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Understanding the quality-of-life impacts of ocular surface disease

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ABSTRACT

Purpose: This study aimed to explore the lived experience of adults with different types of ocular surface disease (OSD) to understand their quality of life (QoL) impacts.**Methods:** Lived experiences of participants diagnosed with aqueous deficient dry eye disease (DED), meibomian gland dysfunction (MGD), anterior blepharitis, neuropathic corneal pain (NCP), ocular surface involvement of autoimmune disease and contact lens discomfort (CLD) were explored using in-depth, semi-structured interviews. Participants were recruited from specialized dry eye clinics in Australia, United Kingdom, as well as online support groups. Thematic analysis of interviews was performed to identify key QoL themes.**Results:** Sixty-two participants participated in an in-depth interview (median age: 46 years, range 22–78). There were 16 male participants (median age: 38.5 years; range: 23–74) and 46 female participants (median age: 50 years; range 22–78). The distribution of participants by condition as follows: DED – 9, MGD – 12, anterior blepharitis – 8, NCP – 8, ocular surface involvement of autoimmune disease – 14, and CLD – 11. Thirteen major QoL themes emerged. The most significant impact observed was on the emotional wellbeing with participants describing feelings of annoyance, depression, frustration, reduced self-confidence, worry, and anxiety related to their condition. Many expressed concerns about the chronic nature of OSDs, characterised by persistent symptoms and lifelong treatment. Economic impact extended beyond direct medical expenses, affecting employment, and productivity. Participants also described difficulties with daily activities, driving and mobility. Coping strategies included adjustments to their daily routine and environment.**Conclusion:** OSDs significantly impact multiple aspects of an individual's life. These findings lay the foundation for developing a comprehensive and technologically advanced patient reported outcome measure (PROM) tailored to individuals with OSDs. Addressing these QoL concerns through targeted interventions and policy updates will be crucial in enhancing patient care and optimizing disease management.

1. Introduction

Ocular surface disease (OSD) encompasses a spectrum of conditions that disrupt the homeostasis of the ocular surface, including, but not limited to, dry eye disease (DED), meibomian gland dysfunction (MGD), blepharitis, ocular surface involvement in autoimmune diseases, neuropathic corneal pain (NCP), thyroid eye disease (TED), and contact lens discomfort (CLD). [1–4] OSD often arises from multifactorial aetiologies, including tear film instability, inflammation, neuropathic, and structural gland dysfunction such as MGD or lacrimal gland hypofunction. [1,2,4,5] OSD affects millions of people globally, and represent

a significant cause of reduced quality of life (QoL) among those affected. [6,7].

The impact of OSD extends beyond physical symptoms, affecting multiple facets of daily living, including emotional wellbeing, social interaction, and functional capabilities such as driving and mobility. [8–11] A plethora of mental health impacts are associated with symptoms and the economic burden of managing the chronic debilitation resulting from OSDs. [8,12,13] Emerging evidence highlights the value of patient-reported outcome measures (PROMs) in capturing the multifaceted impact of OSDs on patients' lives. [14] PROMs offer a nuanced understanding of disease burden and treatment efficacy from

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the patient's perspective, enabling care strategies to align with individual needs. [15,16] Systematic reviews of existing QoL PROMs for OSD has demonstrated the existence of many PROMs but the absence of a disease-specific and comprehensive PROM that provides high quality psychometric measurement. [14,17,18].

The absence of a comprehensive OSD-specific PROM limits the ability to understand the wide impact of OSD on all relevant QoL dimensions. Evaluating QoL outcomes is increasingly essential in clinical trials and in the development of medical products. [19–21] This is particularly significant for OSDs, where advanced therapies such as intense pulsed light (IPL), radiofrequency, lacrimal gland injections of platelet rich plasma, meibomian gland probing, and various other products are currently being investigated. [21–27].

This study aimed to explore the lived experience of individuals with OSD through in-depth interviews to identify gap in existing PROMs. [14] Insights gained from these experiences were intended to guide the development of a comprehensive OSD-specific QoL outcome measure that captures the full impact of OSDs across relevant QoL domains. The QoL domains most affected by OSDs were explored through thematic analysis of in-depth interviews. [28–30] This enabled the identification of patient-centred themes, offering valuable insights into the daily challenges of living with these chronic conditions. By delineating these themes, the research deepens the understanding of QoL impacts in the context of OSD and informs development of a targeted PROM. The overarching purpose for this qualitative study was to generate content to inform and complement PROM development for assessing QoL impacts in individuals with OSDs.

2. Methods

The scope of OSDs to be included in the study was defined to include DED, MGD, CLD, blepharitis, NCP, or ocular surface involvement of autoimmune diseases (TED, Sjögren's disease and rheumatoid arthritis). The inclusion of different OSDs in this study was grounded in the overarching aim to explore the common and shared QoL impacts across a spectrum of OSDs and possibility to develop shared item banks for them. An interview guide was developed based on the literature review and the authors' clinical experience. Ethics approval was obtained from the Human Research and Ethics Application Panel D: Biomedical of University of New South Wales (Reference number HC230139). Ethics governance approval was also obtained from the Research Services at Aston University in Birmingham, United Kingdom.

Eligible participants were aged 18 years or older, with a confirmed diagnosis of one or more of the OSDs listed above. Additional inclusion criteria required participants to have the ability to speak and understand English and to provide informed consent. Recruitment was conducted through specialized dry eye clinics in Australia and the United Kingdom, as well as through social media support groups in these countries.

A purposive sampling technique was used to recruit participants to cover the breadth of OSD included. Sample size in qualitative research is guided by the principle of data saturation, the point at which no new themes or information emerge from the data. Saturation of concepts was considered to determine thematic saturation. Data collection and analysis occurred concurrently, allowing for iterative refinement of the study. [31–34] All eligible participants were provided with a written participant information sheet and consent form. They were either handed a hard copy or provided with a link to the participant information sheet through the University of New South Wales (UNSW) hosted REDCap database. [35,36] Participation was voluntary and those who consented to participate provided an additional optional consent to obtain their clinical details such as visual acuity and diagnosis of OSD. They also provided their demographic information such as their age, sex and address postcode.

In qualitative research, interviews are used to generate new insights and examine existing knowledge. [33,37] They are often iterative, with each interview shaping the next. Focus groups help capture diverse

perspectives, while individual interviews allow for deeper exploration of personal experiences. [33] Both methods require a structured approach to maintain consistency and depth. For this study, semi structured in-depth interviews were conducted via Microsoft Teams by the same interviewer (PB). The interview guide for this study was developed based on the combination of existing literature, expert input and researcher's prior knowledge of OSDs and their impacts. Furthermore, the interview guide in this study was informed by established ophthalmic QoL domain definitions ensuring alignment with the theoretical foundation of the research. [30,38–41] While grounded theory in its purest form advocates for an open-ended exploration free from preconceptions, its application in the development of PROM is often adapted to incorporate sensitizing concepts. [42] These are preliminary concepts drawn from existing literature, clinical knowledge, or expert input that relate to the condition of interest and serve to guide, still allowing an open-ended exploration of participant experiences. [42,43] The interview guide and the concepts within are flexible and adaptable to emerging concepts. [42,43].

