

## Experience of caregivers with the survivors of Hepatitis C

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### Abstract

**Objectives:** To assess and describe the experiences of those caring for hepatitis C patients in Karachi, Pakistan.

**Methods:** Using a qualitative approach, the study adopted a descriptive exploratory design for which 8 caregivers were selected through snowball sampling technique from different parts of Karachi. Data was collected between May and July 2010 through semi-structured interviews from the caregivers. The interviews were recorded on tape and were transcribed verbatim. The data was manually analysed for extracting themes and categories.

**Results:** The analyses of data led to one theme - 'deadly, dangerous, and devastating. Two associated categories could also be noted: 'perceptions and misperceptions of the caregivers about hepatitis C' and 'challenges and adversities of the disease.'

**Conclusion:** The diagnosis of hepatitis C had a profound impact on patients' and the caregivers' wellbeing. Although to some extent, caregivers were found to have fulfilled their role, but it was evident that better disease knowledge, funds and social support could have further helped them to address issues related to the disease.

**Keywords:** Caregivers, Hepatitis C, Knowledge. (JPMA 62: 1057; 2012)

### Introduction

Globally, 3-5% of world's population is suffering from hepatitis C virus (HCV).<sup>1</sup> The prevalence of HCV is 4.5-8% in Pakistan, which is the second highest in the world.<sup>2,3</sup> Once a patient is diagnosed with hepatitis C, a number of physical, psychosocial and financial needs surface due to its symptoms, complications and increased cost for healthcare.<sup>4</sup> Consequently, the family caregivers may be substantially burdened because in addition to financial constraints, the disease could be taxing physically, socially and emotionally.

Considering the poor quality and access to healthcare structures in Pakistan that lack nursing homes, support group and health insurance facilities for the patients with chronic conditions such as hepatitis C; caregivers are required to assume multiple roles. The caregivers, who generally do not look after other family members, now have to take up a new role of providing physical, financial and emotional assistance to the patients in daily living.<sup>5,6</sup> In addition, as the diseases progresses, the lack of personal care, financial pressures and, eventually, a sense of losing a loved one diminish the caregivers' own physical and emotional wellbeing.<sup>7</sup>

Though studies are conducted in Pakistan about the prevalence, medical management, and the complications of hepatitis, no work has been done on exploring the experiences of caregivers.<sup>8-11</sup> As the experiences of an

individual are significantly influenced by the surroundings of their living environment,<sup>12</sup> in Pakistan there are stark differences of culture, living conditions and availability of resources, thus the experience of caregivers caring for the patients with hepatitis C in Pakistan may not be the same as in other countries. Therefore, the current study was undertaken to explore experiences and perceptions of caregivers living with hepatitis C patients in Karachi. The study aimed at answering two questions: What are the perceptions and experiences of caregivers in caring for patients with hepatitis C; and, what roles are performed by the caregivers in caring for the patients?

### Methods

Considering the aim of the study, a qualitative descriptive exploratory design was considered appropriate. A purposive sample of eight caregivers was selected via snowball sampling technique from various parts of Karachi. Following the principle of maximisation,<sup>13</sup> the participants included both male and female subjects with variations in age, education, and their relationships with the patients. Only caregivers who were living with hepatitis C patients, had awareness of their patients' diagnosis, and were willing to reflect on their experiences voluntarily were selected for the study.

The data was collected between May and July 2010; a

semi-structured interview guide was used to conduct in-depth interviews with the participants. The interviews were conducted at place and time which were mutually agreed by the researcher and the participant. The interviews lasted for 40-60 minutes and were recorded on a digital recorder. The study was approved from the Aga Khan University's ethics review board. A written informed consent was obtained from all the caregivers at the beginning of the interview. Appropriate emotional support was also provided to the caregivers who became emotionally overwhelmed during the interview. To maintain the privacy and confidentiality, each participant was assigned a code indicating their gender (as 'M' for male and 'F' for female) and a serial number.

Interviews were transcribed verbatim and checked for accuracy by reading the transcripts and listening to the recorded interview. Data was manually analysed following the process of content analysis.<sup>14</sup> The data were coded and the codes with similar meanings were grouped into categories in the search of a theme that was reflective of all the categories.

## Results

Of the 8 caregivers, 6 (75%) were females. The age of the caregivers ranged from 18 to 60 years with an average of 28 years. Except one female caregiver, all were married. Half of the participants (n=4; 50%) had a baccalaureate degree, two of them had secondary education, and two were illiterate. In terms of their employment status, four were housewives, one was a student and three were working at a private organisation. The majority of the participants were living in a nuclear family. With regard to their relationships with the patients, they were sibling, children, parent, spouses, and a sister-in-law.

The analysis of the data from the caregivers' interviews led to two categories "perceptions and misperceptions about hepatitis C" and 'challenges and adversities of the disease.' Both the categories were reflective of one theme, that is - 'deadly, dangerous, and devastating'. The data is described below with pertinent excerpts from the participants' narratives with their coded identities given in paranthesis.

