Quantifying the Societal Burden of Acanthamoeba Keratitis: Results from a Patient Survey

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INTRODUCTION AND OBJECTIVES

Disease background

- Acanthamoeba keratitis (AK) is an ultra-rare, progressive, sight-threatening parasitic corneal infection.[1,2,3]
- This debilitating condition often causes excruciating pain and extreme light sensitivity (photophobia), making it difficult for patients to work or maintain normal daily activities until the infection is resolved.[4,5]
- Even after resolution of the infection and corneal epithelial healing, patients may face chronically disabling long-term consequences that significantly impair quality of life.[3,4,5]
- There is currently no international consensus on managing AK, leading to wide variability in clinical practice. Lack of standardized protocols, coupled with a low index of suspicion, frequent misdiagnoses, diagnostic delays, and inconsistent treatment approaches, leads to an increased reliance on burdensome and complex care, ultimately exacerbating patient burden and outcomes[6].
- Despite the well-documented clinical burden of AK, there remains a gap in the evidence regarding its impact on productivity losses and informal care needs depending on the severity of the disease.

Objectives

- **This study aims to quantify the societal impact of AK from the patient perspective, focusing on productivity losses and informal care needs across different disease phases (active infection and post-AK resolution). It also evaluates how current AK management affects patient outcomes.**

METHODS

- Members of a Dutch-Belgian AK patient association participated voluntarily in the online survey. The link to the survey was shared within the target group. No financial compensation was provided.
- Patients were asked to assess the societal burden of AK (Table 1), by reflecting on their personal experience during both the active and the post-AK resolution phase. In this last phase, the assessment was anchored to their own visual outcomes obtained following AK infection resolution, categorized according to the best corrected visual acuity (BCVA) levels:

Good vision (GV): BCVA ≥20/40	**Poor vision (PV):** BCVA ≥20/200 and <20/40	**Severe vision loss (SVL):** BCVA <20/200	**Complete loss of eye functionality (LEF):** Due to evisceration, enucleation

- The contribution of photophobia and psychological burden to productivity losses and informal care needs was assessed based on each respondent's personal experience.
- During the active infection phase of AK, targeted questions were formulated to separately characterize the intensive and maintenance treatment phases. This approach aimed to gain insights into how the frequency of eye drop application influences productivity losses and informal care needs.
- To enhance the robustness of the estimates, respondents provide their estimate of AK societal burden by considering hypothetical scenarios by imagining themselves as patients in different BCVA categories.

Table 1 – Main topics included in the online survey

Estimates	Description
Occupational disability	Assessed whether individuals were unable to work due to the disease itself or its associated treatment, abandoning the workforce without coming back in the short term.
Informal care needs	Unpaid care provided by family members, friends, or other non-professionals to patients, due to illness, disability, or vulnerability. Measured by the average daily hours of informal care required.
Absenteeism	Estimated proportion of working time lost due to the disease and by BCVA level (both actual and hypothetical) in the post-AK resolution phase of the disease.
Presenteeism	Measured by the proportion of time effectively worked while present, based on post-resolution BCVA category.
Impact of photophobia and depression	Explored how these symptoms contributed to occupational disability, absenteeism, and presenteeism based on the patient's own experience.

Questionnaire description

- No personal information was collected (e.g., names, email addresses, or other personal data).
- The survey was created, distributed, and analysed using SurveyMonkey platform.
- The questionnaire consisted primarily of continuous interval and closed-ended questions to facilitate quantification of the societal impact. It included eight core questions:
  - The first three questions were common to all participants and focused on the active infection phase, which all respondents had experienced.
  - The remaining five questions explored the impact of AK in the post-AK resolution phase, stratified by the patient's BCVA and by hypothetical scenarios.
    - If respondents indicated that their visual category was linked to productivity losses, a follow-up question was provided to assess the impact of photophobia and depression.

