

RESEARCH ARTICLE

Experiences of Family of Patient with Newly Diagnosed Advanced Terminal Stage Hepatocellular Cancer

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Abstract

Background: Hepatocellular carcinoma (HCC) is the most common primary liver cancer and the third leading cause of cancer-related death worldwide due to its generally poor prognosis. Caregiver burden for liver cancer cases is higher than with other cancer and needs especial attention. **Methods:** To explore the experiences of families of patients with newly diagnosed advanced terminal stage hepatocellular cancer by interview. **Results:** Nine participants were recruited in this study. Content analysis of the interviews revealed four themes: blaming oneself, disrupting the pace of life, searching all possible regimens, and not letting go. **Conclusions:** This study provides new insight into the needs and support of family members especially when they are facing loved ones with newly diagnosed advanced terminal stage HCC. These results will inform future supportive care service development and intervention research aimed at providing assistance in reducing unmet supportive care needs and psychological distress of these family members.

Keywords: HCC - liver cancer - qualitative experiences - family members - Taiwan

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Introduction

Hepatocellular carcinoma (HCC) is the most common primary liver cancer and the third leading cause of cancer-related death worldwide due to poor prognosis (Parkin et al., 2001). This disease leads to ~600,000 deaths annually (Parkin et al., 2005). This malignancy occurs more often among men than women, usually with a ratio of 2:1 and with the highest incidence rates reported in East Asia (Curado et al., 2007; Shariff et al., 2009). The incidence of HCC in China is particularly high accounting for 55% of all cases diagnosed worldwide (Hua et al., 2011). In Taiwan, cancer is also the leading cause of death. In 2011, 28% of people died from the ten leading causes of death in Taiwan. Among them, liver cancer (18.9%) is the second place of cancer death. The prevalence is in people between ages of 50 and 70 years (Executive Yuan, Taiwan, ROC, Department of Health, 2013). In Chen's research (1993), hepatitis B virus (HBV) is the first cause of HCC. Eighty to Ninety percent of chronic liver diseases and HCC are caused by HBV. The major worldwide risk factors for HCC are the presence of cirrhosis, and HBV infection (Shariff et al., 2009). In countries where HBV infection is not endemic, hepatitis C virus (HCV) and alcoholic cirrhosis are generally considered to be the most important risk factors for HCC (Llovet et al., 2003).

It is estimated 300 million people carry the HBV in the world, and HCC may develop in as many as 25% of

them. Unlike most risk factors for HCC, HBV can be hepatocarcinogenic in both non-cirrhotic and cirrhotic liver disease (Shariff et al., 2009). Studies showed that HCC risk in those with chronic HBV infection have been conducted in East Asian countries, where most patients acquire HBV vertically. Patients with HBV-associated cirrhosis were found to have a 1000-fold greater risk of developing HCC, compared with HBsAg-negative individuals (Beasley et al., 1981). In a large Taiwan prospective HBV study revealed that HBV is the primary driver of the high HCC incidence rates in regions of high HBV endemicity (Beasley, 1988).

The majority of HCC patients present with advanced disease that is not amenable to resection; 84% with extensive intrahepatic disease do not undergo any resective or ablative therapy. Currently, the primary therapy and worldwide acceptance over the past 20 years for unresectable HCCs is transarterial chemoembolization (TACE). The TACE technique consists of the selective embolization of the artery feeding a tumor preceded by the injection high concentrations of chemotherapeutic agents. The combination of highly concentrated chemotherapy, including cisplatin or doxorubicin, and some degree of ischemia in the tumor was postulated to be synergistic in causing tumor necrosis (Konno, 1990).

In prospective, randomized, controlled trials (Llovet et al., 2002; Lo et al., 2002), TACE improved the rate of survival in patients with unresectable HCC compared with

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that achieved with the best supportive care. Despite the recently encouraging intention-to-treat studies (Lee et al., 2002). TACE is still considered as a palliative option. A study conducted in China by Mao et al. (2012) to assess the survival of the HCC cases receiving TACE showed that all patients survival rate was at 5 years was 42% while both HBV Ag and HCV Ab positive patients showed significantly low survival rate at 5 years. It revealed the IV TNM stage was related to a heavy increased risk of death of HCC patients, and Child C grade group showed a significant moderate increased risk.

Family members when facing patients with terminal cancer, they are at high risk of experiencing both psychological and physical distress due to the patient's multiple symptoms (Kwon et al., 2006) and their own psychological suffering (Emanuel et al., 1991; Emanuel et al., 2000). A terminal diagnosis of cancer brings with it emotional strain and the challenge of coping on caregivers of family members (Yetes, 1999). Study showed negative expectation coping strategies (worrying, expecting the worst, and getting nervous) and cancer caregivers' perceptions of not coping well were most significantly associated with emotional distress and negative psychological outcomes (Gaugler et al., 2013). In addition, caregivers reported fatigue, poor health, and insufficient time for themselves, other family members, and friends (Hull, 1990; Yetes, 1999).

