FaCe It Hepatitis C Best Practice: Patient Support

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Summary  
In order to provide support for hepatitis C patients, including those who do not speak fluent English, Opal Greyson developed a “buddying scheme” to match and introduce patients from similar backgrounds. Opal’s work has also involved activities to increase awareness and knowledge about the virus, particularly among the South Asian community in East London.

Aims and Objectives  
The overall aim of the project was to ensure patients successfully completed treatment, by providing bespoke and personal support. Key audiences included:

- Patients who do not speak fluent English
- Patients who do not live near the hospital
- Patients who are reluctant to publicly discuss their hepatitis C status

How was the project carried out?  
As a specialist hepatitis nurse, patients are referred to Opal shortly before they commence treatment. This is a time when patients may have queries and concerns about their treatment, which can have severe side effects in some cases. Patients can benefit from the support of another person who has already been through treatment themselves.

Opal’s patients come from a wide range of countries and cultures, and speak a number of different languages. In some cases, patients speak only a limited amount of English, and prefer speaking their native language when possible. Due to these issues, Opal recognised the need to provide services tailored to the individual needs of different patients.

In 2005, it was agreed that the nursing team would aim to establish two separate support groups, one for English-speaking patients, and one for patients from the
South Asian community, which formed a significant proportion of patients receiving treatment for hepatitis C at the hospital.

Opal identified two female patients to lead each of the groups. Both patients had successfully completed treatment and had expressed an interest in offering support to others. The support groups would aim to answer patients’ questions from a peer perspective, while fully appreciating any cultural sensitivities.

The nursing team intended to host the support groups at the hospital and secured agreement from the head of department. It was agreed that the English-speaking group would be trialled as a pilot initially, and the Urdu-speaking group would take place based on any learnings from the pilot.

The team went to great lengths to publicise the support groups, speaking to all their patients on an individual basis, and by posting flyers advertising the groups throughout the outpatients area of the hospital.

Despite the team’s efforts, the first support group meeting was not a success, with only one patient attending aside from the lead patient whom Opal had identified in advance. Patients receiving treatment at the hospital came from a wide geographical area, and the team believed that patients were being dissuaded from attending due to the large distances they would need to travel.

**Establishing a Buddying Scheme**

While the support group had not proved to be a great success, the team still felt patients should have access to peer-to-peer support should they want it. Opal felt this was particularly necessary for South Asian patients who did not speak English fluently, as they would not be able to access other forms of support, such as websites, so readily.

The South Asian patient whom Opal had identified previously – Shahnaz - had a detailed understanding of the virus and its treatment. As well as having undergone treatment herself, Shahnaz had also acted as a translator for her Punjabi-speaking husband when he underwent treatment a couple of years after her.
The nursing team firmly believed that the obstacle in establishing support groups in the first place had been the distances people would need to travel to attend. To overcome this, Opal consulted Shahnaz to see if she would be happy to offer support on a one-to-one basis, as she had for her husband. The team decided to trial a system where patients could be put in touch with Shahnaz to discuss any concerns they had with her over the telephone. As a fluent speaker of Urdu and Punjabi, as well as English, Shahnaz could communicate with the other patients in the most appropriate language.

**What was achieved?**

To date, over two years, Opal has facilitated the opportunity for ten patients to speak to Shahnaz, or in some cases her husband, and has offered the opportunity to many more. Opal always contacts Shahnaz in advance to check she is happy to be contacted, and briefs her on any specific questions or topics that may be raised.

Generally, the conversations simply involve the discussion of treatment and the best ways to manage any side effects. As current research indicates that hepatitis C is more prevalent among the South Asian community, it is not uncommon for patients to have heard horror stories about distant friends or relatives’ experiences of treatment. While the treatment can sometimes have significant side effects, it is important that patients are not put off treatment due to excessively negative reports.

There are no fixed rules in terms of how often buddies are expected to speak. While in some cases, patients are suitably reassured about treatment after one conversation, others are grateful for the opportunity to speak to their buddies as the treatment progresses.

Opal believes the scheme has been a successful way of ensuring appropriate support is available for patients who may have difficulties in accessing other forms of support due to a language barrier. Due to a shared cultural background, and personal experience of the virus, patients were sometimes more open to listening to what Shahnaz and her husband had to say about the virus and its treatment than they were to healthcare professionals. Anecdotal feedback has indicated the scheme is a successful way of providing support for such patients, with some patients speaking to Shahnaz and her husband throughout treatment.
The team also recognised that other sensitivities, aside from cultural differences, may prevent some patients from attending a 'public' support group meeting, and they may prefer to speak to other patients on a one-to-one basis. For example, Opal is in touch with two separate female patients who both have high-profile jobs. They share concerns about discussing the virus in a public setting through fear that it may have a detrimental affect on their careers. Opal has offered these two patients the opportunities to act as ‘buddies’ and support each other through treatment.

Due to the nature of her work, Opal learns a lot about the backgrounds of her patients (around 120 per year). Rather than referring to a database to pair patients, she will pair them based on personal attributes that she remembers about them. For example, patients may be paired because they have similar jobs, such as a counsellor and a social worker, or sometimes because they are a similar age or share similar interests or personality traits.

Over time, Opal has also paired a number of patients who are not from the South Asian community. However, as it is quite an informal scheme, there is no conclusive figure on how many ‘buddy pairs’ have been formed.

**Key Learnings**

1. “Support groups don’t work for everyone”
   The team recognised that while it is necessary to ensure patients have access to appropriate support, traditional support groups are not always effective. A number of factors, including cultural sensitivities and geographical distances can act as barriers to the success of support groups in some areas of the country. Buddying schemes can act as an appropriate alternative to support groups and in some case can provide a greater level of support.

2. “Good nurse-patient relationships are key”
   The buddying scheme is predominantly reliant on nurses building a good relationship with patients. Through this relationship, the team can pair appropriate “buddies” and secure the support of former patients in turn to offer their support to new patients.

**Future Work**

Opal feels the buddy scheme has successfully improved the level of support available for patients. In the future, the team aims to build on this success by
partnering more patients, specifically those from backgrounds where traditional support groups may not be the most appropriate.

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