All interviews were conducted in English. The interviews were recorded, and the audio files were extracted and transcribed verbatim. The data collection and analysis occurred simultaneously to establish thematic saturation and determine end point of data collection. The analysis followed a phenomenological approach. The phenomenological research approach offers a valuable means of exploring, investigating and interpreting individuals' lived experiences. [32,44–47] It is centred on understanding how people perceive and make sense of a particular phenomenon such as a disease through the lens of those directly affected. [44] Several authors have suggested that combining insights from lived experiences with the systematic coding of those experiences into a coherent conceptual framework is an effective strategy for identifying relevant items and domains for PROM. [30,42,43,48–51].

The interpretative phenomenological analysis approach enables researchers to gain an in-depth understanding of participants' lived experiences and their underlying reflections and deliberations. [44] This approach facilitated the condensation of rich qualitative data and the identification of meaningful connections between participants' lived experiences and the research objective related to QoL. [44,48,49,52] The method of constant comparison was applied, enabling iterative comparisons of narratives within and across transcripts to identify both similarities and differences. Following thematic analysis participant responses were inductively coded into items aligned with a predefined framework of ophthalmic QoL domains developed in the Eye-tem Bank project. [38–40,53–55] These domains served as the overarching themes providing a structured framework for organizing and interpreting the qualitative findings (See Fig. 1).

While the analysis was guided by an existing theoretical framework of the ophthalmic QoL domains, the process also allowed for the emergence of novel themes beyond the predefined categories. This approach was particularly well-suited to the aims of the study which sought not to generate a new theory or model, but to gain a comprehensive understanding of the various dimensions of QoL as experienced by and articulated by the participants. Data management and qualitative analysis were facilitated using NVivo qualitative data analysis software (Version 12, QSR international Pty Ltd).

2.1. Methodology rigour

To ensure rigour and trustworthiness in this qualitative study, multiple strategies were employed addressing key dimensions including credibility, dependability, confirmability, reflexivity, authenticity, transferability, and ethical integrity. [47,56,57] Dependability was supported by maintaining an audit trail by the interviewer, while confirmability was enhanced through grounding findings in participants' accounts and presenting illustrative quotes. [47,57] Reflexivity was addressed through journaling and regular peer debriefings to mitigate potential researcher bias due to prior clinical experience in

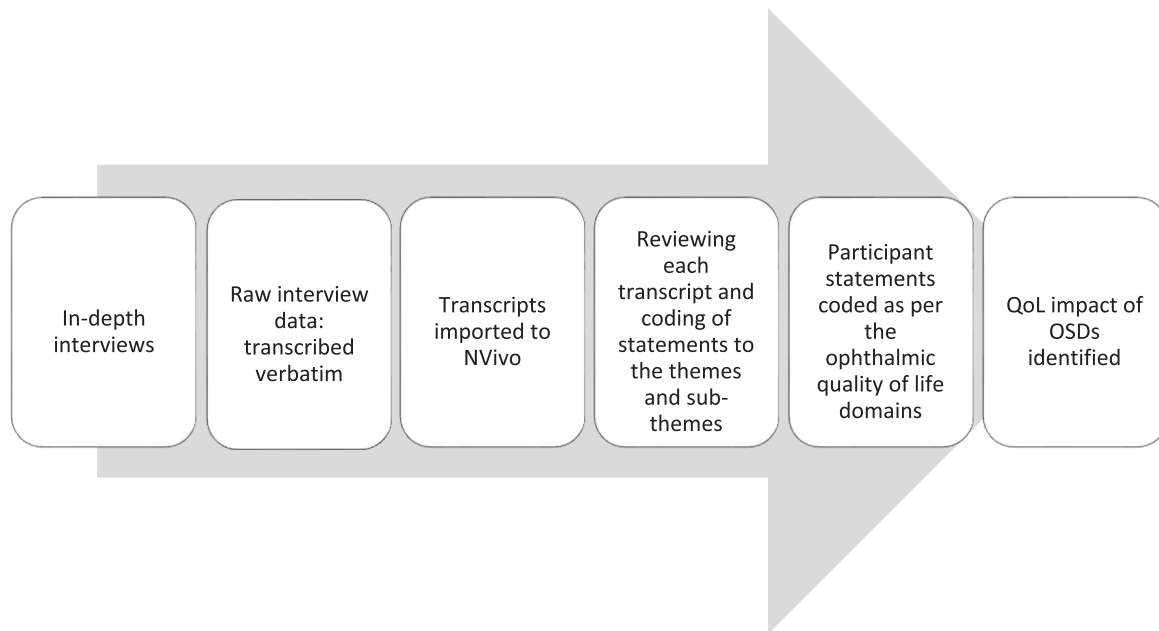


Fig. 1. Qualitative study framework: data collection, coding and identification of QoL impacts.

optometry. [47,57,58] The researchers involved have a mix of qualifications in optometry, public health, ophthalmology and experience in conduct of qualitative research. Methodological rigour was further strengthened through independent review of early interviews and transcripts by an academic supervisor and researcher (SK) and cross-checking by a non-clinical peer to ensure alignment with participants' perspectives. [47,57,58].

Credibility was reinforced via prolonged engagement, persistent observation, and triangulation. Although focus groups could not be conducted due to logistical constraints, triangulation was achieved through interviews conducted at different times and across multiple recruitment sites. Transferability was supported by detailed reporting of the clinical context, participant characteristics, and methodological procedures, along with a transparent discussion of study limitations.

3. Results

Sixty-two participants participated in an in-depth interview. Their median age was 46 years and ranged between 22 to 78 years. The clinical and demographic characteristics of the sample are provided in Table 1. The average time taken for the interviews was 40.72 min. The in-depth interviews revealed 13 key QoL themes that encapsulate the multidimensional impact of OSD. Within these major themes several sub-themes were identified (Fig. 3). Below the impacts highlighted on each of these domains are presented along with some select participant insights tabulated verbatim in Table 2.

Fig. 2 demonstrates the concept of thematic saturation for the in-depth interviews conducted. Fifty percent of codes were obtained after 33 interviews. The new codes continued to emerge until 50 interviews were conducted.

3.1. Activity limitation

OSDs significantly impaired ability to carry out daily activities, especially those related to career and hobbies, as outlined in Q1 to Q4 in Table 2. Difficulties with digital screen use were a recurring theme, particularly for those whose work or study required prolonged screen time, leading some to consider alternative career paths (Q1, Q4). Physical activities and hobbies were also severely affected, with participants reporting an inability to engage in sports, running, gym

Table 1
Demographic characteristics of the sample.

