

PERSON-CENTRED HEPATITIS C VIRUS TREATMENT IN COMMUNITY SETTINGS

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ABSTRACT

The World Health Organization (WHO) has set a target to eliminate the Hepatitis C virus (HCV) as a public health threat by 2030. To achieve this, HCV treatment needs to be accessible through primary health care providers in community settings. In Australia, general practitioners and nurse practitioners can prescribe nearly free direct-acting antiviral (DAA) medication. However, there are still many barriers to the provision of HCV treatment in community settings. Considering the characteristics of HCV infection, people with HCV, and the Australian primary health system, person-centred HCV treatment is suggested to improve treatment uptake and adherence. Although the provision of person-centred HCV treatment in community settings is emphasised, the characteristics of these models are not well described. This short report describes the characteristics of person-centred HCV treatment in community settings to inform policy and practices in supporting HCV elimination. The characteristics were developed based on the analysis of findings of studies conducted by the author using person-centred care framework. The studies included a mixed methods systematic literature review, a Delphi study, and a mixed methods case study on a community-based model of care for treating HCV.

KEYWORDS

Hepatitis C, elimination, primary health care, person-centred care.

INTRODUCTION

In May 2016, WHO's first-ever viral hepatitis strategy was announced, and Hepatitis C virus (HCV) infection has been targeted to be eliminated as a public health threat by 2030 [1, 2]. The introduction of highly tolerable and effective direct-acting antiviral (DAA) medication provides opportunities for the provision of HCV treatment in community settings to achieve the WHO's aspiration for HCV elimination [1, 2]. Community-based models for treating HCV are defined as providing HCV treatment outside of the hospital through primary health care providers to remove barriers related to accessibility and acceptability associated with tertiary centre based HCV treatment [1, 2]. In Australia, the listing of DAA medications

on the Pharmaceutical Benefits Scheme (PBS) in 2016 improved HCV treatment uptake. However, the number of treated people decreased from 33,202 in 2016 to 5,205 in 2022. The proportion of discontinuation of treatment increased from about 6% in 2016 to 12% in 2022 [3]. These are observed despite the implementation of different general practitioner and nurse practitioner led models for treating HCV in community settings [4]. The decreased number of people initiating HCV treatment and increased number of discontinuations of treatment are considered threats to achieving HCV elimination by 2030 in Australia [5].

There is stigma associated with HCV infection and people with HCV often have a recent history of injecting drug use, suffer from psychiatric comorbidities, experience homelessness, and have a history of imprisonment [6, 7]. Considering the characteristics of HCV infection, people with HCV, and the Australian primary health system provision of person-centred HCV treatment in community settings is emphasised to improve treatment uptake and adherence [8]. However, the characteristics of such treatment are not well described.

This short report aims to describe the characteristics of person-centred HCV treatment in community settings to inform policy and practices in supporting HCV elimination. These characteristics were developed based on the analysis of findings of three studies conducted by the author [4, 8-12] using person-centred care framework [13]. The studies included a mixed methods systematic review on community-based models for treating HCV, a Delphi study with experts from Australia to identify the key organizational and operational elements of community-based models for treating HCV, and a mixed methods case study on a community-based model of care for treating HCV which included reports of health and health service outcomes and barriers to and enablers of the provision of HCV treatment in community settings [4, 8-12].

Person-centred care is described differently in different contexts. However, all descriptions emphasise shared power in the relationship between person and health care provider in the decision making and treatment planning [14]. The framework used to analyse the findings of studies was based on the descriptions provide by Stewart et al [13]. The description includes six interconnected components: 1) exploring both the disease and the person's experience of illness, 2) understanding the whole person, 3) finding common ground regarding HCV treatment, 4) enhancing the person and healthcare provider relationship, 5) incorporating prevention and health promotion, and 6) being realistic [13].