Statistical analysis

- A descriptive statistical analysis was conducted on the collected data. The results reflect the average estimates provided by the participants.
- For each question, mean values and measures of uncertainty were calculated, including standard deviation (SD), and 95% confidence intervals (CI) calculated by normal approximation.

RESULTS

1. Active AK infection phase

- 14 patients responded to questions in this section.
- The societal burden was higher during AK intensive treatment phase; most patients ceased working entirely and required more hours of informal care per day compared to the maintenance phase (Table 2).

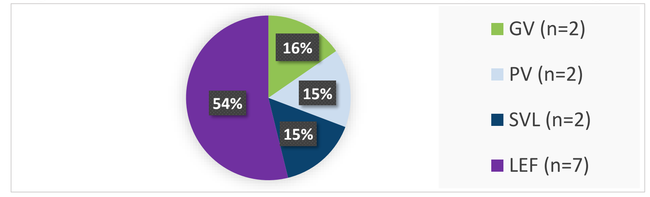
Table 2 – Results first part of the survey - number (%)

Variable	Intensive Phase	Maintenance Phase
Occupational disability	13 (92.9%)	12 (88.7%)
Patients still Working during active AK	1 (7.1%)	2 (4.3%)
Absenteeism (among those working)	40.0%	55.0%
Average Informal Care (hours/day)	8	6

2. Post AK infection resolution phase

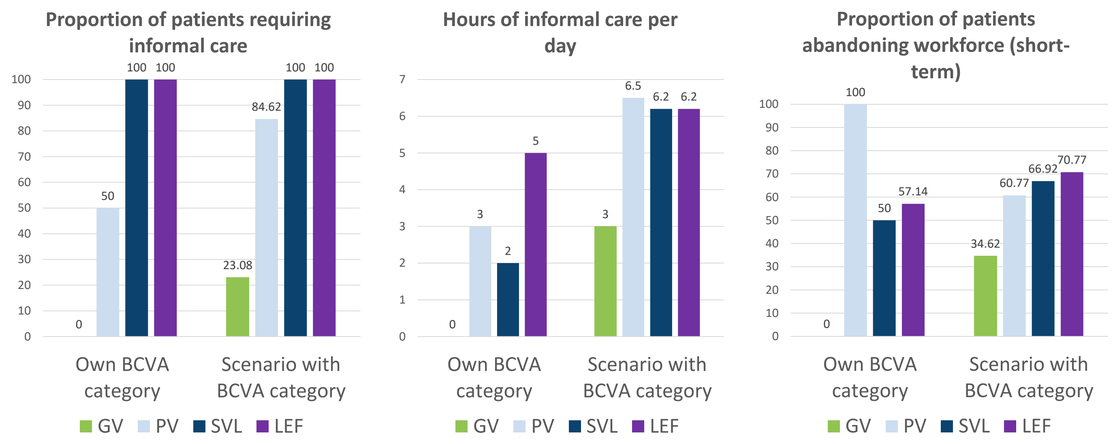
- 13 patients completed this section of the survey, that included stratification based on BCVA categories.
- More than half of the respondents reported LEF as their own BCVA category in the post-AK resolution phase (Figure 1).

Figure 1 - Distribution of AK respondents by BCVA category



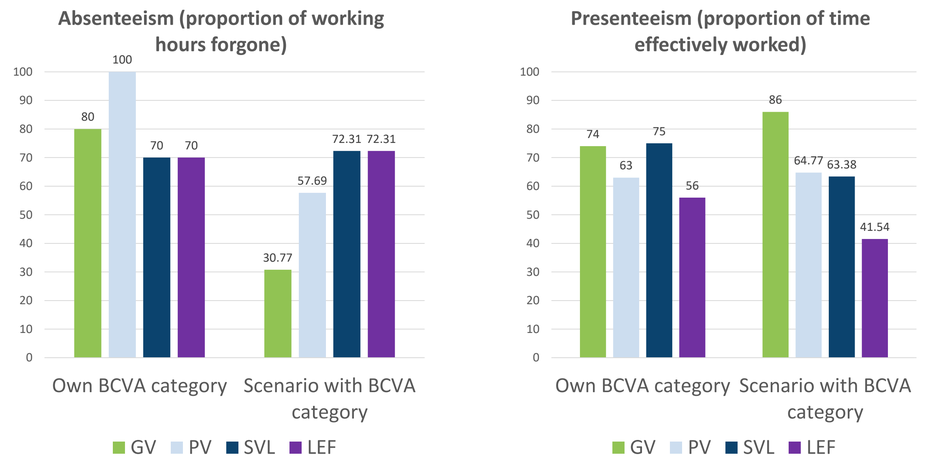
- Patients informal care and occupational disability estimates based on their personal experience differed from those elicited based on hypothetical BCVA categories following AK infection resolution (Figure 2).

