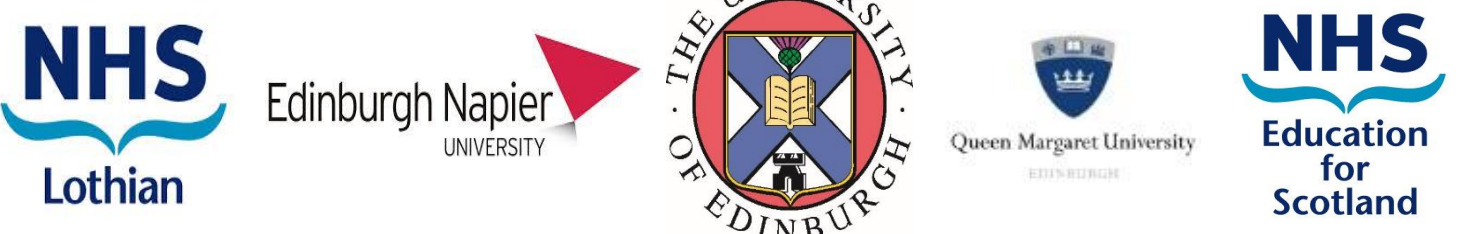


The Lived Experience of Interferon-free Treatments for Hepatitis C: A Thematic Analysis

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This work was completed as part of a doctoral research degree funded by the Clinical Academic Research Career (CARC) scheme. The CARC scheme is a collaboration between



BACKGROUND AND AIM

Recent years have witnessed a rapid evolution in the treatment options available for people living with the hepatitis C virus (HCV). The summer of 2011 signalled the beginning of a new era in the fight against the disease, with the first direct-acting antivirals (DAAs) entering clinical practice in many high-income nations. Swift pharmacological developments have resulted in second generation DAA regimens which no longer require the notoriously unpleasant drug interferon to be part of standard treatment¹.

To date, there has been no qualitative exploration into the experience of taking these interferon-free therapies. The prevailing discourse surrounding these new treatments emphasises their ease and tolerability². However, this understanding is largely based on the results of quantitative health-related quality of life measures³, which provide little context as to how an ‘easier’ treatment is actually experienced, and what it means for those taking the medications. The aim of this study is to explore how interferon-free HCV therapies are experienced and contextualised by individuals undergoing a period of treatment.

METHODS

The study design comprised 16 in-depth, face-to-face, semi-structured interviews with eight participants, before and after their period of HCV treatment. Participants were purposefully sampled from an infectious diseases outpatient clinic based at a university hospital in Scotland. Inclusion criteria consisted of being aged 16 years or over, diagnosed with HCV for more than six months, and able to converse in English.

All interviews were conducted between June 2015 and March 2016, and lasted a mean duration of 40 minutes. Topic guides were used, however, the semi-structured approach allowed participants the freedom to talk about their personal experiences as they wished. All interviews were conducted by DW, a registered nurse with ten years’ experience and who had worked as an HCV nurse specialist between 2009-2013. The interviews were recorded, and field notes were made upon completion and added to a research diary. Audio-files of the interviews were transcribed verbatim by DW, during which any patient identifiable information was obscured from the narrative.

Six phases of thematic analysis guided the analytical process⁴. Each transcript was initially read and reread, and coding was conducted using NVivo v.10 software. Codes were combined, reviewed and revised, a process which drew groups of codes together to form a number of sub-themes. Whilst depicted as a linear progression, the interviewing, transcribing and coding process occurred in parallel, with each activity informing the others. This iterative process aided the identification of data saturation; no new codes were created during the coding of the final two transcripts.

The sub-themes were then combined into candidate themes which were examined in relation to the corpus of data, field notes, and the research diary. During this process, all four authors met regularly to review, challenge and interrogate the evolving analysis.

The study was approved by the South East Scotland NHS Research Ethics Committee 01 (15/SS/0010). All participants were offered a £15 supermarket gift voucher for each interview they completed in line with national guidelines.

Table 1: demographic information for the eight participants

Gender	Male	6
	Female	2
Ethnicity	UK	6
	Other	2
Age	0 – 39	1
	40 – 49	2
	50 – 59	5
Opioid substitution therapy	Yes	3
	No	5
Mode of acquisition	Injecting drug use	5
	Other	3
Date of diagnosis	Up to 2011	4
	2011 and after	4
Degree of liver disease	Pre-cirrhotic	6
	Cirrhotic	2
Previous interferon-based HCV treatment	Yes	2
	No	6

NOTE: Whilst all participants received interferon-free treatment, they did not all receive the same drug regimen. A variety of factors resulted in the use of four different treatment regimens among the eight participants: Sofosbuvir/ledipasvir; Ombitasvir/paritaprevir/ritonavir + dasabuvir; Sofosbuvir + daclatasvir + ribavirin; Glecaprevir/pibrentasvir.

RESULTS

The characteristics of the sample are shown in table 1. Each individual participated in two interviews, pre- and post-treatment, with no participant drop out. The themes which resulted from the analysis: ‘expectations and realisations’; ‘an honour and a pleasure’; and ‘treatment needs’, will now be examined.