EXPLORING BOTH THE DISEASE AND THE PERSON'S EXPERIENCE OF ILLNESS

An emphasis on the clinical signs and symptoms of HCV may not be enough to convince or motivate people to initiate treatment as they are often asymptomatic or may attribute experienced symptoms to the use of drugs and alcohol [11]. This may be exacerbated by lack of

knowledge about HCV [11]. Thus, there is a need to clearly differentiate between HCV infection as a defined medical problem and the individual's experience of illness [4, 11]. A person-centred approach involves exploring feelings, ideas, functions and expectations of individual in conjunction with the biological aspect of the disease [15]. Exploring feelings, especially fears regarding HCV [10, 11], can help primary care providers to understand the psychological and emotional impacts of HCV on a person's life. People with HCV may be concerned about dying from HCV and infecting their family members [11]. They may also experience stigma, shame, or guilt due to having a blood-borne virus acquired through injecting drugs [11]. Primary care providers need to consider a person's ideas about the disease and symptoms and the meanings they ascribe to them and investigate the effects of experienced illness on a person's daily activities [15]. A majority of people in Australia acquire HCV through sharing ancillary injecting equipment and most of them are aware of the route of contracting HCV [16]. If drug use is considered an illegal and socially deviant activity, people might consider HCV infection as a punishment for their use [17]. This idea needs to be fully considered and support provided to improve healing and engagement with HCV treatment.

Understanding what people want from HCV care providers can help to ensure effective and acceptable HCV treatment plans. Primary care providers need to understand the person's expectations of consultation and access to HCV treatment. People want to be clear of the virus, which they consider a source of shame in their life [10, 11]. They need to have access to safe environments where they are respected and empowered [4, 9-11]. Considering the characteristics of people with HCV, they also need to have access to the required support and be fully informed about medicines and the treatment processes [11].

UNDERSTANDING THE WHOLE PERSON

Considering the context in which the person is living is a hallmark of person-centred health care [15]. People with HCV need to be seen as people living in a community, who may be members of a family and have family commitments [11]. Primary care providers need to understand the many other factors that influence people's experience of having HCV and their ability to initiate and adhere to a treatment plan. For example, people who are using drugs, cycling through the criminal justice system, experiencing homelessness and struggling with many psychosocial and economic problems may not consider

fatigue and mild depression as a serious problem that needs to be treated [10, 11]. They may be more strongly compelled to consider treatment when witnessing HCV consequences (e.g., a friend or family member suffering or dying from HCV); are concerned about infecting family members; or are informed that they have access to free, safe and effective medicines and psychosocial support [11]. In these complex situations, primary care providers need to consider these factors and help persons to manage competing priorities to enhance their ability to initiate treatment and adhere to the treatment plan.

FINDING COMMON GROUND REGARDING HCV TREATMENT

People with HCV should be actively involved in treatment planning. Primary care providers need to work with the individual to define the problem, establish the goals and priorities of the treatment, and clearly define roles and responsibilities [15]. Disagreement between the healthcare provider and person about the definition of the problem, the goal of treatment, and their roles and responsibilities may result in treatment management failure [11].

Considering the characteristics of HCV infection and the people with HCV, finding a definition or understanding of HCV infection that is agreed by both person and primary care provider is an essential step to progress the treatment planning [15]. To achieve an agreement on the definition of HCV infection, HCV care providers need to understand that the problems the person is experiencing relate not only to the clinical signs and symptoms but also to emotional, social and other considerations [11]. The agreed understanding may encourage people to be involved in the process of and adhere to HCV treatment; thus, helping primary care providers to easily manage patients' treatment [15].

When an agreed definition is achieved, the primary care provider and the person need to work together to develop achievable goals and priorities [15]. The goals of HCV treatment are clearing HCV from the person's body, preventing re-infection, and healing the person's experienced illness [10, 11]. These goals and their priority need to be fully understood by both the HCV care provider and the person [10, 11]. People with HCV need to be informed about the cure rate of DAA medications and the duration of treatment, monitoring tests, and any side effects [18].

The final part of finding common ground regarding HCV treatment is defining the person and the HCV care provider's responsibilities and roles. To find common ground, the power in the relationship between the HCV care provider and the person with HCV needs to be balanced. These responsibilities need to be mutual, defined and agreed upon by both patients and primary care providers [15]. Primary care providers need to clearly explain when and where patients can fill scripts; how the medicines need to be taken; the duration of treatment; the importance of adherence to treatment, monitoring, and final sustained virological response (SVR) tests; and the importance of being in contact with primary care providers during treatment [11, 18]. People with HCV need to be convinced that SVR is an important part of treatment that allows them to be sure that they are clear from the virus.

