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Hepatitis C treatment – better outcomes through partner support

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BRIEF REPORT --- STUDENT

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Abstract

Background

Globally, it is estimated that 170 million people are living with hepatitis C and between three and four million are newly infected annually. In Australia, around 1% of people are living with chronic hepatitis C, with two-thirds of these being men.

Aims

This research aimed to determine the impact of hepatitis C treatment on partners of patients using in-depth exploratory techniques.

Method

Four infected men and their partners (n= 8 participants) and three service providers were recruited and interviewed separately to identify the needs of female partners supporting patients with Hepatitis C. Discussion was based on the experiences of female partners during the treatment phase of male hepatitis C patients.

Results

All participants recognised a need for greater assistance for partners of hepatitis C treatment patients. It was also recognised that strong social support improved treatment outcomes and helped to maintain the survival of family relationships during the intensive treatment phase.

Conclusion

Although this research was limited by size, it provides valuable insights into ways to enhance hepatitis C management outcomes beyond traditional medical treatment regimes, for example through formal partner support.

Key Words

Caregivers/caring; coping and adaptation; partners; hepatitis C.

What this study adds:

1. What is known about this subject?

Little research has been conducted to date addressing the role partners play in supporting people undergoing hepatitis C treatment programs.

2. What new information is offered in this study? This research offers some insight into the impact of hepatitis C treatment on partners of patients with hepatitis C.

3. What are the implications for research, policy or practice? A greater understanding of the role partners' play in the treatment process of those with hepatitis C can lead to better outcomes and a greater quality of life for patients and their families.

Background

Globally, it is estimated that 170 million people are living with hepatitis C and between three and four million are newly infected annually.[1] In Australia, around 1% of people are living with chronic hepatitis C, with two-thirds of these being men.[2] Hepatitis C treatment can be difficult for patients, with numerous side effects often resulting in prolonged ill health. During treatment, the lives of partners of patients also often significantly change. Changes may include: becoming the primary caregiver; taking on the responsibility for maintaining medication regimes; attending medical appointments; running the household; and preserving the normal family flow. A small sample of patients with hepatitis C, their partners and their services providers were interviewed to document the experiences of partners during treatment.

To date, there has been limited research focussing on the needs of partners of patients with hepatitis C. Previous research has been conducted with partners caring for patients with conditions such as cancer and HIV,[6] but none at the time of research had looked at the specific intricacies associated with hepatitis C, such as disclosure, stigmatisation, treatment duration and treatment side effects.

Method

The term ‘patient’ is used in this paper to describe the hepatitis C positive person who has undertaken treatment. The term ‘partner’ describes the person designated by the patient as their primary caregiver throughout the treatment period.

Recruitment methods

Due to confidentiality concerns around the release of patients’ names from hepatitis C services and difficulty in recruiting directly from the public to the study due to a culture of fear amongst the infected population, all hepatitis C service providers based in Western Australia were approached by the researcher to assist in recruitment of participants based on the following criteria:

- patients had completed a course of combination therapy (pegylated interferon and ribavirin) for hepatitis C;
- adult male patients with adult female partner; and
- couples who had been together throughout the treatment process.

Service providers who were willing and able to assist with this research contacted the patients initially to request permission for the researcher to contact them. Once contact between the patient and researcher was made, all liaison was done directly, leaving out the service provider to aid in eliciting open and honest answers from participants. Four couples were recruited (n= 8 participants) and interviewed separately, again to facilitate free communication with the researcher. Three service providers were also interviewed to provide some currency around the health care service experiences of partners and to identify support gaps. Two of these service providers worked in community hepatitis C support roles and the third as a nurse involved in hepatitis C treatment. These participants were chosen randomly from a group who have daily, direct contact with people living with and affected by hepatitis C. Active consent was gained from all participants prior to interview.

Data collection and analysis

Interviews were conducted between September 2008 and January 2009. All participants were interviewed at their nominated location or via telephone and partners and patients were interviewed separately. Interviews were kept semi-formal but were based on a pre-set list of questions in order to maintain consistency and compare participants’ answers in analysis. Where appropriate, participants were encouraged to elaborate on specific topics they felt were most relevant to them. Partners and patients were asked about their own personal experiences, what they found difficult during the treatment period, what coping mechanisms worked well for them and any advice they could recommend to someone facing a similar situation. Discussion with service providers centred around common concerns seen in their clients, what coping skills they see and recommend to clients, what information and advice they provide and how they see the treatment support improving in the future. Interviews were digitally recorded and transcribed in full. Grounded theory was used to analyse the data[3] and social theories were used to guide analysis of discussion around stigmatisation.[4]

Ethical considerations

Ethics approval was granted by the Curtin University Human Research Ethics Committee (SPH-0039-2008). A reciprocal ethics agreement was granted by the Fremantle Hospital Hepatology Department.