Theme: Expectations and realisations

Despite each participant receiving an interferon-free regimen, the discourse surrounding treatment expectations was entangled with societal understandings of interferon-based therapy. The influence of the drug that defined HCV treatment for over 20 years was prominent within the narratives:

“...I mean, if I spent three months of feeling a bit groggy, tired and miserable and I come out in the end, with err, you know, with err, good err, blood, err then it’s, you know, it’s worth that sacrifice...”

(John, multi-tablet regimen)

Common side-effects of interferon were referenced explicitly as expectations for interferon-free treatments, with discussion of practical preparations to forestall the impact of these perceived inevitabilities commonplace. For Stewart, the strength of his beliefs around the detrimental effect of treatment on his wellbeing was demonstrated in the meticulous planning that accompanied his first dose of the drugs:

“First tablet, went home, sick bowel, towel, duvet, tissues, waiting for it to come on (...) I prepared ready to be sick, I’d, I’d sent my partner away in case I was, really ill, know, kind a’, I don’t want a’ be sick or, or screaming at people. I thought I was gonna be agitated, angry...”

(Stewart, single-tablet regimen)

For the majority of participants, the realisation of their worst fears did not materialise, although a discourse surrounding physical side-effects did become evident. These were rarely stressed or emphasised, however, more commonly mentioned in passing or casually alluded to as minor inconveniences.

In addition to physical side-effects, a number of participants also related accounts of low mood and transient depression during treatment, however potential explanations for these ailments encompassed more than the pharmacology of the drugs. Emotional strain grew from the importance participants placed on being cured of HCV. The physical act of taking HCV therapy brought the disease to the forefront of participants’ minds, and meant confronting a reality many had previously been able to put to one side:

“...it’s got a lot to do wi’ the mental side of it like, y’know, because you’re really wanting this treatment a’ work an you’re conscious of it, you’re conscious of always being on this treatment, so likes, when I wasn’t I, I’d forget about it for months, I forgot all about I had hep C.”

(Steve, multi-tablet regimen)

Theme: An honour and a pleasure

The majority of participants related a largely positive and favourable account of their treatment, constructing their experience of interferon-free therapy as physically undemanding and relatively straightforward:

“I’d, six o’clock at night, come home, have my dinner, take my inhaler, take my tablet, ten o’clock – bed. Nothing. Nae, nae disruption whatsoever. Absolutely fantastic...”

(Stewart, single-tablet regimen)

Whilst the participants’ narratives were chiefly positive in tone, a perception that they had been fortunate or lucky to access these treatments underpinned the discourse. Those with histories of drug use described feeling guilty at what they perceived as their good fortune in being prescribed these expensive drugs, underlining an understanding that interferon-free therapy was not available to everyone, but a privilege and an honour. The price-tags of these medications were not only discussed in relation to other treatments for HCV, but also in the context of distributive justice within other diseases:

“It makes me feel...bloody privileged, ‘cause, y’know what I mean, ‘cause...no’ many people are getting that, I mean there’s people out there that’ve got cancers an’ stuff an’ they’re getting knocked back for treatments that cost that much.”

(Keith, single-tablet regimen)

Theme: Treatment Needs

The belief that HCV treatment should be an onerous undertaking, rather than a straightforward and undemanding process, constructed a compelling discourse relating how participants subsequently searched for signs and indicators that their treatment was working. A need to substantiate the efficacy of the drugs permeated the participants’ narratives, shaping a perception that side-effects were almost desirable and advantageous:

“...when I came after four week I ask [the HCV nurse], she said do you feel anything? Are you tired or this? An’ I say no, I say actually sometime I think I’m on a placebo, because there is no any effect at all.”

(Peter, single-tablet regimen)

The hunt for side-effects was not the only method by which markers of efficacy were sought. The importance to participants of hearing how they were progressing through treatment from healthcare professionals also became a recurring refrain. The significance of hearing blood-test results detailing the downward trajectory of the HCV viral load was repeatedly emphasised, situating them as beacons of reassurance, hope and motivation. In addition, a couple of participants described a further instinctive approach to evaluating the effectiveness of treatment: they simply felt better whilst taking it than they had previously.

For those with a history of drug use and recovery, support remained an expected, integral and essential component of the HCV treatment package, irrespective of the HCV drug combination or ease of therapy. The experience of HCV therapy was shaped by an expectation that support would be available, and a high degree of importance was placed on obtaining the utilising it rather than relying on existing networks:

“Even with the new treatment, I think you need that support there (...) Jus’ someone saying here, there you go, like you would at your pharmacy an’ no’ having any - I think that puts people on an illusion of fear”

(Gary, multi-tablet regimen)

