



Research Paper

Caring and curing: Considering the effects of hepatitis C pharmaceuticalisation in relation to non-clinical treatment outcomes

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ABSTRACT

Background: The development of simplified and effective hepatitis C (HCV) pharmaceuticals enables treatment scale up among the most marginalised. This potentiates a promise of viral elimination at the population level but also individual level clinical and non-clinical benefits. Reports of transformative non-clinical outcomes, such as changes in self-worth and substance use, are primarily associated with arduous interferon-based treatments that necessitate intensive care relationships. We consider the implications of simplified treatment provision in the era of direct acting antivirals (DAAs) for the realisation of non-clinical benefits.

Methods: We draw on qualitative data from ethnographic observations and longitudinal interviews with people receiving (n = 22) and providing (n = 10) HCV treatment in London during a transition in HCV biomedicine. First generation DAAs in conjunction with interferon were standard of care for most of this time, with the promise of simplified treatment provision on the horizon.

Findings: Patient accounts of care accentuate the transformative value of interferon-based HCV treatment derived through non-clinical benefits linked to identity and lifestyle change. Such care is constituted as extending beyond the virus and its biomedical effects, with nurse specialists positioned as vital to this care being realised. Provider accounts emphasise the increased pharmaceuticalisation of HCV treatment; whereby care shifts from the facilitation of therapeutic relationships to pharmaceutical access.

Conclusion: HCV care in the interferon-era affords identity transformations for those receiving and providing treatment. Biomedical promise linked to the increasing pharmaceuticalisation of HCV treatment has disruptive potential, shifting how care is practised and potentially the realisation of non-clinical treatment outcomes.

Introduction

Pharmaceutical development in the hepatitis C (HCV) field has led to the increasing availability of direct acting antiviral (DAA) treatments – more efficacious and less toxic than previous interferon-based combinations. This “therapeutic revolution” (Rice & Saeed, 2014) holds great promise for scaling-up HCV treatment provision, particularly for key populations most marginalised from treatment such as people who inject drugs (PWID). This is important, not only in relation to realising a vision of HCV elimination, but for the transformative benefits that HCV treatment can potentiate. A nascent literature, situated in the interferon-era, indicates various non-clinical HCV treatment benefits among PWID, such as reductions in substance use and positive identity re-configurations. The advent of second-generation DAA treatments marks a shift away from the intensive therapeutic engagements of difficult interferon-based treatments to the relatively simple delivery of all-oral pharmaceuticals. In this paper we draw on qualitative data generated

with patients and providers during a transition in HCV treatment provision in the UK, to explore the how shifts in the provision of care may impact on non-clinical treatment outcomes in the DAA era.

The trajectory of HCV treatment commenced in the early 1990s with the use of interferon-based regimes. Interferon requires subcutaneous injection and is associated with a variety of adverse effects. Treatment regimens are typically long (24–48 weeks), arduous and only 50–70% effective. The development of first generation NS3/4A protease inhibitors in 2011 marked the beginning of the DAA era (Burstow et al., 2017). Used in combination with interferon, these early DAAs improved viral clearance rates but compounded treatment toxicity. Second generation DAAs, variously approved for use from 2014, mark a ‘revolution’ in HCV biomedical advance (Asselah, Boyer, Saadoun, Martinot-Peignoux, & Marcellin, 2016; Rice & Saeed, 2014). Highly effective, with limited toxicity, these all-oral regimes have supplanted interferon-based combinations as standard of care for HCV treatment.

DAA biomedical advance has implications not only for HCV

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treatment acceptability and uptake, but for the provision, location and social relations of care. Traditionally, HCV treatment has been the provenance of the specialist and tertiary sector, given the complexity of interferon side effects and associated need for regular monitoring. While some multidisciplinary drug treatment services were able to offer HCV treatment in the interferon-era (Aspinall et al., 2013), the advent of simplified DAA regimens enables an increased democratisation of access – with provision also expanding to general practice (Facente et al., 2018; Kattakuzhy et al., 2017; Norton et al., 2017) and pharmacy settings (Radley, Tait, & Dillon, 2017). Australia provides a case example. In March 2016, DAA treatments were listed on the Government Pharmaceutical Benefits Scheme, enabling ‘universal’ unrestricted access and provision through non-specialist prescribers. From March to December that year, the proportion of individuals prescribed DAA treatment by a general practitioner increased from 8% to 31% (The Kirby Institute, 2017).

Treatment provision in community settings acts upon a primary barrier to access, given that many PWID perceive hospital-based care to be punitive and inflexible (Harris, Martin, & Rhodes, 2013; Treloar & Rhodes, 2009). Other barriers such as interferon toxicity and regular monitoring requirements are also ameliorated by DAAs – enhancing opportunity for treatment scale-up among PWID and other marginalised populations. This biomedical promise feeds a public health narrative of hope of a society without HCV. With DAA regimens replacing interferon-based treatments, HCV elimination becomes a pragmatic possibility (Grebely & Dore, 2014; Rice & Saeed, 2014). DAAs are presented as overcoming the complexities of living and caring with interferon, and the challenges these imply regarding access, adherence and clinical outcome. The image of DAAs as the pharmaceutical solution to the social problem of HCV acts to reposition those most-at-risk and most marginalised from care as critical to potentiating elimination impact at the population level. An elimination agenda rehabilitates PWID as a treatment priority population; but in relation to their potential as HCV ‘transmitters’, rather than as individuals deserving of care (Fraser & Moore, 2011; Harris, Albers, & Swan, 2015).

