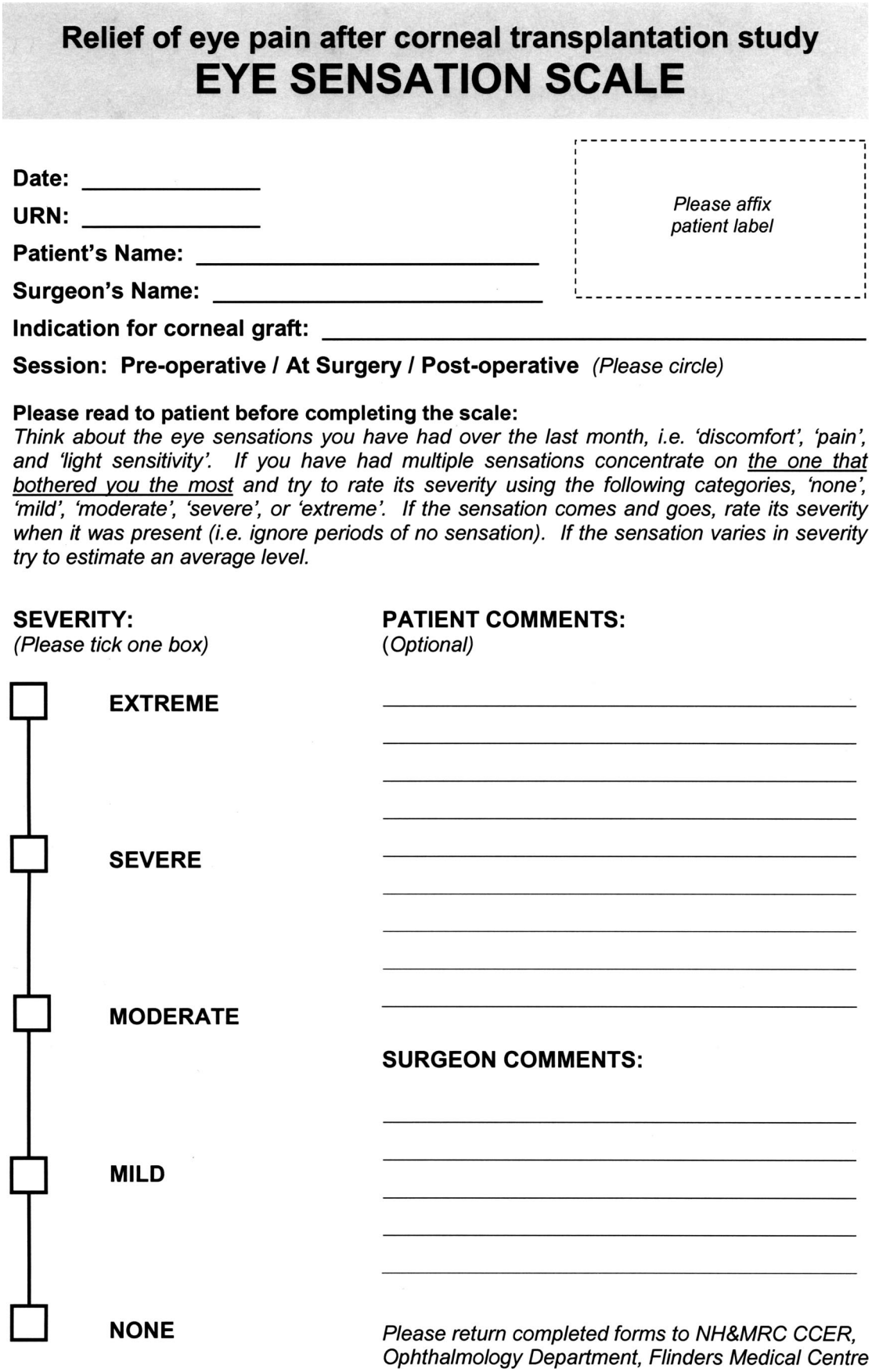
The final Eye Sensation Scale (Fig. 3) was developed directly from the findings of the focus group data as described above. The preamble of the instrument, (to be read to the patient before completing the scale) is very important as it outlines the painful eye sensations the scale is intended to measure (i.e., sensations conceptualized/described as "pain," "discomfort," "light sensitivity," or any other descriptor synonymous with pain), as well as the time period over which to recall these sensations. The patient is then requested to only assess the sensation that *bothered them the most* if they had experienced multiple sensations, and asks them to rate its severity using one of five categories on the severity scale ("none," "mild," "moderate," "severe," and "extreme"). They are also asked to only assess the severity of the sensation when present, rather than averaging the severity level over periods of no sensation, as occurs with cyclical or intermittent sensations. Varying severity of the sensation being assessed, such as when the painful sensation increases or decreases in severity over appreciable time periods, is also addressed by requesting the patient to estimate an average level.