| Gender | n (%) | Median age (Min, Max) |
|--|-------------------|------------------------------------|
| Male | 16 (25.81 %) | 38.5 (23, 74) |
| Female | 46 (24.19 %) | 50 (22, 78) |
| OSD Type | Gender M:F | Median age (Min, Max years) |
| Aqueous deficient dry eye | 2:7 | 59 (26, 74) |
| Meibomian gland dysfunction | 4:8 | 59 (31, 72) |
| Anterior blepharitis | 5:3 | 41.5 (23, 72) |
| Contact lens discomfort | 1:10 | 38 (27, 57) |
| Ocular surface involvement in autoimmune disease | 0:7 | 65 (51, 73) |
| Thyroid eye disease | 1:6 | 55 (37, 78) |
| Neuropathic corneal pain | 3:5 | 35 (22, 66) |
| Employment status or sector | n (%) | |
| Professional artist | 1 (1.61 %) | |
| Researcher | 3 (4.84 %) | |
| Administrative | 11 (17.74 %) | |
| Mobility trainer | 1 (1.61 %) | |
| Finance | 2 (3.23 %) | |
| Health Sector | 9 (14.52 %) | |
| Student | 4 (6.45 %) | |
| Basic life support trainer | 1 (1.61 %) | |
| Consultancy | 2 (3.23 %) | |
| Academia | 2 (3.23 %) | |
| Home maker | 2 (3.23 %) | |
| Construction | 3 (4.84 %) | |
| Disabled to work | 1 (1.61 %) | |
| Marketing | 3 (4.84 %) | |
| Social support | 1 (1.61 %) | |
| Child Care | 1 (1.61 %) | |
| Information technology | 1 (1.61 %) | |
| Retired | 14 (22.58 %) | |
| Ethnicity | n (%) | |
| Australian | 19 (30.65 %) | |
| Asian | 20 (32.26 %) | |
| Chinese Asian | 6 (9.68 %) | |
| White American | 3 (4.84 %) | |
| Caucasian | 5 (8.06 %) | |
| White British | 3 (4.84 %) | |
| New Zealander | 3 (4.84 %) | |
| Celtic | 2 (3.23 %) | |
| Latin American | 1 (1.61 %) | |

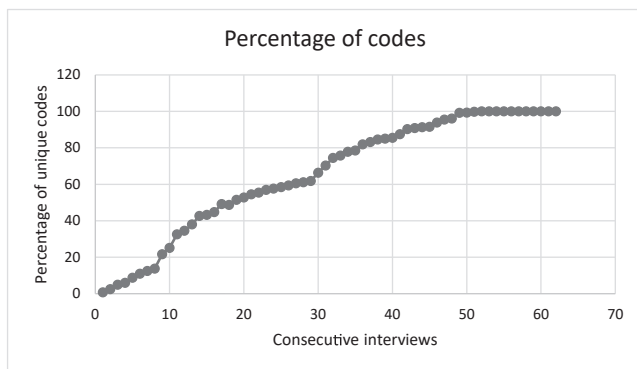


Fig. 2. Unique codes compared to the number of consecutive interviews conducted.

exercises or even reading activities they once enjoyed (Q2, Q3). These challenges have restricted their motivation and engagement in career-related activities, hobbies and academic pursuits. Activity limitation was more common in participants in the severe spectrum of all conditions.

3.2. Driving

Participants shared significant challenges related to their condition and driving. Some mentioned that ocular discomfort and pain had forced them to discontinue activities such as weightlifting because they were unable to drive to the gym (Q19). Night driving proved particularly difficult for others, with some resorting to wearing sunglasses in low-light condition yet still feeling unsafe and only driving at night in emergencies (Q20, Q22). For some participants alleviating eye pain became a necessary step before driving, as they felt it was crucial for safe driving (Q21). Additionally, a few participants noted that as their condition worsened with age, and they increasingly avoided night driving, relying on others for evening transportation when possible (Q22).

3.3. Lighting

Participants reported significant challenges related to light sensitivity when performing certain tasks. One of the participants noted that reading on a phone was especially difficult due to glare, whereas reading a book posed no such issues (Q35). Several participants mentioned increased sensitivity to sunlight, which impacted their ability for outdoor activities (Q36). Other participants highlighted the need to manage lighting in their environment, with one needing to lower blinds and to tint windows in house to avoid direct sunlight as direct sunlight aggravated eye discomfort and symptoms (37, Q38). Another participant mentioned that they limited their driving to avoid sunlight exposure, ensuring they did not drive into the sun (P38).

3.4. Mobility

Participants shared various challenges affecting their mobility situations. One participant described experiencing severe pain episodes that made walking difficult requiring assistance from their partner or even a wheelchair for mobility (Q39). Another noted that the physical demands of commuting, such as driving and long hours in an office environment became unmanageable due to their condition (Q40). One of the participants highlighted difficulties walking in crowded places, particularly with the need to close one eye due to eye pain, which impacted their ability to navigate crowds and maintain balance (Q41). Additionally, some participants found that using specialized glasses or other aids helped improve their mobility, though they still faced significant challenges, such as needing to keep their eyes closed in environments with dry air during bus or train rides (Q42).

3.5. Health concerns

OSD prompted broader concerns beyond immediate symptoms, often tied to long-term impact on ocular health (Q5 to Q10 in Table 2). Participants with CLD were concerned about a declining tolerance for contact lens use, with some restricted to wearing lenses only occasionally due to pain, dryness, and irritation (Q5, Q10). Participants feared worsening symptoms, and the potential for corneal complications that may lead to vision blur or permanent vision loss (Q6, Q8). The chronic nature of OSD and the sense of having no cure heightened apprehensions about the long-term health outcomes (Q7, Q8). Nonetheless, participants expressed strong commitment to caring for their eyes and actively seeking ways to manage their condition and mitigate its impact (Q9).

3.6. Convenience

Participants emphasized the inconvenience associated with managing their condition and adjustments needed on daily routines. Some expressed a preference for contact lens wear over glasses during outdoor activities for ease of use but defaulted to glasses at home for convenience (Q11). Others described frustration with the significant time commitment required for eye care, which interfered with their ability to focus on other activities (Q12). The persistent ocular symptoms while working was also noted as a source of inconvenience (Q13). Additionally, participants shared the challenges of adhering to time-consuming daily regimens, such as frequent use of eye drops, removing eye masks, using specialized lenses such as scleral lenses, and minimizing eye exposure to air, which disrupted their ability to relax or maintain flexibility in their routines (Q14).

3.7. Economic impacts

Under the economic impact domain, participants expressed the financial burden of managing their eye condition and the financial burden that arose from the associated work limitations. Many reported high costs for necessary treatments, such as expensive eye drops, expenses for supplements, eyecare products, and specialist visits which may not be covered by public health insurance (Q23, Q25). Some participants mentioned the limitations within public health systems which only allows for one free eye check per year, leading them to avoid additional visits to specialists due to the costs involved (Q25). One of the participants had to quit their job due to the eye condition, resulting in a loss of income (Q24). Several participants shared frustrations of the cumulative expenses of purchasing eye care products, with one noting they had spent thousands of dollars in treatment to find a relief (Q26). The potential costs of ongoing treatments such as IPL therapy was also a significant concern, with one participant worried about the financial burden, especially if the treatment did not provide substantial benefits (Q27).

