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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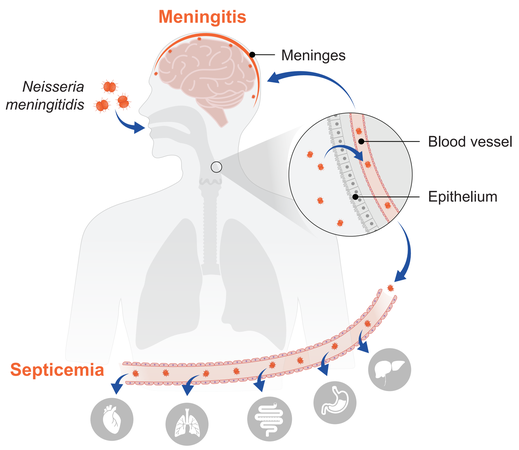
Digital poster
Supplemental data
Narrated summary

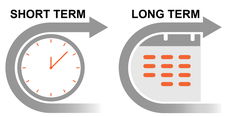
SCAN ME

Audio File

Background

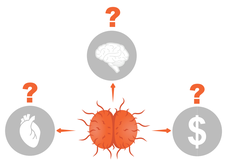


Neisseria meningitidis (N. meningitidis) is the gram-negative bacteria responsible for **Invasive Meningococcal Disease (IMD)**, a severe condition which is transmitted through respiratory secretions and saliva, and often leads to life-threatening outcomes[1].



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

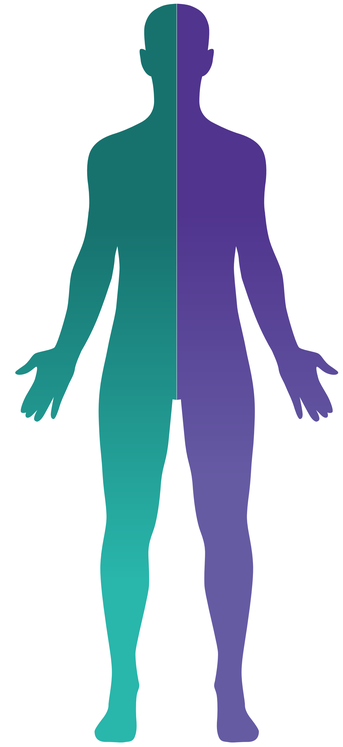
- Fatigue 55%

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

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Disclosures

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Supplemental materials

Topics covered by the PIS

Sections	Topics explored	Response options
IMD sequelae	Survivors, and caregivers (on behalf of survivors) were asked about long-term consequences (sequelae) of the disease such as amputation, hearing loss, cognitive deficits from a pre-specified list of sequelae derived from the conceptual model.	Response options include answers in form of 'yes' or 'no', hence data will be summarized for number (%) of survivors having sequelae. Questions on impacted life had response options from 'no effect' to 'major effect'.
IMD impacts	Impacts of IMD on various aspects of lives such as behavior, emotions, relationship. Further, impacted areas of work/education over the past month were also explored. In this section, caregivers were asked about their own lives and burden as a result of providing care to the IMD survivor. The last part of the survey captured HCRU over last year and frequency of the use.	Participants were asked to answer questions on a 5-point scale ranging from 'not at all' to 'extremely' for impacts. For work/ education and HCRU participants answered 'yes', 'no' or 'not applicable'.

