Burden of invasive meningococcal disease in survivors and their caregivers in the United States: A cross-sectional non-interventional mixed methods study

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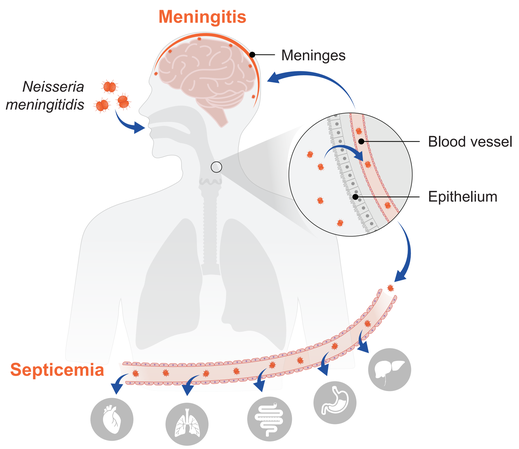
Digital poster
Supplemental data
Narrated summary

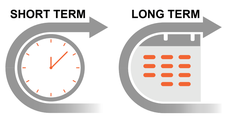
SCAN ME

Audio File

Background

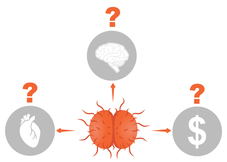


Neisseria meningitidis (N. meningitidis) is the gram-negative bacteria responsible for **Invasive Meningococcal Disease (IMD)**, a severe condition which is transmitted through respiratory secretions and saliva, and often leads to life-threatening outcomes[1].



IMD occurs as meningitis or septicemia with potentially profound short- and long-term consequences and even death.
IMD primarily affects infants and children[2,3].

Objective



To investigate the long-term physical, psychological, and financial burden of IMD in survivors and their caregivers in the United States (US).

Demographics

Participants included 11 survivors (mean age 36 years [range 14-51]) **and 3 caregivers** (mean age 58 years [30-60]). At IMD diagnosis, survivors were infants (n=2), children (n=3) or adults (n=6).

Methods

Cross-sectional, non-interventional, mixed methods (quantitative-qualitative) study conducted in **IMD survivors** (adolescents and adults) and their **caregivers**, living in the US.

Patient advocacy groups collaborated with recruitment and engagement.

Quantitative survey

Qualitative interviews using probes were conducted*.

*Following informed consent/assent, screening, and a pre-interview survey. Quantitative data were analyzed descriptively. Qualitative analyses used inductive-deductive methods. Institutional Review Board approval was obtained.

Key takeaways

1. Amputation appeared to be the most impactful sequalae (very severe impact reported in 4/7 amputees).

2. Substantial long-term costs included rehabilitation, specialized medical care, and prosthetics/hearing aids.*

3. Many survivors had concerns about insurance coverage.

4. Working-age survivors (8/9) cited full-time work challenges including physical limitations and memory issues/brain fog.

5. Caregivers experienced emotional distress and career impacts. The psychological burden of survivor's care persisted long after IMD onset.

*Requiring out-of-pocket expenditure

Results

All survivors described transitioning from "perfect/healthy/normal" lives to becoming "medically fragile" and reliant on others.

Direct quotes from survivors and caregivers are available in the supplementary materials (scan QR code).

Acute phase

Long-term sequelae, started during acute phase, reported by survivors included physical sequelae

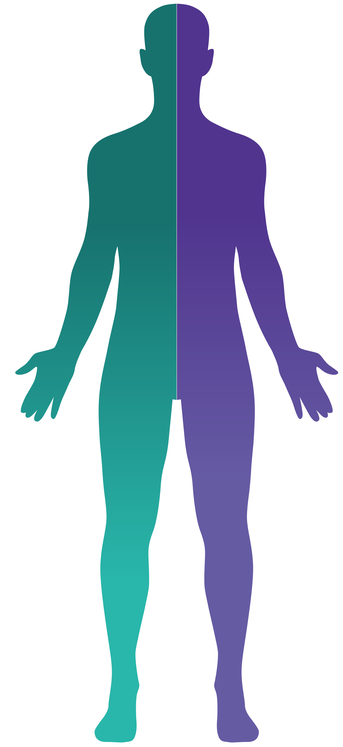
- Fatigue 55%

Neurological sequelae

- Light sensitivity 36%
- Numbness 45%
- Nerve related pain 27%

Systemic sequelae

- Musculoskeletal pain 82%
- Kidney issues 45%
- Repeat secondary infections 82%
- Balance issues 91%
- Difficulty walking 100%



Post acute phase

Most survivors reported

- 64% Memory
- 45% Attention
- 55% Sleep disturbances
- 91% Problems using devices (prosthetics/hearing aids)
- 82% Trauma/post-traumatic stress disorder
- 82% Worry
- 91% Social difficulties
- 91% Functional activities

Long-term sequelae reported by survivors included physical sequelae (difficulty walking [11/11], fatigue [9/11], balance issues [10/11]); neurological sequelae (numbness [5/11], nerve-related pain [3/11], light sensitivity [4/11]); and systemic sequelae (repeat secondary infections [9/11], musculoskeletal pain [9/11], kidney issues [5/11]).

Most survivors reported impacts on memory (7/11), attention (5/11), sleep disturbances (6/11), physical problems using devices (prosthetics/hearing aids) (10/11), trauma/post-traumatic stress disorder (9/11), worry (9/11), and social difficulties (10/11). Functional activities (10/11) were severely impacted.

Conclusion

IMD burden in survivors and caregivers is broad and with lifelong physical, psychological, and economic consequences. Prevention is key to mitigate the impact of IMD.

References

(1) Stein-Zamir et al. Human Vaccines & Immunotherapeutics, 2019;15(1), 242–248.
(2) Guedes S and al. BMC Public Health, 2022;22(1), 521.
(3) Pardo de Santayana, C. et al. Epidemiology and Infection, 2023;151, e57.

Acknowledgements

The authors give thanks to the survivors and caregivers who participated in the study and shared their stories, and acknowledge the American Society for Meningitis Prevention (previously the Meningitis B Action Project) (https://meningitisprevention.org/), The Emily Stillman Foundation, and The Kimberly Coffey Foundation patient advocacy groups for their valuable collaboration and guidance during study recruitment. Business & Decision Life Sciences Medical Communication Service Center provided editorial assistance and publication coordination, on behalf of GSK. Kavi Littlewood (on behalf of GSK) provided medical writing support.

Disclosures

OHR, ESC and ZK are current employees and shareholders of GSK. NA, MR, FG, RK, and OO are employees of IQVIA and conducted the analyses of this GSK-sponsored study. AS is the founder of the Emily Stillman Foundation and co-founder of the American Society for Meningitis Prevention. PW is the founder of the Kimberly Coffey Foundation and co-founder of the American Society for Meningitis Prevention. MR is consultant of the American Society for Meningitis Prevention. AS, PW and MR did not receive compensation for their participation in this study. The authors declare no other financial and non-financial relationships and activities.

Funding

GlaxoSmithKline Biologicals SA (study number 219353)

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