3.8. Emotional impacts

Participants described profound emotional impacts linked to their conditions. One participant revealed feeling overwhelmed by the severity of their symptoms, to the point of contemplating suicide, which they refrained from due to their love for the family members (Q28). Despite having a strong support network, one participant admitted to coming close to suicide multiple times, reflecting on the added emotional burden for those without such support (Q33). Several participants described challenges with depression, opting for psychologist counselling over medication, but found it unsuccessful (Q29). The frustration of not having perfect vision, or the inconvenience caused by OSD, was another common cause of emotional strain (Q30). Concerns about worsening symptoms and potential future consequences contributed to feelings of worry (Q31). The persistent symptoms caused annoyance to several participants (Q34). Issues with self-confidence

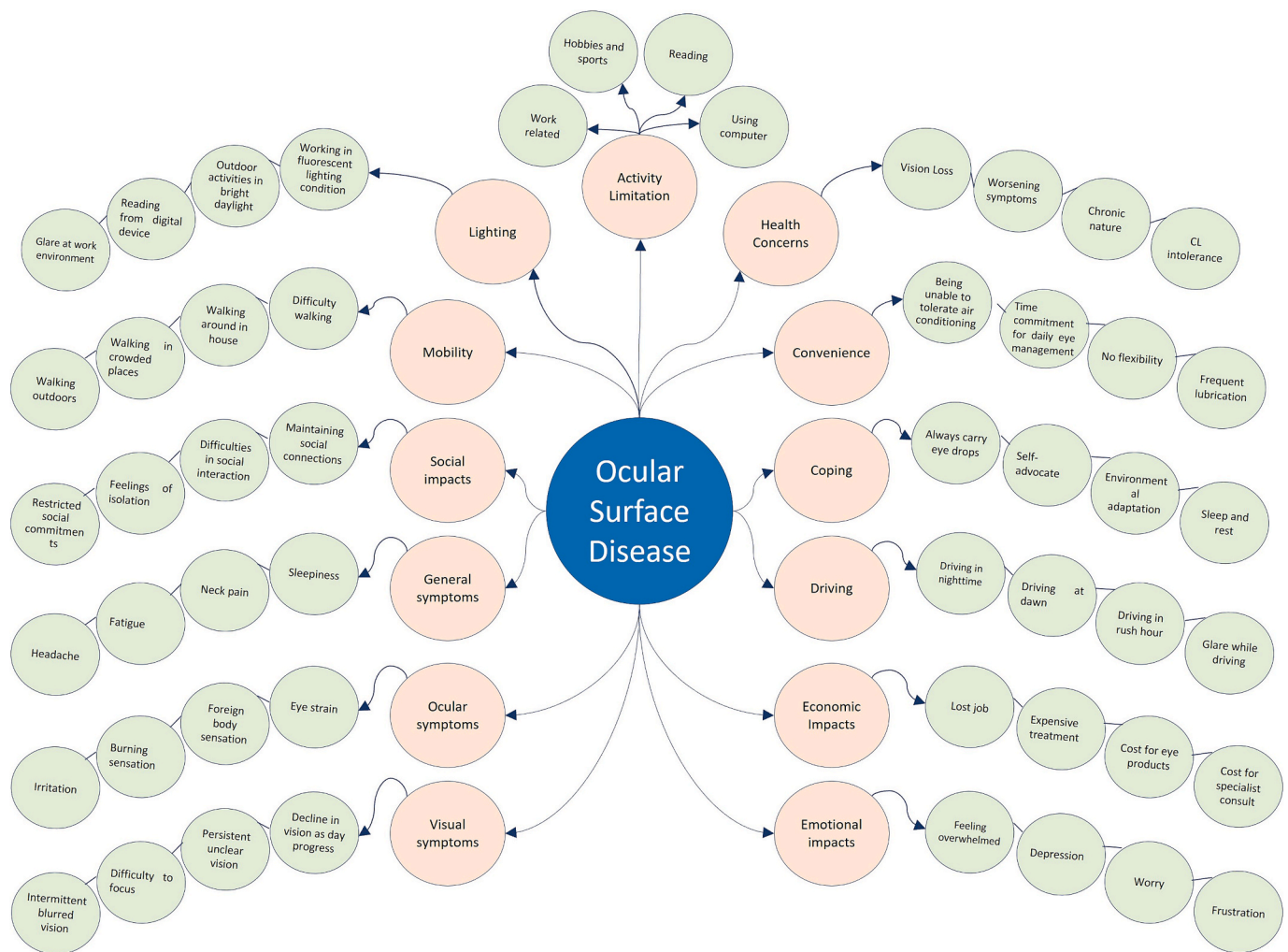


Fig. 3. Quality of life themes identified. Orange circles represent themes, and green circles represent sub-themes.

were also reported, particularly in professional settings, where the need for help was sometimes met with confusion or lack of support (Q32).

3.9. Social wellbeing

Participants reported significant challenges in maintaining social connections and participating in social activities, often stemming from others' misunderstandings about the severity of their eye conditions. One participant described how their lack of changes in appearance led others to dismiss their need for support, such as reluctance to offer transportation assistance due to the absence of a visible physical disability (Q43). Others highlighted difficulties in social interactions, noting that DED forced them to avoid direct eye contact, which hindered natural communication and connection with others (Q44).

The pain and discomfort associated with their condition also made it nearly impossible for some participants to engage in conversations or social activities, further contributing to feelings of isolation (Q45). The frustration of having their experiences undervalued by others, who compared their severe symptoms to occasional mild dryness left some feeling unheard and reluctant to express their struggles (Q46).

Despite these challenges, some participants acknowledged the support of their families. However, limitations remained such as the inability to engage for extended periods or avoiding visually demanding activities like watching games or movies on projectors persisted (Q47). Others noted how their condition restricted their social commitments with friends or children, as they could no longer participate in activities

they once enjoyed (Q47, Q48). They also often relied on ocular devices, such as moisture chamber glasses, which were functional, but not aesthetically pleasing, further impacting their confidence in social settings (Q48).

3.10. Ocular symptoms

Participants described a wide range of ocular symptoms highlighting the persistent nature of their symptoms and challenges associated with managing their condition and wellbeing. While multiple ocular symptoms were described, the most common were sensations of eye strain, fatigue and heaviness of eyelids accompanied by a frequent foreign body sensation and burning sensation (Q53, Q56). Some shared that specific symptoms like itchiness were relieved by using eye drops, but they remained a recurring issue (Q54). Others described managing their ocular discomfort through personal care routines such as removing crusts from eyelids to mitigate itchiness (Q55). Additional symptoms included irritation, redness and a sensation of eyelids sticking when blinking (Q56, Q57). These symptoms were reported to often exacerbate by prolonged use of computer or sustained visually demanding tasks.