Evaluation of the Scale by the Focus Group Participants

Fifty-six percent of participants responded to mail-out evaluation of the Eye Sensation Scale. All answered yes to both questions: 1. In your opinion, does the severity scale of the Eye Sensation Scale, with its choices of "extreme," "severe," "moderate," "mild," or "none" allow you to adequately describe the intensity or severity of the eye pain/sensations you have experienced?; 2. Do you think that the Eye Sensation Scale, as it currently exists, allows you to adequately describe the pain/sensation you have experienced? Many participants made further comments: "Like the way it's done and the more options"; "It's a good scale. It evaluates light sensitivity as pain"; "Light sensitivity has been debilitating, but I was still able to cope. While the next level up—being "extreme"—it would mean that I was not coping at all! I think the scale does work!" This last comment indicates people incorporate their level of coping into their assessment of level of pain or eye sensation—this is indicated by the high frequency of references to behavioral aspects of pain mentioned by participants. Therefore, the severity scale, and the instrument overall, was adequate for assessing their painful eye sensations.

DISCUSSION

The experience of ophthalmic pain is subjective, personal, complex, and emotive; even so, significant commonalties in how participants described their pain exist and were important in designing an ophthalmic pain scale that was relevant and meaningful. Because participants variously described different painful eye sensations, the final ophthalmic pain instrument incorporated sensations described as "pain," "discomfort," "light sensitivity," and any other eye sensations related to ophthalmic comfort. Previous investigators working on the development of general pain scales have also noted the reluctance of



Relief of eye pain after corneal transplantation study

EYE SENSATION SCALE

Date: _____

URN: _____

Please affix patient label

Patient's Name: _____

Surgeon's Name: _____

Indication for corneal graft: _____

Session: Pre-operative / At Surgery / Post-operative *(Please circle)*

Please read to patient before completing the scale:
Think about the eye sensations you have had over the last month, i.e. 'discomfort', 'pain', and 'light sensitivity'. If you have had multiple sensations concentrate on the one that bothered you the most and try to rate its severity using the following categories, 'none', 'mild', 'moderate', 'severe', or 'extreme'. If the sensation comes and goes, rate its severity when it was present (i.e. ignore periods of no sensation). If the sensation varies in severity try to estimate an average level.

SEVERITY:
(Please tick one box)

- ☐ **EXTREME**
- ☐ **SEVERE**
- ☐ **MODERATE**
- ☐ **MILD**
- ☐ **NONE**

PATIENT COMMENTS:
(Optional)

_____
_____
_____
_____
_____
_____
_____
_____
_____

SURGEON COMMENTS:

_____
_____
_____
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Please return completed forms to NH&MRC CCER, Ophthalmology Department, Flinders Medical Centre

FIGURE 3.
The final Eye Sensations Scale.

some people to describe their experience as "pain."[41] In this way, eye sensations such as light sensitivity, that some subjects described as light sensitivity but conceptualized as a pain or discomfort, will be assessed by the instrument.

A five-category scale was chosen to assess eye sensation severity as indicated by the participants' scale preferences and category choices. The performance of five categories will be tested using Rasch analysis once sufficient pilot data are available. The utility of a five-category pain severity scale has also been shown in previous work, in which the scale performance of a five-category scale was shown to be superior to a seven-category scale, after elimination of category redundancy and overlap using Rasch analysis.[39,40]

