

A large, stylized yellow fingerprint graphic that serves as a background for the main text. The lines of the fingerprint are concentric and form a shape that resembles a human head in profile, facing right.

Social and care experiences during and after mpox illness:

a qualitative study



Summary

What were our research questions?

- “What are the social and health experiences of people affected by mpox?”
- “How can people with mpox be better supported in healthcare?”

What did we find?

- Mpox was highly distressing, involving severe symptoms and difficult isolation periods.
- Beyond acute illness, there were longer-term social and physical long term effects from mpox.
- Most participants’ accounts portray negative experiences with healthcare providers.

Why is it important?

- People previously diagnosed with mpox may require extra considerations: trauma-informed approach and clinical support with scarring and other aftereffects.
- Vulnerabilities in health system capacity to provide culturally-appropriate care related to an unfamiliar disease outbreak linked to sexual practices and anogenital symptoms.

A perfect storm for stigma: gay and bisexual men's experiences of mpox

Krishen Samuel | 27 July 2023 | Estimated reading time 6 minutes



Dr Anthony Smith at IAS 2023. Photo by Roger Pebody.

- Presented late-breaker oral presentation at IAS2023.
← aidsmap write-up

Mpox in context

- The 2022 mpox outbreak is a consequence of global neglect of mpox and health in Africa.^{1,2}
- 2022 global mpox outbreak: 89,385 cases; 154 deaths.³
- 145 notifications in Australia, 0 deaths.³
- Early journalist accounts: inadequate pain management, experiences of stigma & discrimination, difficulties accessing care and isolating.^{4,5}
- A multi-country survey by WHO has documented similar experiences to journalist accounts.⁶
- Scarce published research focused on qualitative accounts of mpox illness and interactions with healthcare.

¹ Adetifa et al. (2023). The Lancet. ² Mitjà et al. (2022). The Lancet.

³ <https://www.cdc.gov/poxvirus/mpox/response/2022/index.html> [Accessed 25/08/23].

⁴ Ryan, Benjamin. (7th July 2022). [NBC News](#). ⁵ [WHO Europe](#). (15th July, 2022). ⁶ [WHO Europe](#).



“We always think it’s not going to happen to us” – a sexual health worker’s first-hand experience of monkeypox

Ethics approval:

UNSW Human Research Ethics Committee – HC220484

ACON Research Ethics Review Committee – 202214

Methods

- Qualitative methodology.
- 1hr in-depth interviews with people who had mpox & close contacts Oct-Dec 2022.
- 6-month 45m follow-up interviews with people who had mpox in April-May 2023.
- Eligibility criteria:
 - Living in Australia and 18 years or older
 - Diagnosed with mpox in or after 2022 OR a close contact*
*Close contact = sexual/romantic partner or living in same household.
- \$50 compensation to participants.
- Recruitment via ‘monkeypox survey’ and snowball sampling.
- Sample = 13 diagnosed with mpox, 3 close contacts.

Monkeypox Survey



<https://monkeypoxsurvey.org.au/>

MacGibbon et al. (2023). Sexual Health.

Participant Demographics

Participants diagnosed with mpox (N=13):

- Diagnosed 2022: July (n=8) or August (n=5).
- Likely acquired mpox: outside of Australia (n=11), in Australia (n=2).
- Location of isolation/care: outside of Australia (n=7), overseas (n=5), mix (n=1).
- Follow-up interviews (n=11).

Other key demographics:

- Close contacts (N=3) included partners (n=2) and housemate (n=1).
- All participants gay or bisexual cisgender men.
- All participants from Anglo/European ethnic backgrounds.
- Aged 25-56 years old; primarily in 40s.
- Living with HIV, on treatment and UVL (n=1).

Experiences of symptoms

- Varied experiences between ‘mild’ to ‘severe’ symptoms.
- Hospitalisation reported (n=3); another participant also recommended to present to hospital but declined due to fears of stigma.
- Concerns about visibility of lesions/scarring (e.g., on face, arms, genitalia).
- Difficulty managing symptoms exacerbated by negative experiences of care.

It would be the worst pain I have ever experienced in my life. It was extremely unmanageable. I was in tears. I was bleeding. Quite frankly, it felt and looked like my rectum was rotting or ulcerating away. (Miller)

I feel super lucky that I only ever had two blisters and there was nothing else that came of it. They got relatively big, [...] but I had it so mild, I feel so fortunate. (Matt)

Characterising care

- Dissatisfaction with care:
 - Inadequate pain management.
 - Perceived judgement about sexual behaviour.
 - Stigmatising experiences in hospital.
 - Focus primarily on lesions (and onward transmission) to the exclusion of other symptoms or issues of concern.
 - Challenges communicating with contact tracers.
- Positive experiences of care:
 - Non-judgemental attitude.
 - Empathy expressed (as simple as ‘how are you?’).
 - Moral blame for infection actively challenged.
 - Reassurance provided about distressing situation.
 - Proactive pain management.