The perceptions and misperceptions of the caregivers related to the nature of the disease, its transmission and their attitude towards the disease. Most of the caregivers were fearful about the disease transmission and its ultimate outcomes. One of the caregivers described her perception, "It's a fatal [jaan-laiwa] disease; it's the worst condition of jaundice. Most of my relatives diagnosed with hepatitis C were at the last stage; they all passed away" (F-Cg4).

The participants held different perceptions about the transmission of the virus. Of the 8 caregivers, 3 (37.5%) perceived that hepatitis C spreads through dirty water and hot

nature of food. One of the caregivers stated "A diet that has hot effects [Garm hoti hain] also causes hepatitis C" (F-Cg8). It was noted that the participants' level of knowledge about hepatitis C affected their attitude towards precautions. For example, a daughter who thought that her mother's symptoms were due to an 'evil eye' effect instead of hepatitis C isolated her mother as reflected in the excerpt, "Mamma used to go for prayers daily and she suddenly became sick. She suffered from 'Nazar,' we went through the process of removing the effects of the evil eye [Nazar utarna]; we told Mamma, 'Please don't go daily, just visit on big religious occasions,' (F-Cg2).

With respect to the disclosure of diagnosis among the relatives and the friends, caregivers shared multiple scenarios. It was noted that sometimes the caregivers were reluctant, while at times the patients wished to hide the diagnosis from others. A male spouse who anticipated the rejection of his partner by the family members stated, "I thought that her [wife's] diagnosis may create differences among their [wife and in-laws] relationships, maybe one day they [in-laws] would say something to hurt her. Therefore, I haven't shared her diagnosis." (M-Cg3).

Several challenges were encountered by the caregivers that had a negative impact on their caregiving abilities. In most instances, the caregivers had to assume additional roles, which included provision of direct patient-care activities, facilitation of care through financing or surrogating for patient roles, such as doing household chores on behalf of the patient. For some caregivers the provision of direct physical care was quite strenuous, as reflected by an aged woman with frail health who was caring for a bedridden husband: "His hands shiver all the time; he can't even stand up. Therefore, I assist him in eating, toileting and bathing. I also do other household tasks because of which I feel tired. Though all of my relatives suggested hiring a maid for him [husband] but as far as I can serve my husband, I have to do it on my own. (F-Cg5)"

In cases where the caregivers were required to surrogate the multiple roles of their patient, they had to juggle their several responsibilities. A teenaged daughter whose mother was being treated for HCV said: "When my mother got ill I was under a lot of pressure. I had to wake up early in the morning. I had to give him [father] the breakfast and send the younger brother to school. Then I would get ready for my college. Sometimes I got lunch from my cousin's side or on payment. It was really impossible to rest in the afternoon, I had to serve lunch and send my brother for tuition. At night, we used to visit Mamma in the hospital. I was unprepared for doing all this before, as Mamma was looking after all the household chores. All that affected my studies. (F-Cg2) "

As noted in the field notes of the researcher, the facial expressions of the above caregiver during the interview

reflected extreme stress and devastation because such additional responsibilities prohibited her from attending to her own needs. In some cases, the male caregivers were also required to surrogate these roles, which was somewhat opposed to the prevailing socio-cultural norms. A male spouse taking care of his wife shared: "I am very good at cooking, washing clothes and utensils; after coming from my duties, I used to do all the household chores. I didn't want her [wife] to think about the household tasks." (M-Cg3).

Most of the participants were providing emotional support to their loved ones. However, being caregivers of patients with hepatitis C, they also experienced several emotional setbacks within themselves. For some caregivers, the diagnosis of their loved ones was a complete shock as one of the caregivers expressed: "She [the patient] didn't share this, because we were so young .... It was really painful. Our mother, who has done a lot for us throughout her life, had ignored her disease and suffered because of our education and comfort. I was in a shock. I cried. I felt guilty... I should have recognised this before, when she used to be tired even after doing small tasks." (M-Cg1)

Considering the fatal consequences of hepatitis C, several caregivers were fearful of their loved ones, death. Others feared about contacting the disease. For instance, one participant, who was the caretaker of his wife, shared: "At times we had intercourse without taking precautions. Although doctors told me that only less than 5% people might get the virus sexually, but to satisfy myself that I am not among those 5%, I went through the blood tests." (M-Cg3). Similarly, a woman caring for her sister-in-law in a joint family also expressed her concerns: "This disease is very dangerous. I used to tell her children not to use their mother's utensils. I also kept a separate water cooler for her, because we had an urn [Matka] in the house. You had to dip your hand in it to get water, and I didn't want her to do that." (F-Cg6)

One of the caregivers, whose wife was under treatment expressed: "She used to behave in a weird way. Sometimes she became stubborn and refused to take the tablets, and/or get injected. I used to get irritated. I had to treat her with little anger by raising my voice, so that she takes her tablets." (M-Cg3).