3.11. Visual symptoms

Participants described a range of visual symptoms that significantly impacted their daily activities and recreational aspects of life. Intermittent blurred vision and difficulty with focusing was the predominant

Table 2

Quality of life domains and quoted responses by participants.

| a. Domains | b. Domain definition | c. Quotation number, participant number, their age, gender and quoted responses |
|------------------------|--|--|
| d. Activity Limitation | e. The difficulties an individual has in executing vision-specific physical, social, or recreational activities due to impairment resulting from an eye disease/condition and its treatment/s (e.g. difficulty reading, watching television, performing job related tasks) | <p>f. Q1 P50. 37 years old female: <i>I struggle with screen time working is a huge issue, so I'm trying now to retrain to do Counselling so that it's something that perhaps in time I want to qualify, I won't be on a screen all of the time, but obviously that is difficult now because I'm working out and studying, so that's hard.</i></p> <p>Q2 P46. 66 years old male: <i>My, all my gym, my running, my activity, even reading, doing things that I enjoyed doing previously alone no longer available to me, that that feels as if everything that I'd love doing I can no longer do</i></p> <p>Q3 P36. 31 years male: <i>So now I go I can't. I can't go and do that umm. Yeah. So that, uh, pretty much, most sports, to be perfectly honest, I couldn't go out and play football or soccer or anything like that. So yeah, Career, hobbies.</i></p> <p>Q4 P23. 30 years female: <i>The rest of the time, I think is fine and then also I think the Dry eye will limit it my study motivation, like if I comfortable with my eye, maybe I can put more time on my study or work. Yeah, but because this one sometimes I I I don't wanna use my laptop or my phone.</i></p> |
| g. Health Concerns | h. The health-specific issues that affect an individual's attention, interest, care, safety, or welfare associated with an eye disease/condition and its treatment/s (e.g. concerned about going blind, losing independence) | <p>i. Q5 P45. 29 years old female: <i>I mean in my situation like I I was wearing contacts since I was 15. So for like 10 years and the time that I could wear contacts were getting shorter because I would get, you know, irritation from contacts, my eyes would dry out and I usually basically what I did, I stopped wearing them and only wear them like 2 times per year. But even that would become even I mean, even once a year it would be very like only for a couple of hours and it would give me pain.</i></p> <p>Q6 P4. 57 years old female: <i>I guess my only worries I I worry about the the dry spots in my eyes as I become older, so I just worry about what that course will be and I I don't think I feel like as I'm getting older and I'm moving through middle age I'm it is my eyes are becoming increasingly drier and I don't I guess I do have</i></p> |

Table 2 (continued)

| | | |
|----------------|--|--|
| j. Convenience | k. The quality of an individual's comfort, time, needs, desire, and purposes compromised due to an eye disease/condition and its treatment/s (e.g. administering eye drops frequently, having to attend frequent appointment with eye care provider) | <p>l. Q11 P2. 27 years old female: <i>Umm, I think despite all the discomfort it is on, I actually I do prefer not wearing glasses in terms of the you know activities like you know outdoor activities, it's just easier. But if I'm at home, I just wear glasses if I can.</i></p> <p>Q12 P42. 38 years old male: <i>It it does bother me. Yeah, it's it's just a big-time commitment, it's It's kind of frustrating when you wanna be getting on with other things to to kind of have to carve out time out of the day.</i></p> <p>Q13 P47. 62 years female: <i>Well, it's inconvenient in the sense of, you know, I'm sitting, doing work and my eyes are feeling really irritated and it's not pleasant.</i></p> <p>Q14 P35. 23 years male: <i>You know, someone might have to go into a wheelchair every morning or whatever, but you know, I wake up. I</i></p> |
|----------------|--|--|

concerns about what will happen as I continue to get older is it going to be a more of an issue for me.

Q7 P16. 67 years old female: *Umm, that can't go along with this sort of chronic condition where it's not there doesn't seem to be any medication and and whilst they've tried different form Uh pharmaceutical what we called prescription eye drops and things most of them.*

Q8 P22. 44 years old female: *Yeah, I always feel if if the dry eye is going to increase then I may get some corneal epithelial staining or something like a defect because it can. The worst condition can lead to corneal, you know, some erosions or something or and that can again lead to some permanent blurry vision.*

Q9 P5. 43 years old female: *Definitely want to be able to see. Umm. Obviously I'll know what to do if I do loose my vision, but that's not. I don't want that to happen. So yeah, so it does worry me a little bit, but I try not to focus on that and just try and think about well, what can I do to make it better and what can I do to try and make sure I don't ever get to that stage.*

Q10 P2. 27 years old female: *It's OK, but after realizing that my eye health are getting worse because with the contact lens wear now it's concerning me, yeah.*

Q11 P2. 27 years old female: *Umm, I think despite all the discomfort it is on, I actually I do prefer not wearing glasses in terms of the you know activities like you know outdoor activities, it's just easier. But if I'm at home, I just wear glasses if I can.*

Q12 P42. 38 years old male: *It it does bother me. Yeah, it's it's just a big-time commitment, it's It's kind of frustrating when you wanna be getting on with other things to to kind of have to carve out time out of the day.*

Q13 P47. 62 years female: *Well, it's inconvenient in the sense of, you know, I'm sitting, doing work and my eyes are feeling really irritated and it's not pleasant.*

Q14 P35. 23 years male: *You know, someone might have to go into a wheelchair every morning or whatever, but you know, I wake up. I*

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Table 2 (continued)

| | | |
|------------|--|---|
| m. Coping | n. The adaptive mechanism an individual follows to overcome difficulties arising due to impairment resulting from an eye disease/condition and its treatment/s (e.g. wearing moisture chamber glasses, switching off air conditioning) | have to take my eye mask off. I have to then have a shower and then put my scleral lenses in. I can't really just lay in bed for a couple hours being lazy because if I do my eyes are exposed to the air and you know I have severe Aqueous tear deficiency. |
| | | o. Q15 P14. 57 years old male: <i>Life was to advocate for myself and try to help myself because nobody out there really understands the disease and the and the health care system doesn't understand the quality-of-life issue with this disease, which is associated with this disease, and they don't want to pay for it.</i> Q16 P16. 67 years old female: <i>But it's just having to always carry eye drops with me to always have them on hand, no matter where I go. Even just to the shops or, you know, wherever you know, even visiting people, I always have to have the drops with me.</i> Q17 P51. 62 years female: <i>So, I do a lot of traveling, driving. I just make sure all the air con is off which in Townsville can be a bit hard going, but I don't have any of the fans ever pointing at me. I always make sure that the fans where I'm sitting, I always drive, so I always have them turned off because I can't be sitting in a car with a, you know, fan on my face.</i> Q18 P44. 44 years male: <i>No, I What I feel it when eye get dryness I cannot concentrate on the study for whole day and it's been so bad so want to close my eyes and want to sleep.</i> |
| p. Driving | q. The difficulties an individual has in driving due to impairment resulting from an eye disease/condition and its treatment/s (e.g. driving long distance is difficult due to watery eyes, driving at night) | r. Q19 P40. 22 years old female: <i>Umm I was very into weightlifting. Umm I'm I'm mostly stopped that just because I couldn't drive to the gym.</i> Q20 P34. 55 years old female: <i>Umm, I drive at night with sunglasses on. Yeah, but yeah, so you know, I wouldn't be able to drive at night. Unless it was kind of an emergency. I wouldn't feel safe.</i> Q21 P10. 74 years male: <i>I've got these sore eyes. I gotta get that sorted out before I I drive off. So I can drive safely and all that.</i> Q22 P56. 42 years female: <i>I don't like driving at night anymore. Yeah, it's getting worse. So, I'm getting older. That's something I'm noticing as well. If I can, I</i> |

Table 2 (continued)