Difficulties with contact tracers:

They were very poor at recording information, and at times I would say they broke privacy. [...] They had this overarching “I don’t believe what you’ve told me” [...] I felt vilified, victimised, felt like I was dirty, like I was not honest.
(Paul)

Experiences of care

Empathy and challenging moral blame:

This lady called from [Public Health] and she just said, “How are you?” and I started to cry. [..]
She said, “Look, this is not your behaviour. It’s a disease. It could be anyone,” and made me feel a lot better. (Calvin)

Appropriate and professional:

He honestly was the only one that acted like an actual doctor. He asked questions. He had gloves on, so he wasn’t afraid to touch me. The other ones seemed like they didn’t even want to get within breathing distance. (Johnny)

Sexual assault in an Australian hospital:

He wanted to do a rectal exam on me. [..] I was really reluctant because I really hadn’t consented, but he convinced me it was going to be fine. It was not fine. [..]
I cried. My vision went to like tunnel vision.
I was in so much pain. I was really unhappy. It seemed completely unnecessary. (Daniel)

Discrimination and inadequate pain relief overseas:

They put me in a side room. They catheterised me with no pain relief, which was horrific. [..] I got left in the side room for at least 6 hours, I was screaming in pain.
I honestly would’ve rather died. It was almost like being an AIDS patient back in the ’80’s. I felt so discriminated against. (Miller)

Long term effects

- For some, experience of mpox confined to acute illness period.
- Half the sample (n=7) reported longer-term issues:
 - Changes to sexual practices (reduced/avoiding sex)
 - Ongoing illness – fatigue or proctitis (improved over time).
 - Psychological distress related to pain or clinical care.
 - Concerns about major scarring.
 - Need for corrective rectal surgery (n=2).
- All participants reported concerns about the duration of post-infection immunity and whether vaccination is necessary in the future.

Shifts in self and future:

I feel like there's a portion of my life just cut away. [...] I'd lost all this weight when I came back from overseas, and now it all has gone back on. [...] I've been pushing people away that I would normally catch up with, I've probably become more of a hermit from it. (Paul)

Experiences of mpox aftereffects

Psychological distress:

It's still giving me trouble in terms of like social anxiety, nightmares, flashbacks. Every time I'm near the hospital, my heart rate goes up and I almost have a panic attack. It's like little things that I didn't expect all of this. (Daniel)

Reduced sexual practices:

I didn't want them to touch me at all. Like at all. I think it has messed up my mojo a little bit. (Leo)

Chronic fatigue (improved over time):

For about a month after I left isolation, it hits 3pm and I'm in a ball, literally in a ball shaking, just extremely fatigued [...] And the fevers and the body aches just still continuing, just going on and on and on. (Pete)

Rectal surgeries and complications:

I've just had surgery last week for a perianal abscess which they believe has come from the monkeypox scar tissue. We're waiting on results for really terrible proctitis [...] So, the pain and torture and the mindset has not changed. It's something I'm still having to deal with. (Miller, Nov 2022 interview)

It's been nearly a whole year of not having normal gastrointestinal function. The last 10 days I've actually had no pain, no fear, and had control of my bowels. It's been a very long road. (Miller, May 2023 interview)

Discussion

- Limitations: small sample across multiple health settings; lack of professional accounts on health encounters.

Implications:

- Follow-up care considerations with people with a history of mpox infection:
 - Trauma-informed care important given possibility of health-related distress.
 - May require support around scarring and other ongoing mpox sequelae.
 - Advice about immunity duration and vaccines?
- How do we ensure future responses to (re)emerging disease outbreaks focus on quality patient care, and are free of stigma?²
- Mpox reminds us that acute illnesses (especially related to sex / anogenital symptoms) can potentially have long term consequences for wellbeing.

Life after monkeypox: Men describe an uncertain road to recovery

Over a dozen men who contracted monkeypox talked to NBC News about their recoveries and the lingering effects of the skin lesion-causing virus.



¹ Ryan, Benjamin. (25th September 2022). [NBC News](#). ² Logie. (2022). Journal of the International AIDS Society.

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Community partners: John Rule (NAPWHA) and Dash Heath-Paynter (Health Equity Matters)

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Save the date

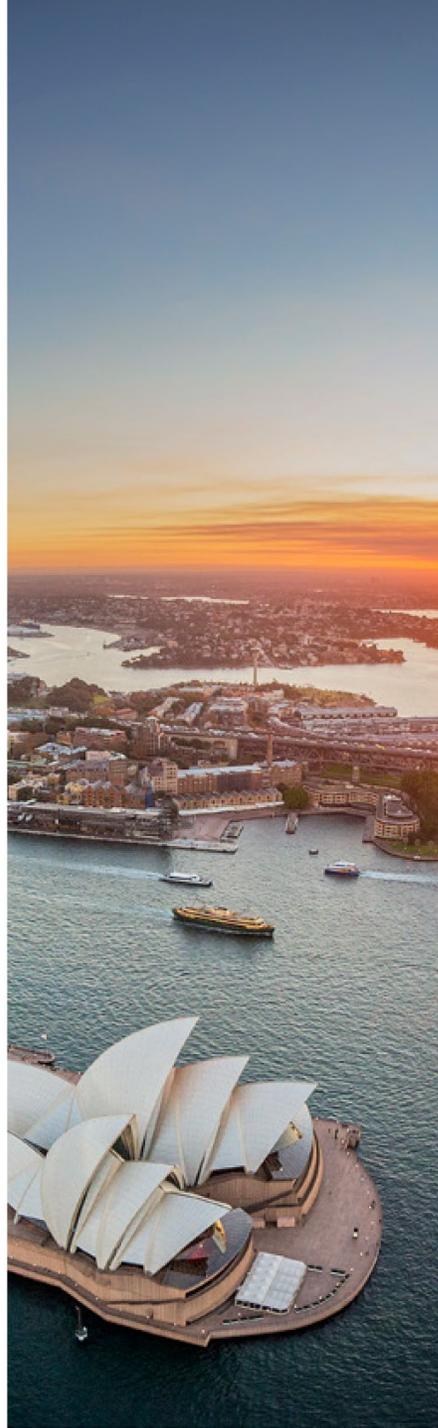
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Key dates:

Abstracts Open:
November 2023

Abstract Deadline:
3 March 2024

Registration open:
November 2023

**Early bird registration
deadline:** 19 May 2024

**Standard registration
deadline:** 31 July 2024

Website:

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