According to Shaw et al.' (2013) research family caregiver revealed significant information and support needs. Family caregiver distress was exacerbated by a lack of patient care knowledge. One study revealed caregivers' burden for liver and pancreatic cancer patients was significantly higher than for colorectal cancer patients (Wang et al., 2011). In Chinese, family caregivers view their role as part of their family responsibility. Filial piety is of the virtues to be held above all else focus on the responsibility to care for, respect, and obey parents. Descendants view taking care of their parents as their duties. Therefore, their emotional needs have not been adequately acknowledged (Laizner et al., 1993; Kristjanson & Ashcroft, 1994) and caregivers receive little support from health professionals (Harrington et al., 1996; Steele & Fitch, 1996).

Research articles revealed about the devastating effect that cancer may have on caregivers, particularly at the end of live (Goldstein et al., 2004; Grunfeld et al., 2004), but little research exists regarding family members' experience to liver cancer at the time of diagnosis. The purpose of this study was to explore the experiences of family of patient with newly diagnosed advanced terminal stage Hepatocellular Cancer.

Materials and Methods

A qualitative research design with in-depth interviews using semi-structured, open-ended questions were used to collect information regarding the subjective aspects of he experience of being a family of patient with newly diagnosed advanced terminal stage Hepatocellular Cancer. The interview questions were piloted and refined before the study. Prior to interview, the participants were

informed on the purpose and the method of the study, so that they could opt for staying in the study or giving up. Interviews continued until the data was saturated and dense.

Purposive sampling was used based on the following criteria: (1) more than 18 years old; family of newly diagnosed advanced terminal stage HCC patient; (3) ability to communicate clearly in Mandarin or Taiwanese; (4) no learning, hearing, or communication difficulties; (5) willing to participate in this study. Nine participants were recruited in this study.

All participants were face-to-face interviewed using the interview guide. The initial questions were broadly based and began with "What has it been like for you caring for your loved one who has just been diagnosed with advanced terminal stage HCC?" Specific prompts were given to invite elaboration about the effect on daily living, and the effect on their families. Interviews lasted 40-90 minutes on average and were audio-taped by using MP3 after getting the permission of the respondents. The participants were assured about unanimity of their identities and kept in a secure place. For this purpose each participant was given a code. Audio-tapes were listened to after each interview in order to increase understanding of substance and nuance. The tapes were transcribed verbatim. The transcription was checked line-by-line and identified the processes, broke the data into meaningful pieces, coded each main sentence by another co-author to ensure it was accurate.

For qualitative data, constant comparative method (Strauss and Corbin, 1990) was analyzed manually by using inductive analytic approach involving content analysis to code transcripts (Silverman, 2000; Silverman, 2001) and categorize the key themes and sub themes to emerge (Mason, 2004). No pre-established conceptual framework or theory was used to guide the analysis. Data was analyzed immediately after the transcription so that the researcher could make improvements for the next interview. Data relating to each of the codes were then read several times, looking for similarities and dissimilarities in family's views and experiences. The relationship between codes was then assessed prior to key concepts were developed. Reflection was done so that more themes could be developed for the subsequent interview. To ensure internal validity of study, further analyses were also carried out by two independent data analyzers who were also co-authors. After both had examined the transcripts independently, discussions were held to identify and come to a consensus about the drawn themes. Translated verbatim passages are reported in total or part thereof depending on the cases and the meanings.

Rigor standards of the data were established by using the criteria of Lincoln and Guba (1985): credibility, dependability, confirmability, and transferability. Validation was obtained from the participants who were enthusiastic about being involved in this study. This process was carried out by asking two participants to evaluate the overall results in order to check the credibility of the findings. Dependability was validated using a peer review analyzing process. Two doctoral prepared researchers specializing in qualitative study completed

the data analysis. The researcher wrote down each memo immediately after interviewing each participant. In this study, the experiences of family of patient were well-grounded in lived experiences. The characteristics of participants were of great range and variation to confirm the transferability. In qualitative research, the sample size was small, but large volumes of verbal data were analyzed. This included interview notes, transcribed audio-taped interview notes, and theoretical and methodological notes used to document confirmability of the findings.

Results

Content analysis of the interviews revealed four themes: (1) Blaming oneself, (2) Disrupting the pace of life, (3) Searching all possible regimens, (4) Not letting go.