Figure 2 - Results of informal care needs and occupational disability disability by BCVA category (own and scenario assessing other BCVA categories)



- Absenteeism and presenteeism estimates based on patient's personal experience differed from estimates provided when assessing other BCVA categories as hypothetical scenarios (Figure 3).

Figure 3 - Results absenteeism and presenteeism estimates by BCVA category (own and scenario assessing other BCVA categories)



3. Associated conditions contributing to disease burden

- Photophobia and depression were key contributors to the ongoing disease burden.
- On a scale from 0 to 5 (where 0= no contribution and 5=full contribution), patients attributed a score to grade the impact of each associated condition on informal care and productivity losses (Table 3).
- Patients with GV or PV reported substantially lower impact compared to SVL and LEF, although, some still experienced these symptoms, amplifying the disease burden even in less severe BCVA categories.

Table 3 – Contribution of photophobia and depression to productivity losses (scale 0 to 5), by BCVA category

Condition	Photophobia				Depression			
BCVA	**GV**	**PV**	**SVL**	**LEF**	**GV**	**PV**	**SVL**	**LEF**
Informal care needs	NA	NA	4.5	2	NA	NA	0.5	4.4
Occupational disability	NR	NA	2	2	NR	NA	0	3
Absenteeism	4.5	5	4.5	4.5	2	0	0	3.2
Presenteeism	3.4	5	4.2	3.2	1	0	0	3.2

CONCLUSIONS

- AK imposes a substantial societal burden during and after the resolution of the infection, especially in patients with worst BVCA categories (SVL and LEF). Photophobia and depression further amplify the disease burden.
- During the active infection phase of AK, a distinction emerged between intensive and maintenance treatment. The intensive phase was associated with a higher proportion of patients ceasing work entirely and requiring a higher number of hours per day of informal care.
- Estimates reported by patients based on their own BCVA category post-AK resolution differed from pooled responses from hypothetical BCVA categories. Most notably, based on the responses from the scenarios, patients may tend to overestimate the burden in GV and PV.
- This study underscores existing unmet needs in AK care and substantial disease burden in the current fragmented clinical practice in a population of patients with significant disease burden.

LIMITATIONS

- The small sample size is a key limitation of the survey. In addition, the distribution between visual outcome categories was not uniform, with most of respondents belonging to the worst BCVA category.

KEY MESSAGES

- These results reinforce the importance of adopting a validated clinical management protocol in future AK guidelines, which has the potential to enhance patient outcomes, reduce treatment burden, and bring consistency to AK care.
- The ODAK trial evaluated the efficacy and safety of new formulation of PHMB (0.8 mg/ml) monotherapy, with a daytime only treatment regimen, combined with a validated clinical management protocol. Results show a high cure rate (more than 86%) without the need of therapeutic and/or optical keratoplasty within 12 months of treatment and without occurrence of serious drug-related AEs[6] .

ABBREVIATIONS: AE: Adverse event; AK: Acanthamoeba Keratitis; BCVA: Best corrected visual acuity; CI: confidence interval; GV: Good vision; LEF: Loss of eye functionality; NA: not applicable; NR: not reported; PHMB: Polihexanide; PV: Poor vision; SD: Standard deviation; SVL: Severe vision loss;

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