A 1-month time period was proposed to capture multiple episodes of ophthalmic pain of differing nature in accordance with the focus group participants' experience of intermittent episodes of ophthalmic pain, however, the time period for assessment could be varied depending upon the indication for instrument usage. The scale assessment specifies consideration of only the eye sensation that *bothered them the most* during the 1-month time period. This was specified in the scale because several focus group participants had experienced multiple types of concomitant pain, and it appeared from the focus group data that the type of pain that bothered them the most was most salient, in that they tended to recall and give more detailed description of this pain and did not tend to discuss the other types of pain experienced unless prompted. The choice of pain "that bothers them the most" is likely to be based on the more the frequent pain descriptor domains taken from the focus group data, such as the nature of the pain, including its temporal qualities, or its effect on their lives (behavioral effects). Because some eye sensations were intermittent or increased/decreased over time, the final instrument assessed average severity of the sensation while present, rather than averaging over periods of no sensation. Thus the instructions for scoring the severity rating of the Eye Sensation Scale are lengthy, however, clarification of these temporal issues are important to the ability of the scale to measure pain outcomes of corneal graft surgery or other ophthalmic interventions.

Participants preferred to describe the nature of their pain in some detail rather than simply report its severity, unless specifically requested. Furthermore, several participants commented that it was important to have a sense that the pain they were experiencing had been well understood by those treating them. Answering questions about severity or being asked to indicate only pain severity was considered to be insufficient. An apparent need to give a fuller account of their painful experience has also been found by others. For example Warms et al. discovered in their survey study of spinal cord injury or amputation pain that providing space for free comment was important, given the number of comments participants wrote in the margins of their questionnaire about the pain they were experiencing.[42] It seems that people suffering pain feel that they are the experts on pain and that it is difficult to communicate effectively with their medical practitioners about their pain. Clearly it was important for participants to be able to describe their unique and subjective experience of ophthalmic pain. The provision of a free response section apart from the intensity/severity scale was a way to fulfill this need, while still keeping the instrument brief.

Comparison of the more commonly used ophthalmic pain nature descriptors (Table 2) with nature descriptors used to describe arthritic, labor, cancer, and phantom limb pain, and toothache[43] revealed several descriptors that were unique to ophthalmic pain, such as "grittiness," "irritation," "light sensitivity," "stinging," "raw," "scratchy/scratchiness," and "niggling." Conversely, commonalities were also found, such as "aching/ache," "sharp," and "throbbing." Scaling of the severity of each of these descriptors, as in the intensity scaling of nature descriptors in the short-from McGill Pain Questionnaire,[44] and as well, scaling of their temporal characteristics using the temporal patterning descriptors (Table 2) indicating continuous sensation, such as "constant," "continuous," "persistent," or "perpetual" (n = 19), or "intermittent" (n = 3) sensation could have been used in this instrument. This would have produced a more detailed measure of all the painful eye sensations experienced within the limitations of recall, but would not have indicated which painful sensation the patient would most like to have alleviated, for example, with corneal graft surgery. This may cause problems in outcomes measurement where the "signal" from the important sensation score may be lost in the "noise" from the other sensation scores. The Eye Sensation Scale, although limited in detailed assessment of the overall pain experienced, does however, assess the intended outcome, while still maintaining the brevity required for clinical administration by eye care practitioners.

It was also evident that individual participants had their own unique understanding or conceptualization of their eye pain, including what causes it, and what makes it better or worse. More importantly, these beliefs and conceptualizations gained from experience seemed to direct their pain self-management, such as, when they would seek medical attention or take analgesics. It was also apparent from several participants' comments, that using analgesics to relieve ophthalmic pain had not been considered, as they believed the nature of the pain they were experiencing would not be relieved by pain killers. This finding may be important to treating eye care practitioners when considering pain relief options for their patients.

This presentation of focus group findings represents the first phase of the development of an instrument to measure ophthalmic pain severity. The data collected in this way are limited by factors such as difficulty of recall of pain.[45] Although the initial evaluation of the instrument suggests validity, piloting the instrument designed herein is critical to the full development of the instrument. Although qualitative data from our focus groups suggests that a five-category scale with four levels of pain would be optimal for measuring ophthalmic pain severity, testing of the instrument using Rasch analysis will be carried out on pilot data. Rasch analysis will provide assessment of utilization of the scale categories, including category redundancy, independence, or overlap,[39,46] and if indicated, will be used to revise and improve the instrument.[47] This should result in a valid and reliable pain severity scale for use in ophthalmic patients with particular relevance to corneal and anterior segment pain.

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