ENHANCING PERSON AND HEALTHCARE PROVIDER RELATIONSHIP

Community-based models for HCV treatment need to consider the importance of the person and health care provider relationship and emphasize the enhancement of this relationship to achieve the goal of HCV elimination. Improving knowledge about HCV and its treatment is essential but this needs to be done in conjunction with empowering people to negotiate treatment options with their primary care providers. An unbalanced relationship can prevent people from asking for treatment and negatively affect the expansion of access to HCV treatment in community settings [11]. This can also increase the risk of loss to follow-up as people may not feel that they have the power to discuss their situation and ask for support to adhere to the treatment when it is needed [4, 10-12].

Community-based HCV treatment needs to consider the importance of the long-term engagement of people with the health service to improve their quality of life. By considering people's characteristics and their lack of access to health services, primary care providers can utilize the opportunities created through HCV treatment to engage people in long term health care [4, 9-12]. This is especially highlighted for people with ongoing risky behaviour (e.g. sharing ancillary injecting equipment) and cirrhosis.

INCORPORATING PREVENTION AND HEALTH PROMOTION

Incorporating harm reduction and health promotion in HCV treatment is a required cornerstone of HCV elimination [8, 9]. An understanding of the person's world, collaboration with the person to find common ground, and

enhanced person and healthcare provider relationship can maximise people's contribution to their self-care and avoidance of harm [10, 11].

People need to fully understand that curing HCV does not protect them from re-infection. Risky behaviours, such as sharing ancillary injecting equipment and ability to practice harm reduction, need to be assessed. It is important that HCV care providers are aware of available harm reduction and drug and alcohol services and encourage patients to access such services when required [8, 9, 11]. For people who may be reticent to access these services, service characteristics (e.g. being free of charge and non-judgmental) should be discussed [4, 11]. It needs to be acknowledged that some people may not be willing to engage with harm reduction or drug and alcohol services [18]. In such cases, primary care providers should be able to provide advice about harm reduction strategies. Developing collaborations with harm reduction and drug and alcohol services can be helpful to incorporate harm reduction in HCV treatment [8, 9, 19]. In terms of health promotion, as many people with HCV suffer from multiple comorbidities and challenges, including mental health problems and social instability [4, 11], it is important that HCV care providers are aware of the availability of mental health and social support services and connect people with such services when needed [4, 8, 9, 11]. This connection can help to improve people's ability to engage with HCV treatment and their quality of life.

BEING REALISTIC

Providing person-centred HCV treatment in the community setting is not without challenges. The design of community-based models needs to recognise the barriers and utilise enablers [11]. To provide person-centred HCV treatment, providers may need to spend more time with some people. The workload and busyness of practices may be an obstacle to providing person-centred HCV treatment. There are some possible strategies to address this. There is the "long consultation item" available through the Medicare Benefits Schedule that HCV care providers can use for the coverage of person-centred HCV consultation [20]. Further, the use of several visits over time for exploring the person's world can be an effective method to manage the duration of the consultation.

Providing person-centred HCV treatment needs collaboration with other related services such as harm reduction, drug and alcohol, mental health and social services [4, 8, 9]. Developing collaboration with these services may be seen as a challenging area for some primary care providers. Considering the culture of these services, which emphasise the social aspects of their clients, person-centred HCV treatment offers a common language for providers to effectively communicate with these services. This can facilitate the development of further collaborations. Further work needs to be done to overcome bureaucratic, logistical and economic barriers to establishing a collaborative team for HCV care.

Loss to follow up is an important issue in HCV treatment. Availability of point-of-care testing [21] and incentivising testing and continuation of treatment can be helpful for some people to improve their engagement with HCV treatment and adherence to the treatment plan [22].

The use of information technology in person-centred HCV treatment is an important area. With the consideration of characteristics of people with HCV, the use of short messages or emails may not be effective for all people. For some people, telephone calls or letters can be effective communication tools to remind them of their next appointments, blood tests, and filling of scripts [4, 8, 23]. Considering people's mobility, HCV care providers need to consider multiple ways to contact the patients. It also needs to be understood that some people may not be able or willing to use information technology. Confidentiality and privacy issues related to the use of information technology in person-centred HCV also needs to be considered.

CONCLUSION:

Providing person-centred care for treating HCV in community settings can improve treatment uptake and adherence. To provide person-centred care, primary care providers need to explore HCV as a defined disease and a person's experienced illness, understand the whole person, collaborate with the individual to find common ground for treatment planning, and incorporate prevention and health promotion in HCV treatment. It is also essential that the person and HCV care providers have equal power in their relationship to ensure engagement in the provision of HCV treatment and long-term health care.

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