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| s. Economic Impacts | t. The economic implications and impacts associated with an eye disease and its treatment/s. These include, but are not limited to, cost of illness (i.e. the cost of buying medications, cost of treatment and accessing health service/s), and impact on employment, productivity, and income (e.g. inability to keeping up with things at work, inability to work) | u. Q23 P5. 43 years old female: <i>Yeah, it's very expensive. Like the drops are expensive, none of it's on the PBS. So, and obviously the ophthalmologist can give you scripts for some of the eye drops. But you know, there's still quite expensive and I use a lot of them. The Omega-3 tablets are really expensive. So, you know, I feel like it's costing me, like, even just for drops and stuff like probably \$100 a month, which you know I'd rather spend that on more fun things, that's for sure.</i> Q24 P36. 31 years old male: <i>Umm And unfortunately, I had to quit my job because of this. So, I don't work behind computers anymore, so working away from the screen my vision stays somewhat the same throughout the day.</i> Q25 P3. 72 years female: <i>Because when you go to have an eye check up the Medicare, Umm uh help you for once a year.</i> <i>But if you wanna check more times you have to pay yourself. So I try not to, and particularly if I need to go and see a specialist that cost more than I try not to.</i> Q26 P9. 57 years female: <i>Ohh yeah, I I would hate to see what I have spent. Find products for my eyes. I mean, you know, it's in, you know, this point I'm like, oh, well, you know what's another 1000 bucks or like this stuff? It's really expensive. It seemed to be helping and so I'm like, well, I'll try it for a while and see, you know, and if it doesn't work, I'll back off of it.</i> Q27 P42. 38 years old male: <i>Umm yeah it it is a fair bit. I think I've been slightly more concerned about that recently. Just because you know, we've been discussing whether I need to have IPL every three months and then thinking well that is gonna add up to. I don't know what it would be \$1500 a year or something just on IPL. So yeah, it is a fairly significant expense, especially when it's</i> (continued on next page) |
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| v. Emotional impacts | w. The emotional and psychological issues or disorders an individual has to face due to an eye disease/condition and its treatment (e.g. feel angry, feel annoyed, feel worried, feel depressed) | potentially not having a huge impact. |
| | | x. Q28 P34. 55 years old female: <i>I'd sometimes say to my husband if they could just pull my eyeballs out, there would be some relief, you know? And this is probably outside the scope of this, but I was a bit suicidal a few months ago this really I took a bunch of pills and I intended to take them. I didn't because I love him very much and I don't wanna hurt him, but just everything got too much for me.</i> Q29 P46. 66 years old male: <i>I'm not on medication. I've been diagnosed as such, but I'm not on medication. My GP wanted me to explore the clinical psychology Umm you have a new first to see whether you know instead of going on global medication for depression. If I can fight my way out of it, if you like with with counselling instead. And that's not really proving to be successful at all.</i> Q30 P1. 59 years female: <i>The thing for me is annoying, and whether that's a dry eye or more just the inconvenience having you know, not having 20/20 vision anymore, which I find really frustrating.</i> Q31 P 25. 27 years female: <i>It wasn't the symptoms that scares me, but the fact that my clinical signs are even worse and that's why I think for the future, I'm more worried. But at the moment right now, because it's not affecting me as much as it probably should, I'm not overly like concerned or paranoid. If that makes sense, yes.</i> Q32 P51. 62 years old female: <i>So, you're asking people for help, and they're going, why do you need help? Like so yeah, that impacts of my confidence. It's probably not outside of work. I'm fine, but at work it does, yeah.</i> Q33 P40. 22 years old female: <i>Ohh so like I said I I have a fantastic support system and even then I came so close to suicide many times so I was always thinking while I was going through this I was like I can't imagine you know what it must be like for other people that don't have this kind of support system because I had.</i> |

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| y. Lighting | z. The difficulties an individual has in performing vision-specific tasks related to different lighting conditions due to impairment resulting from an eye disease/condition and its treatment/s (e.g. difficulties with glare from vehicle headlights to drive in dim light condition) | Q34 P47. 64 years old male: <i>Yeah, sometimes I would, but I'm of the nature, there are things are like that. There are annoying. I don't really think about it too much. It's just annoying.</i> aa. Q35 P6. 69 years old female: <i>And you know, because you don't get any glare from a book whereas you do on a computer or phone reading, something on my phone is just, you know, if I tried to read a book on my phone, it would be hopeless.</i> Q36 P8. 31 years old male: <i>I'm not sure if you said based on because of the trial, but yeah, sometimes I I'm very sensitive to the light like this, mostly of the sunlight. So I try I I used to play cricket in every weekend here in Australia. So I saw that there is a problem and I'm fielding opposite the sunlight. It actually caused some trouble and I have to move the other side like opposite of the sunlight, yeah.</i> Q37 P24. 50 years female: <i>So, I need to make sure my blinds are are lowered. Umm, not sitting in direct light like like sunlight. I need to put a barrier like. I can't too much, too much light Umm Makes my eyes sore and then causes all those symptoms.</i> Q38 P17. 65 years female: <i>The doctors haven't told me, but I won't drive any further than two hours in a day and I always make sure I'm not driving into the sun.</i> <i>All of my windows are tinted, are heavily tinted, so that stops all the glare coming in my house and on the sunny side of my house, which is the kitchen, dining lounge room.</i> |
| ab. Mobility | ac. The difficulties an individual has in performing vision-specific tasks related to mobility situations due to impairment resulting from an eye disease/condition and its treatment/s (e.g. difficulty using steps/stairs, walking in crowded areas, crossing a street) | ad. Q39 P53. 49 years old female: <i>Yeah, but if I I will avoid it if I when I even the worst thing is when I I have got this terrible episodes of pain that I find it even difficult to walk to walk because of the pain. Just I I just end up just being sofa or, you know, my husband had to help me go upstairs or when we are in hospital they have to in a wheelchair because I couldn't walk.</i> Q40 P56. 42 years old female: <i>I do find that I'm conscious that I just</i> |

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| | | <p>couldn't cope with it. I couldn't see myself sitting in an office environment all day doing a full time job because the starters I couldn't face the drive and I've had to commute again. I used to do a 60 mile daily commute to work. I couldn't do that again. No chance.</p> <p>Q41 P46. 66 years male: Umm, we have been on a couple of trips, one to Melbourne to Adelaide, but things like walking down crowded streets I find extremely difficult just with one eye because it had such poor balance and you know walking through crowds, things that you take for granted. Simple things are being able to have a gait and avoid people and not bump into them have suddenly become extremely difficult for me.</p> <p>Q42 P45. 29 years female: I mean, OK, I have my moisture chamber glasses, so they help if I if I didn't have those it would be very difficult and I have them for a year now. So for for half for six months, I survived without them. It was very, very difficult. I had to sit with my eyes closed in the bus because there were air condition and the air is quite dry there. So I basically I had to just sit with my eyes closed. Same with trains and so on, even with chamber glasses.</p> |
| ae. Social Impacts | af. An individual's inability to engage in social activities and fulfill social obligations due to impairment resulting from an eye disease/condition and its treatment/s (e.g. participating in social activities, meeting family and friends socially, maintaining relationships with family and friends) | <p>ag. Q43 P38. 74 years old female: And then you don't feel so alone because the average person just take, for example, my book club. I was asking one of them if because they live near me, if I if I could have a lift and went, oh, why, why do you need a lift all the time and said, oh, you my eyes. And she said, oh, they look OK? Umm I don't wanna keep giving you a lift, so there's very little lack of understanding out there because you haven't got some kind of physical disability.</p> <p>Q44 P37. 23 years old male: With Dry eye disease, it's very difficult to actually be like be with normal people because normal people, even when they speak like they stare at each other and that's something we cannot do as dry eye patients. We usually look like and we look at the floor because it</p> |

