Qualitative Research to Understand the Lived Experience of Patients with Dry Eye Disease (DED), Meibomian Gland Dysfunction (MGD), and Sjögren's Syndrome Dry Eye Disease (SS-DED)

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Introduction

- Dry Eye Disease (DED), Meibomian Gland Dysfunction (MGD), and Sjögren's Syndrome Dry Eye Disease (SS-DED) are conditions associated with symptoms of ocular discomfort caused by inadequate lubrication of the eye.[1-3]
- Key symptoms across the three conditions, such as ocular dryness, grittiness, burning sensation, and pain can cause patients to experience difficulties performing activities of daily living and can significantly impact the physical, emotional, and social domains of patients' Health-Related Quality of Life (HRQoL).[4-6]

Objective

- To better understand the lived experience of DED, MGD, and SS-DED patients, and explore similarities and differences between the three conditions, qualitative concept elicitation (CE) interviews were conducted to explore the most frequent and bothersome symptoms and their impacts on activities of daily life.

Methods

- CE interviews were conducted with 61 US adult patients who reported experiencing ocular symptoms due to their condition and had a physician-confirmed primary diagnosis of either DED (n=21), MGD (n=20), or SS-DED (n=20).
- Key concepts of relevance pertaining to the symptoms and impacts of DED, MGD, or SS-DED were elicited through a series of broad, open-ended questions to obtain spontaneous comments. If patients did not mention concepts of interest 'spontaneously' during initial questioning, focused probes were used to elicit comments on these concepts.
- Verbatim interview transcripts were analyzed using thematic analysis in ATLAS.ti v8, a software designed to facilitate the storage, coding, and analysis of qualitative data.[7]
- Concept saturation was evaluated when analyzing the CE data to ensure all concepts had been explored fully. The findings contributed to development of a conceptual model detailing relevant symptom and impact concepts.

Results

- Participating patients had a mean age of 50 years (range 21-80 years), were mostly female (64%), and were representative of a range of racial, ethnic, and socioeconomic backgrounds. **Table 1** details the patient demographic and clinical information.

Table 1. Patient demographic and clinical information

	DED (n=21)	MGD (n=20)	SS-DED (n=20)	Total sample (N=61)
Age (average, range)	47 (21-74)	49 (20-76)	54.5 (29-80)	50.2 (21-80)
Gender (n, %)				
Female	15 (71.4%)	15 (75%)	9 (45%)	39 (63.9%)
Male	6 (28.6%)	5 (25%)	11 (55%)	22 (36.1%)
Race (n, %)				
White/Caucasian	7 (33.3%)	8 (40%)	12 (60%)	27 (44.2%)
Black/African American	10 (47.6%)	7 (35%)	3 (15%)	20 (32.7%)
Asian	0 (0%)	2 (10%)	2 (10%)	4 (6.7%)
Hispanic/Latino	3 (14.3%)	2 (10%)	2 (10%)	7 (11.5%)
Mexican	1 (4.8%)	1 (5%)	0 (0%)	2 (3.3%)
Other (not specified)	0 (0%)	0 (0%)	1 (5%)	1 (1.6%)
Ethnicity (n, %)				
Non-Hispanic or Latino	15 (71.4%)	13 (65%)	13 (65%)	41 (67.2%)
Hispanic or Latino	6 (28.6%)	7 (35%)	7 (35%)	20 (32.8%)
Work status (n, %)				
Retired	1 (4.8%)	2 (10%)	6 (30%)	9 (14.7%)
Working full time	13 (61.9%)	12 (60%)	13 (65%)	38 (62.3%)
Working part time	3 (14.3%)	1 (5%)	1 (5%)	5 (8.2%)
Looking for work	0 (0%)	2 (10%)	0 (0%)	2 (3.3%)
Homemaker	1 (4.8%)	1 (5%)	0 (0%)	2 (3.3%)
Student	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Volunteer	1 (4.8%)	0 (0%)	0 (0%)	1 (1.6%)
Not working due to eye condition	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Not working due to another health condition	2 (9.5%)	2 (10%)	0 (0%)	4 (6.6%)
Severity of eye condition (n, %)				
Mild	3 (14.3%)	6 (30%)	5 (25%)	14 (23%)
Moderate	12 (57.1%)	10 (50%)	10 (50%)	32 (52.4%)
Severe	6 (28.6%)	4 (20%)	5 (25%)	15 (24.6%)