Blaming oneself

There is large impact on family members when their beloved one recently diagnosed advanced terminal stage HCC. Without noticing patient's signs and symptoms of HCC, disease exacerbated and treatment delayed. Therefore, participants felt guilty and blamed themselves. One participant stated, "*He went climbing this June, traveled abroad in July, and did push-up regularly. I don't believe he got liver cancer not even on terminal stage. I know he always likes to drink alcohol secretly. It's my fault not prohibiting him from drinking. I should have removed all bottles of alcohol from home.*"

Another participant said, "*I only cared about his colon cancer in the past. He did regular check-up for that. I only knew he had chronic liver cirrhosis. He had poor appetite and weight loss recently. I thought it was because heat stroke. Every summer when weather is hot, he has poor appetite. I should've noticed that and have him visit doctor. I just neglected his symptoms and delayed the treatments. It's all my faults.*" The other family member reported, "*He just endured the discomforts until the tumor grew so big. I did not pay attention to his illness.*" Since there are few nerves through the liver, someone with this type of cancer does not feel pain. Unless tumor grows on the surface of the liver, liver cancer usually has no symptoms in its early states. Later symptoms can include pain in the abdomen, fever, yellowing of the skin and eyes and weight loss.

Disrupting the pace of life

Most participants felt their lives were seriously disrupted by their loved one's illnesses, which resulted in increased responsibilities, rearranged priorities, and an inability to plan. Some of them had to struggle among work, family lives, and caring for their loved one. One male participant stated, "*In order to show my filial piety, I want to take care my father by myself and I also discussed with my brothers and sister to take turns as well. We make caring schedule for my father.*" Another male participant said, "*I don't have job now, so I have more time to take care of my father. I feel it's my responsibility to take care of him during his hospitalization...I sleep here several days and my wife complains about it.*" It is Chinese culture to take care of their loved one to show their filial piety.

Another female family member noted, "*It's changed my daily routine. It totally disrupted my life. I have to rearrange a lot of things such as my kids, my work, and getting help for my house cleaning ... doing all the grocery shopping. I have to make sure my kids' routine life such as their homework, going to and coming back from cram school and band lesson as regular as possible.*" Other types of disruptions were noted. One female family member stated, "*I used to prepare dinner by myself. I am not the type of person always eating out. And now, I have to buy fast food or eat out with my kids. I don't have time to cook.*" Others reported that they shifted their priorities to adapt this shock diagnosis. One male family member said, "*I need to take days off to take care of my father and I ask my wife to cook favorite dish for my father. I ask my daughter to be more independent because I don't have much time to take care of her. I ask my subordinate to take more responsibilities for my job.*"

All participants spoke about difficulty in planning ahead since cancer is a severe disease to affect their lives. One family member said, "*I'm afraid to make vacation or take business trip. I am scared of anything happen to him during my absence. I just don't have plan now.*" Another participant stated, "*I used to bring my kids out on weekends and now I don't. I have to come here to take care of him. I told my kids to stay home and I made schedules for them to make sure they don't waste their time watching TV or playing video games all day long.*"

Searching all possible regimens

When doctor announced patient's diagnosis, possible treatments, and prognosis, most family members were shocked and could not accept the news. In addition to cooperate with doctor's treatments, participants wanted to search all possible regimens, such as Chinese herbs, healthy supplements, certain foods, religion, etc. They wanted to make a last attempt to save a hopeless situation. All participants spoke in great detail about the personal effect of the cancer diagnosis. A number of family members indicated their feelings of helplessness and yet they tried to search all kinds of possible regimens. A male participant stated, "*I feel helpless. I don't know how to help him.*" "*I heard Antrodia cinnamomea essence extract is good for liver cancer and I also did the research and made sure it's true. I've already bought one box for him.*" A female participant said, "*Doctor said to me that my father is in acute stage. His condition needs to be controlled first before getting TACE therapy. So, I went to temple and asked for my favorite goddess which Chinese regimen is best for my dad and what he can eat or not to eat. As long as it works, I would try my best to buy it for him.*" Another male participant stated, "*I asked my brother who lives in United States to mail back propolis for him. I know propolis is good for liver.*" "*I am extracting Chinese herb for him to drink. I hope it will work for his disease. At least, this is currently I can do. There is still hope, isn't it?*"

Not letting go

Since the prevalence of liver cancer in Taiwan is in people between ages of 50 and 70 years, most of family

members have been living with their loved ones for a long time and established a bonding with them. Therefore, when doctor announced patient's diagnosis as newly diagnosis advanced terminal stage hepatocellular cancer, they felt unbearable and were filled with dismay. A lot of expressions can be found in the following sentences. One participant said, "Doctor explained he still has a chance to do TACE therapy if his acute stage hepatitis B subsides. I am hoping he can go to that stage. I pray everyday for him. I believed he wasn't so unlucky after all." "I am hoping he has strong will to live. He should wait until his smallest grandson entering university. He should see his grandson marry." Another participant stated, "He is such a good person always helping people. He should live longer." One family member reported, "He is a thrifty person but generous to others." "He still has a lot of plans waiting for him to be completed and I want to accompany him to travel. I never thought his condition was so bad. I hope there is still chance for him."

