

“It was just the most horrible experience of my life” Understanding social and care experiences during and after mpox illness: Qualitative accounts of people diagnosed and close contacts in Australia

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Background:

In May 2022, a global outbreak of mpox emerged, with a small number of mpox cases (n=144) identified in Australia. This study sought to document in-depth qualitative accounts of the social, care, and health experiences of people directly affected by mpox.

Methods:

Semi-structured interviews were conducted between October-December 2022 with 13 people diagnosed with mpox living in Australia, as well as 3 close contacts (household or sexual partners). 6-month follow-up interviews were conducted in April-May 2023 with 7 participants, providing 23 interviews. Interviews were deidentified and thematically analysed.

Results:

All participants were gay or bisexual cisgender men. Most reported acquiring mpox overseas on holiday (n=11) in July or August 2022, and isolated or received care in Australia (n=8). Participants' experiences of mpox illness, diagnosis, care and recovery were highly distressing amidst the uncertainty of the outbreak, and severe symptoms and long isolation periods were difficult to manage. Physical symptoms were primarily confined to the acute illness period, but half of participants (n=7) reported longer-term social and physical sequelae from mpox, including continuing changes to sexual practices, ongoing fatigue, psychological distress, major scarring, and the need for corrective rectal surgery. Most participants diagnosed with mpox (n=10) reported dissatisfaction with clinical care, including challenging communication with contact tracers, perceived judgement about sexual behaviour, inadequate pain management, or stigmatising care in hospital. Participants expressed a desire for greater empathy from clinicians and contact tracers and more proactive pain management.

Conclusion:

Participants' accounts portray negative healthcare experiences during an unfamiliar disease outbreak. This study highlights potential vulnerabilities in health system capacity to provide culturally-appropriate care when responding to a disease that is

linked to sexual practices, anogenital symptoms, and requires pain management. The potentially enduring aftereffects of mpox, including physical symptoms and healthcare-related distress, suggest a need for attention to follow-up care.

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