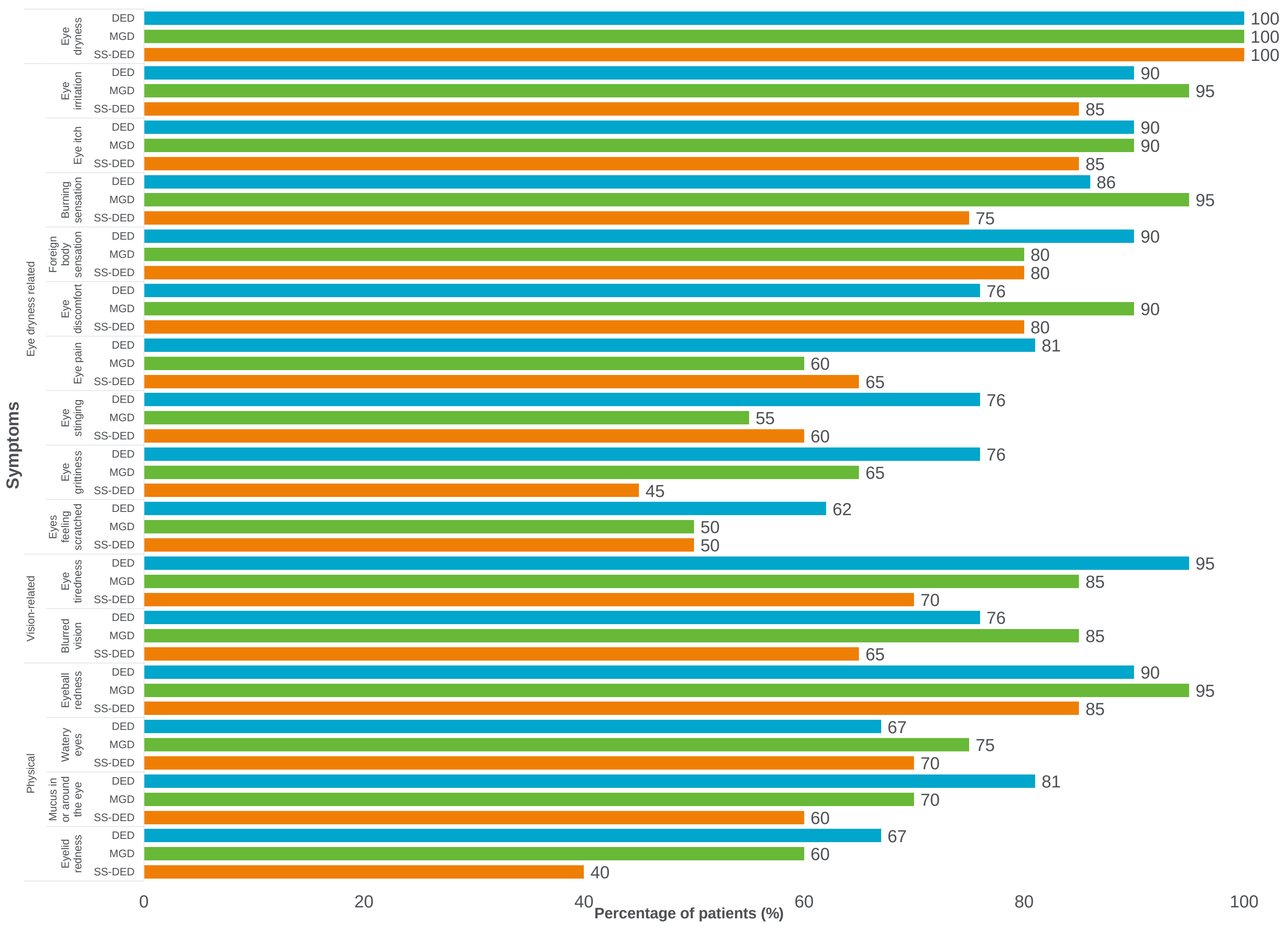
Symptoms of DED, MGD, and SS-DED

- A total of 29 symptoms were reported by patients across the three conditions, with 16 symptoms shown in **Figure 2.** being relevant to all three conditions (i.e., reported by at least three patients with each condition; sample quotations presented in **Figure1.)**
- Across all three conditions, the most bothersome symptoms reported were eye dryness (n=10 [DED: n=2; MGD: n=4; SS-DED: n=4]), burning sensation (n=10 [DED: n=5; MGD: n=3; SS-DED: n=2]), and eye irritation (n=10 [DED: n=6; MGD: n=2; SS-DED: n=2]). No clear distinction could be made between the three conditions so to allocate a symptom more specifically to one of the conditions.
- A greater proportion of patients in the severe subgroup reported experiencing eye irritation (n=15/15, 100%), foreign body sensation (n=15/15, 100%), eye itch (n=14/15, 93.3%), eye tiredness (n=14/15, 93.3%), and blurred vision (n=14/15, 93.3%) compared with those in the mild and moderate subgroups.

Figure 1. Example quotes of the most frequently mentioned symptoms

Eye dryness	Eye irritation	Eye Itch
"On some days… they could be so dry that it's, um—I sort of have to **pry my, my eyelids open**." *-68-year-old male with moderate SS-DED*	"I **get the eye irritation a lot**. Like, um, if I go outside and the wind is blowing, it feels like my eye is irritated and that causes me to rub it. And, you know, like and with the eye being dry, it just, uh, irritates it more." *-59-year-old female with mild MGD*	"The first symptoms that I experienced was itchy and dry eye, watery, um, and **very itchy**." *-23-year-old female with severe DED*
"If a group of my friends, if they want to go out to a hookah bar, I, um, tend not to go only because of the smoke and the **smoke tends to dry out my** eyes as well." *-42-year-old female with moderate DED*		