Interferon-era research makes an alternative case for treatment access – illustrating the transformative potentials of HCV treatment for individuals, over and above population-based measures of morbidity, mortality and transmission reduction. These ‘non-clinical’ treatment outcomes include the reduction of unsafe injecting practices, reduction or cessation of drug and alcohol use, improved employment, housing and education opportunities, and movement away from restrictive and stigmatising ‘addict’ identities (Batchelder, Peyser, Nahvi, Arnsten, & Litwin, 2015; Clark & Gifford, 2015; Harris et al., 2015; Harris, 2017; Maticic et al., 2014; Newman et al., 2013; Rance, Treloar, & Ethos Study Group, 2014; Rhodes, Harris, & Martin, 2013). The way in which HCV treatment facilitates these changes is variably unpacked in the literature, but broadly relates to three interconnected themes: experiencing therapeutic care; persevering through an arduous therapy; and performing patient citizenship. All appear intimately connected to the properties and practices of interferon treatment, and thus may be subject to change in the DAA-era.

Unpacking non-clinical treatment benefits in the interferon-era

The particularities of the pharmaceutical interferon inform a particular social dynamic in HCV treatment delivery. A crucial challenge is how to support patients – primarily people with a history of drug use – in their engagement with an arduous treatment in a context of lives often shaped by difficult social conditions (Butt, Paterson, & McGuinness, 2007; Harris et al., 2013; Treloar & Rhodes, 2009; Treloar, Rance, & Backmund, 2013). The provision of social support through intensive and ongoing therapeutic relationships is an important feature of such care (Sublette et al., 2015). Newman et al. (2013) document HCV treatment uptake and outcomes among 34 current and former PWID attending a community-based, multidisciplinary health centre.

Current injecting and psychiatric co-morbidity was not a contraindication to HCV treatment access. The 14 men who commenced treatment reported reductions in injecting equipment sharing and improvements in social and psychiatric stability – irrespective of treatment outcome. The authors position these outcomes as related to the intensive therapeutic care on offer during HCV treatment, including benefit and accommodation support. For Batchelder et al. (2015), participant psychological and behavioural transformations were enabled through an integrated package of HCV care, including peer support and group therapy. Rance et al. (2014) illustrate how the introduction of HCV treatment in drug treatment services acted to break down some of the entrenched dichotomies and hostilities characterising the methadone encounter. Here HCV treatment enabled a more holistic site of provider-client interaction, one that no longer locked clients into an ‘addict’ identity.

The rigors of interferon-based treatment – highly toxic, lengthy in duration – present a personal challenge (Hopwood & Treloar, 2005). Treatment difficulty, and the promise of viral clearance that it affords, is pivotal in patient accounts of their transformative hopes and experiences (Clark & Gifford, 2015; Harris, 2017). Patients’ sense of pride and accomplishment is closely linked to treatment experienced as a ‘personal trial’ (Clark & Gifford, 2015). It is something to be worked at and worked through and coincides with the patent citizenship work undertaken by many PWID to make their treatment access opportunity (Rhodes et al., 2013). Often cast as ‘not-yet-citizens’ whose access to HCV treatment cannot be assumed, PWID are required to present themselves as good patient citizens ‘deserving’ of interferon treatment (Clark & Gifford, 2015; Fraser & Seear, 2011; Rhodes et al., 2013). This involves demonstration of the self as sufficiently responsible and trustworthy, as committed to a trajectory of addiction recovery, and as able to adhere to rigid appointment protocols linked to a treatment which can feel worse than going untreated. In this way, engaging with interferon treatment can be seen as a project of citizenship, with the personal elimination of HCV diminishing the power of a discredited ‘addict’ identity and affording hope of social re-inclusion (Fraser & Seear, 2011; Harris, 2017; Rhodes et al., 2013). As patients and providers of HCV treatment navigate transitions in HCV biomedical treatments in a post interferon-era, it is important to consider how scaled-up DAA treatment provision might impact on the realisation of care relationships and non-clinical outcomes.

Approach

We draw on three orientating concepts in this analysis: care; pharmaceuticalisation; and patient citizenship.

In the UK, where this study is based, interferon-era care and monitoring were largely the domain of the clinical nurse specialist (CNS). Transformative HCV treatment outcomes have been linked to intensive therapeutic relationships and nursing care (Batchelder et al., 2015; Newman et al., 2013; Rance et al., 2014). Care is referred to as the core or the essence of nursing (Morse, Solberg, Neander, Bottorff, & Johnson, 1990), yet what this care comprises and how it is defined is subject to ongoing debate (Våga, Moland, Evjen-Olsen, Leshabari, & Blystad, 2013). In considering what constitutes ‘care’ and ‘good care’ in the context of the HCV treatment encounter, Annamarie Mol’s work offers a starting point. For Mol (2008), care is relational and process orientated – it is concerned with the values and specificities of practice. She positions this ‘logic of care’ as distinct from a ‘logic of choice’. Whereas a logic of choice is individuated and end-point orientated, based on the weighing-up of pros and cons in relation to a priori evidenced outcomes, care is not universally measurable but performed locally and materially. Mol asks us to observe what is “sought, fostered, or hoped for” in the specificity of the care practice; what is “performed as good” while also attending to what is “avoided, resolved, or excluded”; what is “performed as bad” (Mol et al., 2010:12). In doing so, we are required to entertain ambiguity – as with logics of care and choice, performances

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