

From diagnosis to living well with HIV: The pivotal role of peer support

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NAPWHA Stigma & Resilience Framework



Strategic Priority Action 1.3

**Support people with HIV
to build strong, flexible
and sustained social and
personal networks**



THE UNIVERSITY
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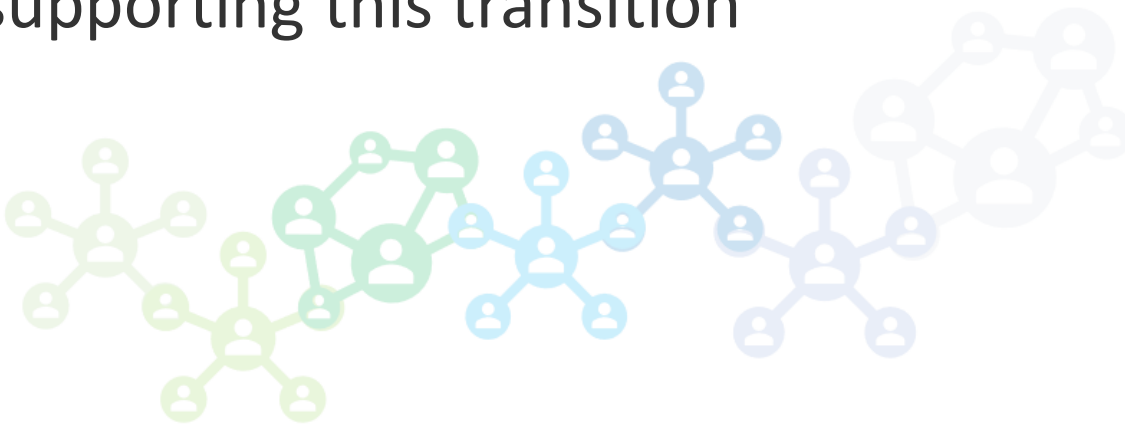
Create change

Research Aims

To explore recently diagnosed people living with HIV understandings and experience of support

To identify the networks that support the transition from HIV diagnosis toward self-management and living well

To highlight the contribution of peer networks in supporting this transition



Methods

The HIV Testing to Treatment Trajectory in Queensland Study

- Queenslanders recently diagnosed with HIV (<5 years)
- Diverse sample (n=40)
- Qualitative social support network mapping (sub-sample of 10)

Exploring the lived experience of HIV testing, diagnosis and treatment in Queensland today

Key support people (n=9)



How did recently diagnosed PLHIV experience peer support?

- Acceptance and non-judgement
- Maintaining stability
- Meaningful connections and solidarity
- Promoting physical and mental health
- Validating HIV positive status
- Encouraging personal growth and development

I don't want to be treated any differently than before (Dylan, 37)

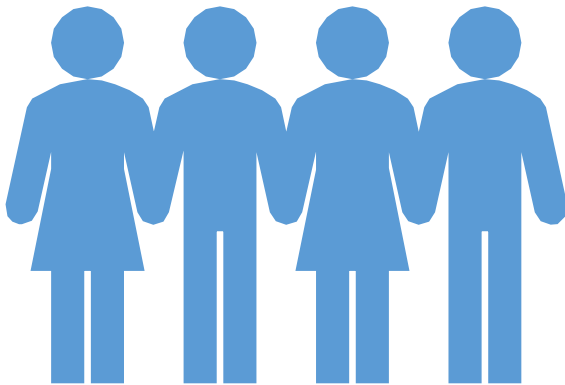
Just someone to help me get out of bed everyday (Rowan, 38)

Hearing somebody say 'I've been positive for years' and seeing they're healthy, I felt on top of the world (Ryan, 27)