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| | | <p>makes like our eyes open less. So we will have more moist in the eyes. So it's it's really difficult to keep up with normal people.</p> <p>Q45 P35. 23 years old male: It's kind of faded away a lot. I'm still in excruciating pain, but it takes it from a an 11 out of 10, incompatible with life, can barely think properly, can't even have a hold a conversation with someone because I'm just in gripping agony.</p> <p>Q46 P50. 37 years old female: So, you kind of if you're trying to talk to somebody and they'll say, oh, yeah, my eyes sometimes get dry as well, or every now and again I have to put drops in, like sort of maybe every couple of weeks I put a drop in. I think that is not the same thing at all, and it's it's hard to get people to understand the severity without feeling like you're just a drama queen or an attention seeker, or you're making it up because it can't possibly be so bad.</p> <p>Q47 P17. 65 years old female: But my family are really supportive and I understand I can only go and see them for short periods of time, especially if the kids are are watching something or playing a game on, you know, a projector onto the wall. Ohh that's too hard in my eyes.</p> <p>Q48 P9. 57 years old female: It was just a more of a controlled thing, you know, and there's times I can't do things with friends that I would like to do, you know Yeah, things like I do have some kind of some moisture chamber glasses. They're not pretty. But yeah, I just you know, I don't commit like I used to do things.</p> |
| ah. General Symptoms | ai. The unwanted non-ocular sensations or manifestations in the body that arise from or accompany an eye disease/condition and its treatment/s (e.g. headache, facial pain) | <p>aj. Q49 P41. 39 years old female: And I don't know of anything else that's causing it, so I believe it's a contact lenses or the dryness from the contact lens discomfort that I attribute that headache sort of feeling too.</p> <p>Q50 P16. 67 years old female: My eyes are burning or you know I'm I'm just fatigued. Whether the fatigue comes from a physical thing or from my eye because it actually is very tiring when your eyes</p> |

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| ak. Ocular Symptoms | al. The unwanted non-visual sensations in and around the eyes arising from or accompanying an eye disease/condition and its treatment/s (e.g. ocular discomfort, watery eyes, red eye) | am. Q53 P23. 30 years old female: <i>I feel eye strain, eye fatigue and also I feel my eyelid is quite heavy for my both side and I always have like umm foreign body sensation. Then yeah, and a burning umm.</i> Q54 P1. 59 years old female: <i>As soon as I start using the drops, it's much better and I haven't had the same itchiness that I was having for a while that I did</i> Q55 P55. 72 years old female: <i>Whenever I feel that my eye itchy, I go into the light a good light. And I Use the mirror and I use. A pair of very good tweezers. And take off any crusts.</i> Q56 P53. 49 years old female: <i>Now that I've been in the computer and so on, even with these glasses and I do think that they help me. I feel them dry and sometimes I feel like when I blink, as if they get stuck, you know, my eyelids gets stuck. And of course a burning sensation also its there like always.</i> Q57 P30. 28 years old male: <i>For example, I have blur vision and I never had blurred vision during my near works or far works. Also, I had some irritation in my eye feel the foreign bodies in my eyes and also irritation, itchiness. I feel like I am Have the red eye frequently recently.</i> |
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| an. Visual Symptoms | ao. The unwanted visual sensations arising from or accompanying an eye disease/condition and its treatment/s (e.g. blurred vision at distance/near, inability to clearly focus) | ap. Q58 P27. 46 years old female: <i>UM, it's just, uh, blurred vision because of the tear around it and find it really hard to focus umm.</i> Q59 P20. 50 years old female: <i>Umm, in the morning I can read it relatively comfortably, but by mid afternoon it's one of those trying to get the focus</i> |
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| right. | Q60 P52. 44 years old female: <i>No, the sight is not very clear. I I can't identify the the the age-related could be anything. I don't see things very clear now.</i> Q61 P27. 46 years old female: <i>Annoyed that I have dried eyes like because like for example I enjoy snow skiing, but I don't I don't want to go do it because my vision so poor from it. So I guess frustrated because of the condition.</i> Q62 P25. 27 years old female: <i>If it is it's, UM, it's like the vision fluctuates a little bit like I have to blink to get it, but very clear at times or like, oh, yeah, me. Probably just the last like 2 years that I've really noticed.</i> Q63 P8. 31 years old male: <i>Uh, it's been probably difficulties being detect the balls properly because we have to use a a cricket ball which is white and shiny as well. So I think there is a trouble like detecting it properly. The vision is not very clear.</i> |
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issue with some attributing the symptoms to tear film related instability (Q58, Q62). Others experienced a decline in vision clarity and difficulty focusing as the day progressed, noting visual tasks such as reading became increasingly challenging by mid-afternoon (Q59). Some participants mentioned persistent unclear vision which they could not attribute solely to age related changes and perhaps are caused by the OSD they have (Q60). These visual symptoms affected leisure activities and visually demanding sports such as skiing and cricket (Q61, Q63).

3.12. General symptoms

Participants described different general symptoms associated with their eye conditions highlighting the impact on their overall QoL. Several reported headaches and discomfort linked to OSD, with one attributing the sensation directly to dryness caused by contact lenses (Q49). Another participant noted that burning eyes and persistent dryness led to fatigue, making day-to-day functioning physically exhausting (Q50).

Some participants described a time-of-day pattern to their symptoms, reporting increased discomfort and tiredness in the late afternoon and evening, which affected their energy levels and prompted the desire to sleep (Q51). Additionally, one participant mentioned that headaches originating from the eyes would lead to muscle tension and chronic neck pain, further compounding their discomfort (Q52). These testimonials highlight the widespread and multifaceted nature of symptoms extending beyond eyes to affect the overall physical wellbeing and QoL.

3.13. Coping

Participants described various strategies and challenges in managing their condition. Many expressed frustrations with the lack of understanding and support from the healthcare system, emphasizing the need to self-advocate to address the QoL impacts of their condition (Q15).

Several participants reporting of constantly carrying eye drops as inconvenience also considered this to be their coping mechanism. and care products to ensure their availability in all settings added an extra layer of vigilance to daily life (Q16). Coping mechanisms also included environmental adaptations, such as avoiding air conditioning or fans while at home, driving, or in the workplace (Q17). Additionally, some participants reported that during periods of impaired concentration due to ocular discomfort, they found relief by resting or sleeping (Q18).

4. Discussion

Existing literature highlight a lack of PROMs that have rigour and precision required for a comprehensive measurement of OSD-specific QoL. [14] This study provides an in-depth qualitative exploration of the QoL impacts associated with OSDs. Thematic analysis of patient experiences revealed the profound and multidimensional challenges these conditions pose in daily life. The findings of this study further emphasize on the necessity for an OSD-specific PROM to comprehensively assess disease burden and guide more patient centred care approaches.