Results

Four main issues were identified as important factors shaping the female partners’ ability to cope during the treatment period. These were: a perceived lack of choice around treatment; isolation and fear; changing relationships and family dynamics; and an overwhelming sense of responsibility.

Perceived lack of choice: In this study, the initial decision for treatment appeared to have been made between the patient and their partner, however there was little information available to the partner that pertained to the impact treatment may have on their life.

> *Partner; “It was mainly his decision, but I certainly was looking for something because when we were first told [about the diagnosis] there was nothing available.”*

Isolation and fear: All women involved in this study relied heavily on a few close friends or family, but kept the treatment a secret from others. One of the main reasons cited was the fear of discrimination, fuelled by the lack of understanding from the people around them.

> *Partner; “There were obvious times when he couldn’t go to things and we would just sort of make excuses for him. He didn’t want people to know that he had hep C at all. For me, that was probably the hardest to deal with.”*

> *Service provider “...[partners], they may become very isolated because they can no longer talk to the partner [patient] they used to talk to, let alone anyone else because it is disclosing their partner’s stuff.”*

Changed relationship and family dynamics: Stress on the couple's relationship and the family unit were clear concerns to the interviewees.

> *Partners; "... a lot of marriages break up, people just can't take it anymore. ... I understand why."*

> *Service provider; "I've seen marriage difficulties, marriage splits. ...[the partners] then begin to question, is it their problem or their partner's problem"*

The parent-child relationship may also alter during treatment. Children were not always supportive because they did not understand what was really happening. One partner said that her older children took on more of a mothering role to cope better with the changed situation while others said there was considerable tension within the family unit.

> *Partner; "We have two teenagers and they were like "oh there is nothing wrong with him, you can't see he is sick" and that is the big thing, because it is not a visual illness, ... so they weren't as supportive because, well because they didn't understand."*

The partner's burden of responsibility*:* An unwillingness to ask for help was another common theme. The burden associated with treatment was both physically and emotionally demanding on partners. As well as maintaining the household, cleaning, cooking, shopping and organising the family, partners were also responsible for patient needs and wants, including administering medication, attending appointments and nurturing during times of acute unwellness. The women in this study felt responsible for the well-being of their partner.

When asked what additional resources may have helped them cope better with the treatment process, partners consistently highlighted volunteered assistance, pre-treatment preparation and relationship counselling.

Volunteered assistance

Asking for help was considered difficult due to the stigma and discrimination that many people living with, and affected by, hepatitis C faced on a daily basis. For example, access to meal delivery and domestic assistance were not available to families as hepatitis C was considered a temporary setback thus did not qualify for assistance.

> *Service provider; "You ring some of those services and people don't fit the criteria for so many of them because this is a temporary thing, acute, not chronic. Anyone doing six months worth is already cut out. Anyone doing 12 months – by the time they are eligible, they are usually actually beginning to sort things out a bit."*

Pre-treatment preparation

Having as much information as possible before treatment commenced and support during the treatment period were considered critical to coping by partners. Partners said they felt reasonably well-informed prior to treatment but that their role was not recognised during treatment and thus was not supported.

Relationship counselling

Counselling was identified by the service providers as a potential aid in preventing relationship breakdowns. Even the most stable, committed relationship could become vulnerable due to the stress of treatment and inadequate preparation. Continued nurturing of the patient and partner relationship was considered vital to success of treatment.

Discussion and conclusion

This study highlights that the need for support for partners is just as important as that offered to patients with hepatitis C. While the regime can be physically[7,8] mentally[9] and psychologically[10] taxing for the patient, the partner usually has to keep the family together, attend to housework, administer treatment regimes, maintain their own health and often cope with increased social isolation fuelled by stigma and discrimination.

The sample size of this qualitative study was limited due to funding constraints and limited time in which to complete the research. The sample was limited to male patients with female partners to maintain some consistency amongst participants and therefore be able to draw some reasonable conclusions. The male patient was chosen as it is estimated that the majority (two-thirds) of people living with hepatitis C are male.[2] The results can thus only be used to inform the support needs of female partners. Further research is needed to explore the experiences of male partners.[5]

In summary, this study found that it is essential that partners are made aware of the possible consequences of treatment to them, their family and the patient prior to treatment. Partners should also be considered as recipients of health care services and, as such, be able to access support services while patients that they are caring for are going through hepatitis C treatment.

It is the responsibility of all involved to find the most effective and workable treatment regime that meets the needs of patients whilst acknowledging and supporting the role of partners as primary caregivers during the treatment of hepatitis C.

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CONFLICTS OF INTEREST

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ETHICS COMMITTEE APPROVAL

Ethics approval was granted from Curtin University Human Research Ethics Committee SPH 0039-2008. A reciprocal ethics agreement was granted by the Fremantle Hospital Hepatology Department.