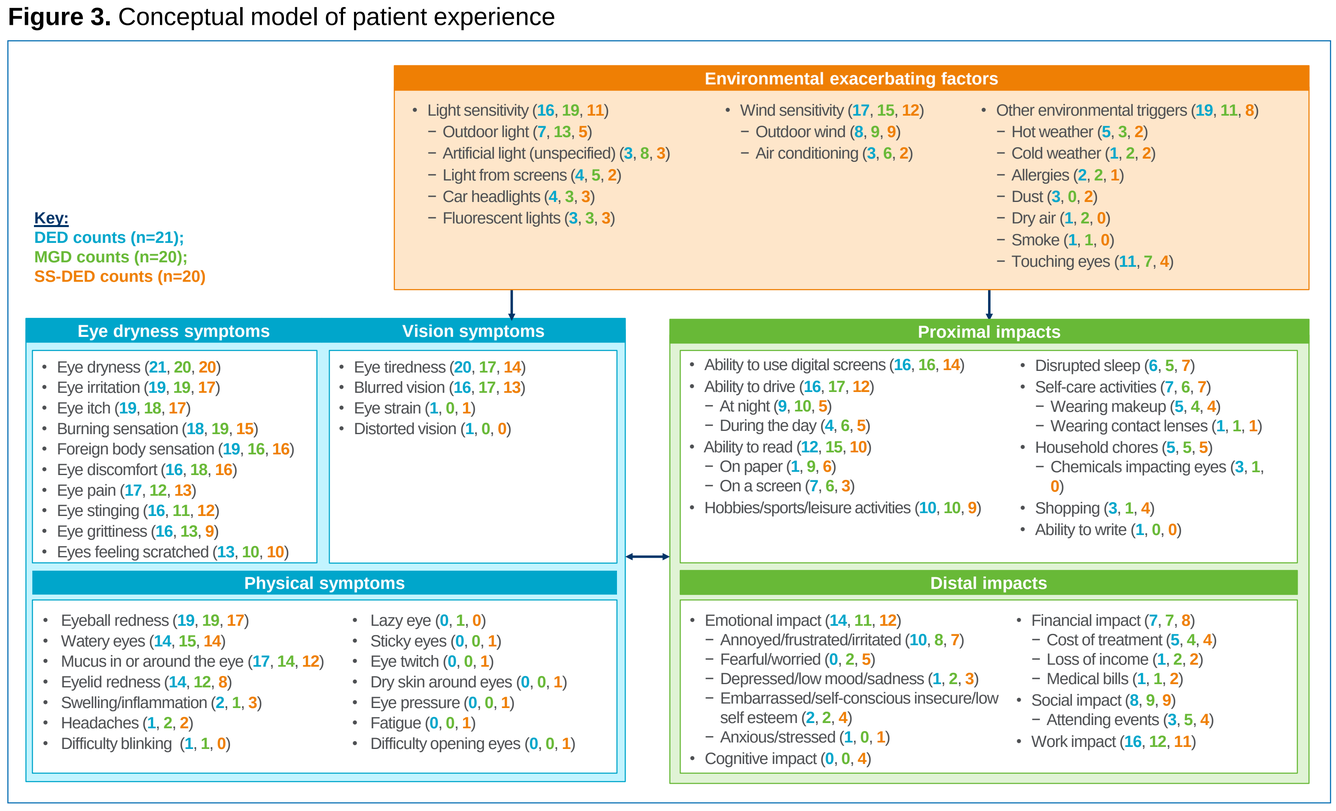
Figure 2. Overview of symptoms reported by more than three DED, MGD, and SS-DED patients



Impacts of DED, MGD, and SS-DED

- A total of 14 impacts were reported, 12 of which were relevant for all patients across the three conditions. These impacts were grouped according to whether they are considered proximal or distal to DED, MGD, or SS-DED
- Across the three conditions, patients most frequently mentioned impacts on using digital screens (n=46/61, 75.4%), driving (n=45/61, 73.8%), working (n=39/61, 63.9%), and reading (n=37/61, 60.7%). Other HRQoL domains impacted included emotional wellbeing (n=37/61, 62%) and social functioning (n=26/61, 43%). No clear distinction could be made between the three conditions.
- Patients in the severe subgroup experienced greater impact on their use of digital screens (n=14/15, 93.3%), social functioning (n=14/15, 93.3%), work (13/15, 86.6%), driving (n=12/15, 80%), emotional wellbeing (n=12/15, 80%), reading (n=11/15, 73.3%), hobbies, sports, and leisure activities (n=8/15, 53.3%), and sleep (n=5/15, 33.3%) compared with those in the mild and moderate subgroups.

Figure 3. Conceptual model of patient experience



Conceptual model

Evidence generated from CE interviews was used to develop a conceptual model of DED, MGD, and SS-DED [**Figure 3.**]

Conclusions

- This research provides an in-depth understanding of the disease experience of DED, MGD, and SS-DED in terms of symptoms and impacts on the patients' lives.
- Despite a few minor differences, most of the key concepts identified were largely similar across the conditions and contributed to the development of a combined conceptual model of the patient experience.
- These patient-relevant concepts were used to support development of a new PRO measure for inclusion in future clinical trials in DED, MGD, or SS-DED.

References

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