HCRU: Healthcare resource utilization; IMD: Invasive meningococcal disease

Treatment	Supporting quotes
Lab work/ biopsies/scans	*PID 006: Yes. After going to the emergency room, they did **blood work**, but they also did **a biopsy**, a spinal tap.* *PID 008: Sure enough, I had several **MRIs,** and they couldn't find what was happening.* *PID 009: **Blood checks**, scans, a ton of testing. They were eventually going to do a spinal tap*
Medications (antibiotics, pain killers)	*PID 012: Pretty much close to that whole stay in ICU. I would say probably 20 days, maybe 21. I received an **experimental antiseptic drug** called Xigris, X-I-G-R-I-S. No longer on the market. At the time, it was in clinical trials for sepsis care. I got that too. I got blood transfusions. As far as other treatments, I mean, I had… Most of my hospital stay was in the burn and wound unit, where I got daily or almost daily debridement treatments, which is where they cut off the dead tissue from my arms and legs.* *PID 009: One of the first things they did was give me an IV. Then, they catheterized me. Then, they started taking me around for checks. Blood checks, scans, a ton of testing.* *They were eventually going to do a spinal tap; however, they gave me like **4 different antibiotics**, and 1 of the doctors said, "You know what, you don't need to do the spinal tap, because one of these antibiotics that she's on would cover the meningitis anyway, so there's no need to do the spinal tap.*
Amputations	*PID 001: Since then, because of the kidney failure and I **lost both my legs and most of my fingers** and the skin grafts and everything, I've had many, many surgeries. Like I'm not even exaggerating, over 100 procedures.* *PID 006: They amputated all **10 of my fingers** and they **amputated both of my feet***
Surgeries and grafts	*PID 012: And I had, believe, **at least 8 or 9 surgeries** while I was in patient there. I had amputations of all of my toes and 9 of my fingers. I had* surgery for skin grafting. *I had lots of inpatient physical therapy and occupational therapy when I wasn't either in surgery or recovering from surgery.* *PID 002: I was in bad shape. I can tell you that my arms and legs, my entire body was black, and they had… A plastic surgeon happened to be…one of my doctors as an infant who was there and immediately had started to try to **wrap my arms and legs in cadaver skin** to save my extremities, and I believe that was probably some of the process that took a while.*
Rehabilitation and therapies	*PID 015: I had some **mouth therapy, front throat therapy, swallow treatments**, and things from the ventilator. Plus, there were some issues where I had some neurological things that weren't working correctly, particularly swallowing.*
Nursing services	*PID 012: Nobody was coming into the home. Well, I shouldn't say that. At times, I needed IV antibiotics, and yes, the **nurse** would come into the home to administer the **IV antibiotics**, but other than that, I was not receiving home care.*

Symptoms experienced during the acute phase

Symptoms	Total reporting (n=14)	Total survivors mention (n=11)	Spontaneous	Probed	Caregivers mentions (n=3)
Skin rash (bruise)	9	7	7	0	2
Fever	8	6	6	0	2
Unconsciousness	7	6	5	1	1
Fatigue	7	6	4	2	2
Flu-like symptoms	7	5	5	0	2
Vomiting	6	5	5	0	1
Coma	5	4	4	0	1
Nausea	4	3	3	0	1
Headaches |migraines	4	4	4	0	0
Runny/stuffy nose	3	3	3	0	0
Neck stiffness	2	2	2	0	0
Swelling/ inflammation	2	1	1	0	1[1]
Muscle aches	2	2	2	0	0
Numbness	2	-	0	0	2
Floppy neck	1	1	1	0	0
Stiffness	1	1	1	0	0
Pins and needles	1	1	1	0	0
Itchy throat	1	1	1	0	0
Facial muscle paralysis	1	1	1	0	0
Inability to focus	1	1	1	0	0

1. Swelling caused by cellulitis

Immediate/short-term impacts

Immediate/short-term impacts	Total survivor mentions (n=9)*	Spontaneous	Probed
Impacts on functional activities	9	5	4
Needing assistance/relying on others	7	3	4
Emotional impacts	6	2	4
Fear	4	4	0
Trauma/shock	2	2	0
Confusion	1	1	0
School impacts	6	1	5
Self-perception/ psychological impacts	5	5	0
Financial impacts	5	0	5
Difficulty with self-care impacts	4	1	3
Work impacts	4	2	2
Difficulty planning/time constraints	3	3	0
Limitations of social activities	3	1	2
Body image impacts	2	2	0
Diet/eating impacts	2	1	1
Communication problems	2	2	0
Falling	2	1	1
Sleep problems	1	1	0
Speech problems	1	1	0
Difficulty swallowing	1	1	0
Memory problems	1	1	0

*Two survivors (PID 002 and PID 008) contracted IMD in infancy and were unable to self-report on short-term impacts of IMD.

References

(1) Stein-Zamir et al. Human Vaccines & Immunotherapeutics, 2019;15(1), 242–248.
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