The narratives indicate that at times the caregiver had to make extensive changes in their personal and social life in order to fulfill their role as a caregiver. Consequently, some of them were socially isolated. As one of the participants, who had the sole responsibilities for her bedridden husband, expressed, "Once in my absence he [the patient] fell down from the bed. Therefore, I resigned from all social and religious activities. Now I usually sit at home, I don't leave him alone even for five minutes." (F-Cg5).

In addition to watching the physical suffering of their

loved ones, few caregivers became overwhelmed by seeing the societal attitude towards their loved ones. Although some caregivers were able to emotionally support their patients, some of them felt helpless, "People stopped hugging mamma on big days (occasions) ... that really hurt us. We used to feel bad, but we were helpless. Every time she [the mother] would cry after such an incident, and used to say: 'stay away from me'." (F-Cg3).

The caregivers became frustrated on the one hand when they had to fulfill the patients' wishes to hide the diagnosis, while on the other, they had to put up with the inquiries of their relatives. One of the caregivers, annoyed with his relatives, expressed, "Our relatives frequently asked, 'why you [patient] are becoming weak, is there something wrong'? When we visited the hospital and people saw us, we used to tell them that we are here to meet someone." (M-Cg1).

It was also noted that for a majority of caregivers, the high cost of diagnostics and treatment of hepatitis C resulted in huge financial expenditure. Some caregivers sacrificed their wishes to meet the expenses of the patients' treatment, while others ran into debt as one of the caregivers, describing the financial implication of her mother's treatment, explained: "Daddy was worried ... he had a lot of burden but he was not sharing with us. He had to go to work early in the morning; his work was such that he couldn't take off for even a day [on daily wages]. He was running here and there for welfare also. He took the loans, and sold our house for Mamma's [patient] hospital bills and for other household expenditures." (F-Cg2).

The narratives of the participants revealed that the caregivers' roles and the related challenges varied because their experience was influenced by several factors such as their knowledge about the disease, their age, financial background, as well as their attitude towards the social norms.

## Discussion

The findings indicate that for most of the caregivers, caring for their loved ones with hepatitis C has been a distressing and a fearful experience. Consistent with the findings of an American study,<sup>15</sup> the caregivers in the current study were apprehensive about the transmission of the disease and the ultimate outcomes of the disease.

The study indicates that the hepatitis C and its treatment imposed huge burden on the caregivers that consequently impeded their performance in the existing roles. In addition, they were faced with increased expenditure to treat the disease. These findings explicate the challenges of caregivers as noted in the international literature pertinent to the caregivers caring for patients with similar blood-borne diseases.<sup>16,17</sup>

In the current study, some caregivers misperceived the source of the disease. They thought that consumption of

specific food or evil eye are major factors behind the disease. This is not surprising in an Asian country like Pakistan, where many people believe that certain diseases are caused by the hot or cold nature of food or by the notion of the evil eye.<sup>18,19</sup> Such misperceptions about the real source of HCV transmission is alarming, as it places the caregivers at a high risk of contacting the disease from the patients.

The responsibilities of caregivers identified in this study could be categorised into three areas: financial facilitations, provision of physical and emotional care to the patients, and surrogating for the patients' roles as being a wife, a mother or a bread-earner. However, variation existed as predominantly more than one family member was involved in caring for patients. The financial support was extended by a male caregiver, whereas the provision of physical care and substitution of other roles were assumed by a female caregiver. Although this finding is consistent with the finding of other studies,<sup>16,20</sup> the current study explained how societal values and expectations forced female caregivers into the roles which depict their strong sense of sacrifice in attending to the needs of the patient. However, psychological support to the patients was equally given by both the genders.

With regards to the substitution of a patient's roles, consistent with an Australian study on hepatitis C patients,<sup>21</sup> in the current study not only female caregivers but, to some extent, even male caregivers helped in the household chores. The involvement of male caregivers in this study in the Pakistani context was somewhat unanticipated because the performance of household chores is usually considered to be the task of females. This finding is indicative of a change in societal norms.

Researches about the role of caregivers of hepatitis C as well as human immunodeficiency virus (HIV)<sup>18,21</sup> indicate the negative implications of patients' emotional sensitivity on the caregivers' wellbeing. Caregivers in the current study also reported similar experiences, such as outbursts of patients' anger and irritability, which not only added to the demand of caregiving, but also had implications on their psychosocial wellbeing.

Empirical evidence<sup>16,21,22</sup> suggests that the availability of higher formal social support, such as nursing homes, transportation, support group and financial aids help lower the patients' as well as the caregivers' burdens. However, with the exception of family support, most of these systems almost do not exist in Pakistan. As a result, the burden of care rests on spouses, parents children or extended members of the family.

## Conclusion

The study indicated that caregivers of hepatitis C assumed diverse responsibilities. They were faced with the

challenges of uncertainty about transmission and outcome of the disease as well as stigmatisation from society. Although their experiences were overwhelming, but almost all the caregivers strived to provide comfort to their loved ones. Therefore, healthcare professionals in Pakistan should be competent to provide them accurate knowledge and extend their support to the caregivers in order to ease their burden of caregiving. In addition, public awareness about the burden of care for hepatitis C patients is also important to recognise the role of family caregivers.

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