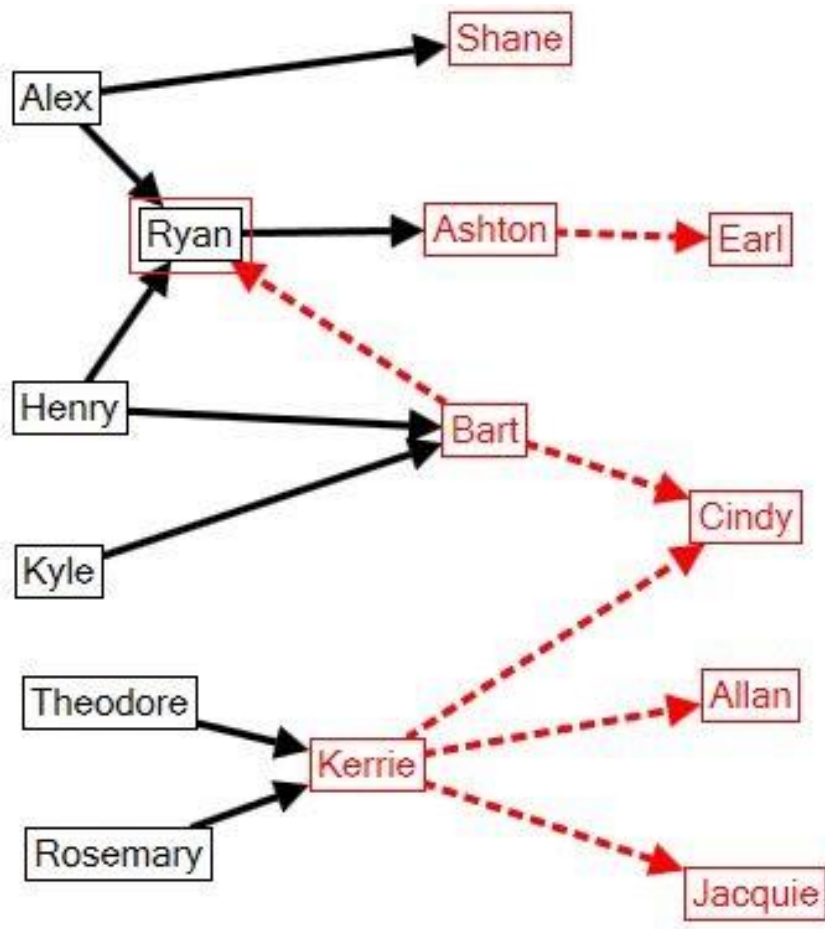
They saw I had all sorts of experiences in life and said 'Why limit yourself'? (George, 37)

How did recently diagnosed PLHIV connect with peer support?

- **QPP formal services**
Peer-led testing, Peer navigation, Newly Diagnosed Workshops, Treatment Support, Case Management
- **QPP informal events**
Social groups, barbeques, community events
- **Existing friends or acquaintances living with HIV**
- **The Institute of Many**
- **Apps and social media**
- **Positive Leadership Development Institute**



Interviews with key support people (peers and peer-led services)



Sampling and recruitment of key supports

- Participants nominated key supports and referred them to the study
- Key supports were in paid and voluntary roles
- Key supports bridged person-centred networks

| | |
|----------------------|----------|
| Peer Navigator | 3 |
| QPP Volunteer | 4 |
| Workshop facilitator | 1 |
| Case worker | 1 |
| Total | 9 |

What were the strengths of peer support networks?

Collective Support

- Many supporting many
- Safe spaces to be visible
- Bridging and expanding personal support networks

Flexible support

- Online or in-person
- Formal or informal
- Group or one-on-one
- Responsive to emerging needs

Reciprocal support

- Mutual benefits
- Powerful in validating lived experiences
- Motivated workforce

To be seen as someone who is positively living with HIV is my way of trying to break stigma down (Ryan, 27)

What were the complexities of providing peer support?



Diverse demographic and social contexts of recently diagnosed PLHIV



Differing needs and outlooks of recently diagnosed PLHIV



Secrecy and fear



Dealing with the fallout from stigma in mainstream settings



Managing personal health and wellbeing



Narrowly targeted and short-term funding models



Feeling under-valued in the context of mainstream health services

In the TasP era...



Peers support networks are a valuable resource for recently diagnosed PLHIV



Tapping in to peer support can strengthen personal networks



One size does not fit all



Flexible modes of peer support allow PLHIV to tap in or out when needed



Investing in peer networks will help to build and strengthen them



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Recommendations

- Upscale HIV education in mainstream settings
- Expand formal multidisciplinary healthcare teams to include peers
- Both formal and informal peer support networks must be funded and promoted

Thank you

The T2TQ participants

(names are changed to protect anonymity)



HIV Foundation QLD



Research partners

APA Scholarship

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