

Why they do not tell

- Many reported a period of denial and self blame following diagnosis
- Factors that influenced participants' disclosure
 - Level of trust in relationship & whether they thought person would tell others
 - Reason for disclosure – does the person need to know?
 - Person's level of knowledge
 - Perceptions about whether person would be judgemental
- Disclosure is a staged thing for most people – as they feel better informed & have greater acceptance of the infection, they are better able to deal with other people's questions following disclosure
- Participants experienced a range of difficulties disclosing their positive status to partners, family, friends
- "I told my partner straight away...she was more upset than I was, so you have to handle other people's upset as well...it is still difficult and emotionally traumatic"(five months later)
- I haven't told my mother...I am being protective of her and also I don't want her to know about my life...it makes me feel vulnerable"
- Many people who are infected are unaware of their rights in relation to anti-discrimination and privacy laws.
- Many reported judgemental attitudes and breaches of confidentiality when the disease status was disclosed in health settings and the workplace.
- "there's a lot of focus on how you got it at hospitals"
- I had a big run in with the dentist...he told me to make appointments in the future at the end of the day as it took longer to clean up after me...I haven't had my 6 monthly call back and I won't go back there anyway"
- "I have not told my employer as I don't want to risk losing my job"
- I haven't had too much control over who has been told in the workplace...people have been told without my consent"
- I had to invent an alternative story...not lying, but omitting some things...just saying I've got a liver condition"
- Participants felt the lack of community awareness about their disease contributes to the fear and stigma
- The disease is not taken seriously by healthcare workers
- These diseases remain largely hidden in the community, which impacts on people's ability to accept the virus & manage it in their lives.
- Significant proportion of people are from marginalised groups, who have:
 - experienced some form of social dislocation
 - have few personal resources
 - low self esteem
 - low expectations of being able to effect positive changes in their lives
 - a lack of trust in health services

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