Discussion

The purpose of this research was to gain insight into the experiences of the study participants focus on patient with newly diagnosed advanced terminal stage HCC. The main themes that explained study participants' experiences were revealed both in psychological and physiological perspectives. The results of this study showed that family members have deep feelings of not letting go of patient. They try to search all possible regimens to cure patient disease. In the mean time, they also feel disruption of their life by caring patient.

Caregiving is time-consuming and sometimes even full time (Rabow et al., 2004). In this study participants stated they have to take days off to take care of their patient. This might affect their work. Unlike in the United States, several states provide Medicaid program with funding that patients can use to pay friends or family members for personal care (Rabow et al., 2004). Most of family members if they have full-time job, either they have to take day off or hire pay nursing assistant to take care of patient. We suggest the possibility of utilizing hospice instead of acute hospital. The types of hospice care currently available in Taiwan include in-patient hospice care (Hospice wards), hospice home care team (home visits by the nurses and other interdisciplinary staff on a regular basis) and hospitals consultation/combined care team (Hospital Foundation of Taiwan, 2013). Another service provided by government for family caregiver for long-term care is respite care service. Since these patients are in advanced terminal stage of cancer, the condition deteriorated very fast and therefore, patients are not transferred to hospice.

According to a study, caregivers demonstrated difficulty in taking a break: active caregivers did not consider taking a break, whereas bereaved caregivers retrospectively admitted needing a break but reported an inability to take one (Ugalde et al., 2012). Even with some programs provided by government, it is Chinese culture that filial piety is the most important of all virtues. Taking care of their parents while they are hospitalized is

common in Chinese society. In addition, there is a different culture in parent offspring relationship between Easton and Western societies. For instance, in the Western world, off-springs are independence from their parents after they grow up. Differently, off-springs and parents live together in the Eastern world even the children grow up. This may strengthen the parent-child relationship and cause more burdens in taking care of their loved one.

Due to lack of knowledge on disease, family member urged trying to find all possible regimens which might not work for or even endanger patient. Information related to patient's disease provided to caregiver may help reduce the stress of caregiving and associated feelings of inadequacy and helplessness (Given et al., 2001). Information about the patient's disease trajectory, anticipated course of disease, and the range of emotions experienced by families helps normalize the experience and enhances a caregiver's sense of control. In Wong et al. (2002) study, priority areas of information and education needs identified by cancer outpatients and their caregivers included management of pain, weakness, and fatigue, followed by the types of services available to facilitate patient care at home. Caregivers report learning most of their caregiving skills through trial and error and would like more assistance from the formal health care system (Given et al., 2001). The results of our study suggest that education must also put emphasis on patient's progression, treatment, and prognosis in relation to liver cancer. The most important time periods during the patient's disease trajectory for caregivers to receive information appear to be the following: at diagnosis, during hospitalization, at the start of new treatments, and at recurrence (McCorkle & Pasacreta, 2001). Health care professionals should evaluate proper time to provide needed information to family caregivers to reduce their stress. Caregiving is complex and extensive. When taking care of their loved one, they probably have many feelings. Knowing the cause and what make them feel that way may help. Sometimes they may feel too busy to take of their own health. People who care for those with advanced cancer are in need of intervention to provide support and assistance to them in their role. In a Korea study, the family caregivers of patients with terminal cancer experience mental health problems and deterioration of health-related quality of care (QOL). The authors suggest that culturally appropriate caregiver support programs are needed to decrease the impact of caregiving on the QOL and mental health of family caregivers (Song et al., 2011).

Study showed that caregivers described three key challenges in coping with their family member's cancer are a profound sense of uncertainty regarding the future as they attempted to understand the patient's prognosis and potential for functional decline, involved time-consuming efforts to manage the patient's emotional reactions to the illness, and as coordinating the patient's medical care, as their greatest challenge. Results suggest that clinical efforts are needed to assist distressed caregivers in providing practical and emotional support to the patient and attending to their own emotional needs (Mosher et al., 2013). Another research suggests that a number of family caregivers of diseased palliative care patients are at risk

of developing depression following their loss (Guldin et al., 2012). The results indicate that bereavement services should be prepared for family caregivers as well since this is an advanced terminal stage of HCC. In positive thinking, cancer causes many caregivers to look at life in new ways. They think about the purpose of life. And they often focus on what they value most.

In conclusion this study demonstrated how family members experienced physical and psychological sufferings when their loved one suffered from advanced terminal stage HCC. These results will inform future supportive care service development and intervention research aimed at providing assistance in reducing unmet supportive care needs and psychological distress of these family members. Patients and family caregivers may profit from health care professionals in understanding the needs so as to provide proper care.

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