

DEVELOPING PATIENT REPORTED OUTCOME MEASURES FOR HCV DAA TREATMENT AMONG PEOPLE WHO INJECT DRUGS: WHAT ELSE BESIDES “CURE”?

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Background:

DAA therapy for HCV provides the biomedical promise of ‘elimination’ with key measures being rates of “cure”. Cure is obviously an important measure, but represents only a single aspect of an experience that can be complicated and multi-faceted. This project examined “patient reported” experiences and outcomes of DAA treatment for people who inject drugs (PWID) to examine factors beyond “cure” that are important to participants and which could impact on treatment goals.

Methods:

Semi-structured interviews (n= 24) were conducted with four groups of PWID who live with HCV: (1) people who are considering DAA treatment; (2) people who are currently undertaking DAA treatment; (3) people who have completed DAA treatment (6-12 months post-treatment); (4) people who have refused or delayed DAA treatment.

Results:

Participants’ comments on treatment experience focused on issues such as venous access and the requirements for blood tests, support from clinicians to understand various decisions (such as impact of genotype and other health conditions on choice of medication and length of treatment) and the attitude and behaviour of clinic staff in relation to drug use. The outcomes of treatment noted as important by participants included: physical effects (less fatigue and feeling “more enthusiastic about life”); social connections (being able to consider intimate relationships and feeling more relaxed about interactions with family in relation to HCV risk); and, changes in identity (feeling relieved to lose the HCV and drug user “label” as well as feeling “lost” without this identity). Provision of information was patchy, especially information regarding post-treatment care for ongoing liver disease.

Conclusion:

Factors beyond cure need to be considered in monitoring the experience and outcomes of HCV DAA treatment for people who inject drugs. The findings from this qualitative study are being used to develop patient reported measures to monitor outcome and experience.