Becoming a Buddy: Accordance and Incompatibility in the Hepatitis C Peer Support Role

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Disclosures

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Background

- Peer support is increasingly recognized as an important element of HCV healthcare delivery for PWID.
- But the parameters of the peer role for PWID who are at risk of, or living with, HCV are not well established.
- To inform better HCV peer support policies and practices there is a need to establish what a peer is in the context of its key relations.

Methods: HepCATT Qual.

"Evaluation of interventions designed to increase diagnosis and treatment of patients with hepatitis C virus infection in primary care and drug treatment settings".

- HepCATT: Hepatitis C Awareness Through to Treatment
- 3 UK drug treatment services. Intervention: HCV facilitator; provider education; HCV testing; streamlined treatment pathways; peer educators & buddy system.
- Qual – pre & post intervention (interviews, focus groups) at 2 sites
  Aim: to inform & assess the intervention, with focus on peer component.
- Pre-intervention:
  - PWID (n=35): 4 focus groups, 9 interviews.
  - Drug service and intervention providers (n=22): 2 focus groups, 9 interviews.
- Post-intervention:
  - PWID (n=13): 1 focus group, 8 interviews.
  - Drug service and intervention providers (n=26): 4 focus groups, 10 interviews.

96 participants in total.

Defining Peers and Buddies

- Pre-intervention, a role distinction was established:

Peer Educator:

- Someone who has experienced HCV.
- Tasked with delivering training to stakeholders (e.g. Homeless shelter staff) and service users by talking about their experiences of testing / treatment.
- Imparts five key HCV 'facts' in line with The Hepatitis C Trust training

Buddy:

- Someone who can sympathise with client's situation and share experiences, but not necessarily have experienced HCV
- Meet client for coffee and a chat at drug centre or elsewhere
- Accompany clients to testing and treatment if desired

- We explored the parameters of these roles with participants …

Commonalities in anticipation

- Participants (PWID, prospective peers & buddies, drug workers) had some common expectations when anticipating peer & buddy roles.
- Peers and buddies are expected to:
  - Be in a position to share their experiences (drug use, HCV treatment)
  - Understand the situations of PWID and other service users
  - Have good knowledge of HCV (but not necessarily experience)
  - To 'just be there' and assist with key practical tasks (eg. appointments)
- Key attributes: honest, trustworthy, reliable, passionate, motivated, self-confident, accepting, empathic, reassuring, informative, communicative & proactive.

"I tell my own story, my life story … My role is to inform people about the fact that this disease is out there and that it can kill. I've got five points to get across. And then to get people to feel a little bit more reassured that there is light at the end of the tunnel if they go for treatment" (Peer, Site B)

Tensions in relation

- Who gets to be a peer/buddy?
- Drug service managers consider people who have 'recovered' from drug dependency – 'Recovery Champions' – to be ideal peers/buddies:
  - CRB-checked, experienced volunteers who present reduced risk in terms of their potential to over-step boundaries in relation to other service users.
  - Have experience of what the organization values/ prepared to adhere to this.
- Recovered status can come before experience of HCV:

"I started off as a recovery champion … [x] approached me about HepCATT … I didn't know anything about hep C, I don't know anyone that's had it" (Buddy, Site A)

- Or drug use: *"A peer doesn't have to be someone who has been drug using it could be anyone" (Provider, Site B)*
- Tensions in relation – re service user expectations, such as 'empathy':

"I haven't buddied anyone so far, I have one ready to go, she's very obstructive towards anyone, she's a pain"; "living in a world of chaos"; "dirty"; "unhygienic" … (Peers & Buddies, Site B)

'Governing the peer's heart'

- Service users & peers want peers / buddies who are *'doing it from the heart'*

"I just think it's come deep from the heart with someone who has been on heroin" [SU, Site B]; "You've just got to have a little bit of understanding, have a heart."[Buddy]

- But peers and buddies were constituted and governed through organisational practices so they could not freely engage with users:

"[Training includes] safeguarding, confidentiality, customer service, general health and safety. They're given an overview of what you should be like in a professional environment, even down to the things you should wear" [Keyworker, Site A]

- Drug centre management anxieties → produced/sustained peers and buddies best suited to fulfill organizational policies.

"[they have to] give something back, but with[in] boundaries" [Keyworker, Site B]

- Some internalisation of risk-averse discourse by peers and buddies:

"Boundaries can become blurred. Physically taking someone in your car to appointments, there's a risk" [Buddy, Site B].

Bonding vs boundaries

- In contrast to providers, service users wanted peers/buddies to escape an organisational role, and be people they could relate to on a personal level.
- However, some reluctance from peers & buddies to build personal relationships: *"Its about boundaries, safeguarding …A lot of service users could misinterpret your support. They've never had a friendship ...So you've got to be careful." (Peer, Site A)*
- Peers and buddies felt that **trust** was important in their roles: *"[clients] have got to be able to trust the fact that you are a genuine safe person to travel with. They've got to feel that they can talk to you." (Peer, Site B)*
- Yet, this conflicted with boundary concerns – ie regarding sensitive disclosures. In this respect, 'trust' was not complete, and bound by organisational rather than personal limits: *"If I feel it's a danger or safeguarding issue, or anything like that, I will speak to someone about it, make no bones. So if you've got anything like that you don't want me to hear then don't tell me." (Peer, Site B)*

A search for legitimacy

- Through clinical responsibilities
  - Some buddies, peers and service users think they should be trained in HCV testing
  - Providers and clinical staff less keen as they believe it blurs boundary between peer and a keyworker or nurse, which they wanted to remain.
- Are peers and buddies workers?
  - Peers and buddies saw their roles as *'a proper job'* although they wanted options for being paid and obtaining professional accreditation.
  - Most peers/buddies aspired to be a Keyworker:

"I would be lying if I didn't say that I would want maybe to get employment in this area or keep working in this area after the project" (Peer, Site B)

  - Peers and some keyworkers felt that funding peers would increase applications, retention and improve future job prospects.
  - However, service users seemed most concerned that the role was voluntary and therefore more authentic and trustworthy:

"If I walked in here and somebody was working here voluntarily, willing to take every day out of their own time to talk to people about hep C, about taking drugs and things like that, I'd respect them a lot more than anybody sat behind that desk" (Service User, Site B)

Discussion

- Much agreement between clients, drug service & intervention providers on what peers & buddies should be as *decontextualised* entities.
- However, there are tensions when they are placed *in practice* and in *relation to other roles* and *organisational responsibilities*:
  - Who can become a peer or buddy was limited by drug service organisational frameworks.
  - Peers' adherence to organizational structures can create tensions with service user expectations: boundaries are often rigid rather than flexible.
  - In part, this was due to a search for (& lack of) legitimacy, with peer work often viewed as a step towards paid employment in the service.
- Peer involvement often posited as unproblematic – a 'good thing' yet its efficacy can be constrained by organizational structures and boundaries – especially regarding who is deemed to be 'a peer'.
- Acknowledging (and working with) different stakeholder perspectives on what a peer is will be key for successful interventions.

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