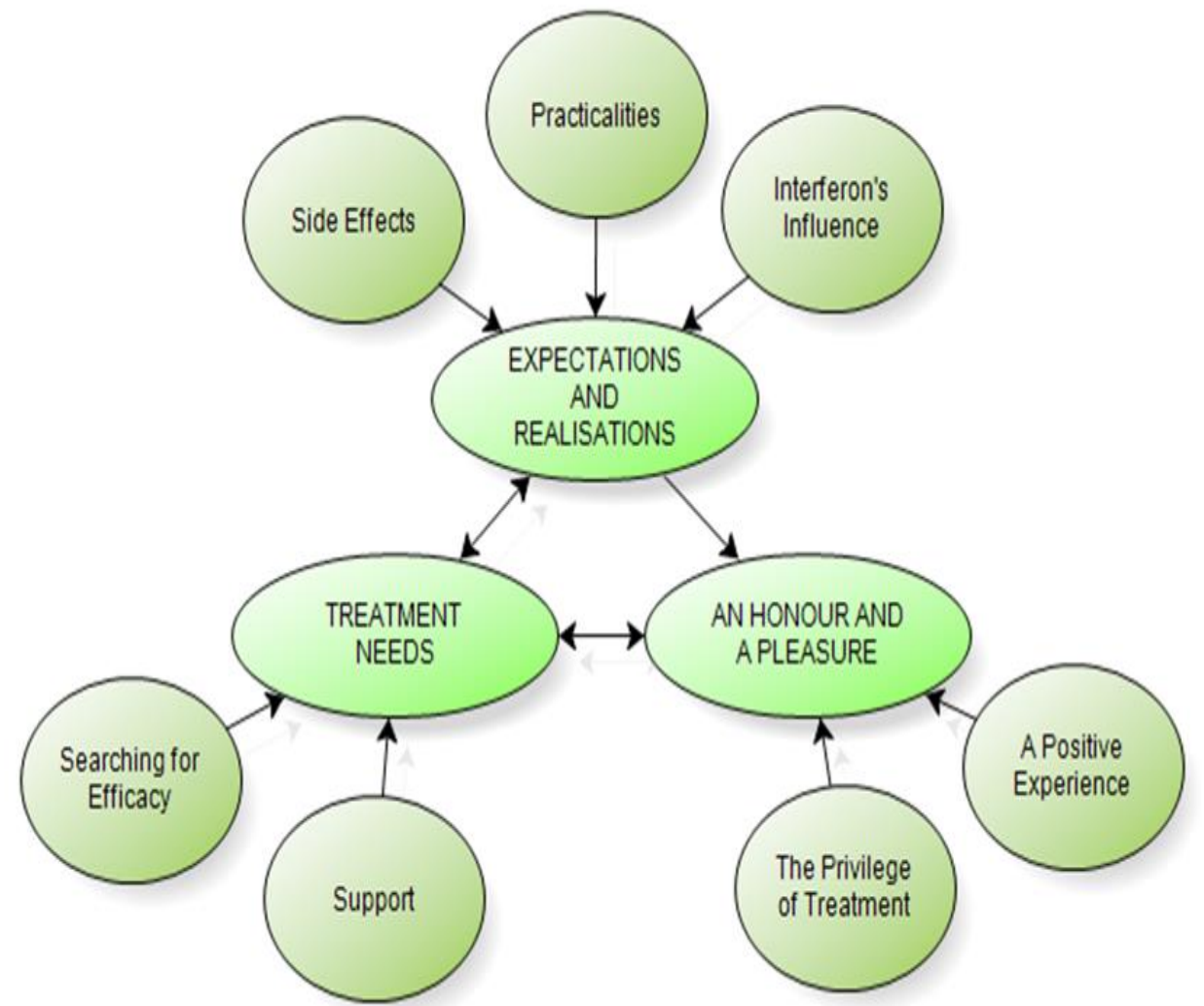


Figure 1: The relationship between the themes.

Discussion

The experience of interferon-free HCV treatment is illustrated by the three themes previously described. These themes do not exist in isolation, but interweave within and between each individual narrative, demonstrating how understandings which have been presented discretely, are necessarily intertwined (figure 1). This study reveals the legacy of interferon currently casts a long shadow over the experience of interferon-free regimens, with the participant testimonies intricately tied to the historical touchstone of interferon-based treatment. The understanding of HCV therapy as a rigorous and demanding undertaking, informed the notion that effective treatment should be accompanied by toxicity and short-term suffering. This insight exposes a cultural lag between the rapid pharmacological developments which have been witnessed, and the social understanding of them, creating conflict between what patients *ought* to need, and what they actually require.

All participants in this study received their treatment through a hospital-based clinic, however, there is an emerging evidence base that moving therapy away from secondary care and into more diverse settings is a feasible objective^{5,6}. Interferon-based treatments have been successfully delivered in opioid substitution settings and prisons, achieving comparable adherence and response rates to those reported in more conventional locations⁷⁻⁸. These support-intensive models of treatment delivery may be reviewed, however, in light of fewer perceived patient requirements with ‘easier’ drugs. This study emphasises that the experience of interferon-free treatments continues to demonstrate a significant and essential discourse of needs, and caution should be exercised in any immediate reconsideration of how best to deliver these therapies to patients.

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