The most profound impact observed was on the emotional wellbeing of participants, who described feelings of annoyance, depression, frustration, reduced self-confidence, worry, and anxiety related to their condition. The chronic nature of OSDs along with persistent symptoms contributed to heightened emotional distress, depression, and in some cases suicidal thoughts in some of the participants. Similar psychological effects have been reported among patients in other high-income countries across Europe and the USA. [10,13,59–61] Some participants indicated that engaging in social media support groups and self-advocacy efforts helped them cope with the psychological burden. Others mentioned that attending counselling session and accepting their condition enabled them to develop effective coping strategies. A qualitative study of patients with different types of DED identified emotional distress linked to challenges in diagnosing, changes in lifestyle and reduction in social interactions. [62].

Social impact of OSDs was a prominent theme identified. The findings of this study suggested OSDs substantially impacted on psychological wellbeing, with participants withdrawn from social interactions, significantly affecting their personal relationships and daily engagements. Social interactions were further impacted by self-consciousness about their appearance, inability to maintain eye contact, and challenges in explaining the severity of their condition to others. Some participants noted a lack of awareness about OSDs among family members and peers, which at times made them feel misunderstood or perceived as exaggerating their eye condition. Others expressed feelings of being a burden to their families, frequently being unavailable for activities with their spouse and children. Some of the social challenges of OSDs have been documented in qualitative studies of patients with NCP, DED, and Sjögren disease [60–62] as well with the lifestyle challenges that may cause OSDs. [63,64] These findings emphasize the broader social implications of OSDs and the need for increased awareness and support systems to help affected individuals navigate social interactions more comfortably.

Participants in this study described notable difficulties in performing daily activities, driving and maintaining mobility due to the impact of OSDs. This aligns with the findings of some OSD-specific PROMs that incorporate the items related to activity limitations. [14,17,18] Activities that require visual concentration such as reading, using digital devices or completing work-related tasks were particularly difficult to perform. Many found themselves struggling to keep with their efficiency and productivity. This often resulted in frustration associated with their eye condition. Social and recreational activities were also affected with some individuals avoiding sports, group events and travel due to the discomfort or visual strain. Driving posed a significant challenge, especially in conditions requiring heightened visual focus, such as nighttime driving, navigating in heavy traffic, or reading road signs. Some

participants felt unsafe behind the wheels for extended periods, while others opted to limit or completely forego driving to reduce stress and risk. Besides driving, mobility was also a concern. Commuting, using public transport, self-driving or travelling long distances became increasingly difficult, contributing to social withdrawal and reduced independence. These findings highlight the widespread impact of OSDs on activities. Having a PROM to comprehensively measure the impact on activities would help in addressing these challenges through better measures, targeted interventions and support systems to improve the ability of individuals in managing their condition while maintaining their independence.

Participants in this study were concerned about the chronic nature of OSDs, characterised by persistent symptoms that often necessitate life-long treatment. [2] Many individuals reported progressive worsening of their symptoms, with exacerbations linked to digital screen use, environmental factors and systemic health conditions. These findings align with broader research highlighting the rising prevalence of OSDs due to environmental and lifestyle factors. [6,64] Additionally, the visible signs of OSDs, such as eye redness contributed to self-consciousness and affected interpersonal interactions. Participants also voiced concerns about inconsistencies in diagnosis between optometrists and ophthalmologists. Similar challenges regarding the lack of standardized diagnostic and management approaches have been documented in Australia and globally. [65–67] These concerns prompted participants to trial multiple therapeutic approaches and consult with multiple healthcare providers, further compounding the economic burden of managing their condition.

The economic burden of OSDs among the participants extended beyond direct medical expenses encompassing a wide range of financial challenges that affected their employment, opportunities available and productivity. Higher expenses and reduced productivity have been shown to be more among severe cases compared to mild or moderate cases of DED. [68–70] Furthermore, discrepancies in insurance coverage for different treatment options for OSDs increased financial difficulties, forcing some individuals to be dependent on their family members. These findings reinforce the necessity for policy interventions aimed at improving healthcare accessibility and financial support for individuals with OSDs.

Most of the PROMs used in OSDs are a short list of symptoms. [14] A wider range of persistent and often debilitating symptoms were mentioned by participants in this study. Environmental triggers such as air conditioning, fragrances, smoke, wind and seasonal changes worsened their symptoms, that ranged from dryness, itching, and foreign body sensation to swollen puffy eyelids, severe burning, pricking sensation in eye, ocular pain, and feeling like poking their eyes out. Some participants described the sensation akin to a hair dryer blowing into the eye or menthol in the eye. Visual symptoms experienced were intermittent blurred vision, heightened glare sensitivity with digital screen and vehicle headlights. Participants in the severe spectrum of the disease or those with NCP and ocular surface involvement in autoimmune disease reported general fatigue, trouble sleeping and lack of energy. The interplay between ocular and general symptoms suggests a broader impact of OSDs beyond eyes.

To alleviate the effects of OSDs, individuals employed a variety of coping strategies. Environmental modifications were common, for instance using humidifiers and avoiding air-conditioning. [8] Participants often adjusted their activities, such as reduced screen time, wearing glasses with a greater wrap around their eyes, moisture chamber glasses and sunglasses. Some individuals engaged themselves in social media support groups sharing experiences. Despite these efforts, OSDs can still lead to significant impact in an individual's life.

Different OSD groups reported varying QoL impacts across specific themes. In addition to symptoms, individuals with severe DED and NCP experienced greater impacts in economic, convenience, social, and emotional domains. Some participants within these groups had to change their occupation or discontinue their work. Across all disease

groups, participants with more severe disease had greater impacts across all themes. Ocular and visual symptoms were common to all groups while general symptoms were more frequently reported by the participants with ocular surface involvement of autoimmune conditions. TED and CLD groups had specific concerns about their appearance contributing to reduced social interactions. Within DED, MGD, CLD and blepharitis groups, frequently reported inconveniences related to daily care of eyes, frequent use of eye drops, and impact on work efficiency. Despite these nuanced differences among OSD subtypes, the study did not identify significant distinctions that would preclude the development of shared item banks across these conditions. Future research on psychometric evaluation for subgroup relevance will provide confirmation if these shared item banks can be used for these OSDs selected.

5. Limitations

Although this study provides valuable insights, certain limitations exist. The sample was limited to English speaking participants from high income countries, Australia and United Kingdom. This may affect the generalizability of findings to other populations. Additionally, the study primarily included individuals who were actively seeking care or participating in support groups, potentially leading to selection bias. Another potential limitation is the absence of focus group discussions which could have provided additional perspectives. Future research should focus on validating these findings in larger, more diverse populations.

6. Conclusion

This qualitative study is part of a larger research initiative aimed at developing OSD-specific item banks to measure QoL parameters. It indicates the substantial QoL impacts of OSDs posed by the variety of symptoms, health concerns, performing daily activities, inconveniences, emotional wellbeing, social engagement and financial impacts. Beyond enhancing understanding of these QoL impacts, the study provides a critical foundation for the development of a comprehensive, technologically advanced PROM well targeted to OSDs. The concepts elicited through this qualitative work will complement the items previously identified in a review of 34 unique PROMs. By exploring key themes and lived experiences, this study contributes essential content for the creation of domain-specific item pools. Future research will integrate these qualitative findings with the reviewed items in a larger, more representative sample to develop robust QoL item banks tailored to OSDs.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.clae.2025.102482>.

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