

RESEARCH ARTICLE

Living Experiences of Male Spouses of Patients with Metastatic Cancer in Taiwan

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Abstract

Background: Cancer is the leading cause of death in Taiwan. Spouses are generally the main caregivers of affected patients but previous studies have seldom investigated the needs of male spouses of patients with metastatic cancer. **Purpose:** To explore the lived experiences of such male spouses. **Methods:** A qualitative design using in-depth interviews was conducted with male spouses of patients with metastatic cancer being treated at the oncology outpatient department in a teaching hospital in northern Taiwan. **Results:** Nine participants aged 31-78 were interviewed. Content analysis of the interviews revealed five themes: suffering and struggling, difficulty in focusing on communication and interaction, shouldering responsibility, cherishing the love between husband and wife, and enabling each other to live better. This study demonstrated how male spouse experienced physical and psychological suffering when their wives suffered from metastatic cancer. They had to bear the pain of their wife's suffering, and also had to shoulder the responsibility for everything. All their efforts were put towards enabling each other to live a better life. They cherished the rest of the time they could spend with their wives, even though they had to live a hard life. As the male spouses of patients with metastatic cancer, the participants exhibited both the masculinity of men and the ability to express care and tenderness. **Conclusions:** The results showed that male spouses need more attention in terms of communication and bearing with suffering. Health care professionals should more actively understand the needs and provide assistance when facing the male spouse of patients with cancer, so as make sure that they possess the ability to take care of their wives. Health care professionals should also assist and properly act as a bridge of communication between husbands and wives.

Keywords: Lived experiences - metastatic cancer - male spouses - Taiwan

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Introduction

Cancer is the leading cause of death for people in Taiwan. In 2011, 28% died of cancer among people died from the ten leading causes of death in Taiwan (Executive Yuan, Taiwan, ROC., Department of Health, 2012). Families especially the spouse are mostly the main caregivers of patients with cancer, the needs of the families should be supported and be paid attention. Many studies have indicated that the emotional distress suffered by the spouse is higher than that suffered by the patient; however, the social support for the spouse is less than that for the patient (Hasson-Ohayon et al., 2010). Moreover, patients' distress is associated with that of the caregivers (Matthews, 2003). Traditionally, caregivers have usually been women, such as wives, daughters-in-law, and daughters, etc. When the patients are female, there will be an increasing chance for men to be the caregivers, for example, regarding a study of female patients with cancer, 2/3 of the caregivers were the spouse (Tsai et al., 2007).

Although the number of deaths and the incidences of men died of cancer are higher than those of women,

the data showed that the number of female patients with cancer going to outpatient visits and hospital admission was significantly higher than that of male ones in Taiwan in 2010 (Executive Yuan, Taiwan, ROC., Department of Health, 2011). In other words, female patients have more chances to use medical resources during their survival period. Patients usually need assistance and care during treatment, especially for those who are recurrent or metastatic cancer patients. Some study showed that the quality of life of the caregivers of palliative patients is worse than that of those for patients that are curable (Weitzner et al., 1999). Moreover, with the worsening of the patients' physical function and emotions, caregivers also experience fatigue and overload (Gaugler et al., 2005). Being as a caregiver, male spouse of metastatic cancer patients are at high risk of physical and psychological distress (Hasson-Ohayon et al., 2010).

The concept of gender equity has significantly affected the world, as well as the responsibilities and roles of men and women in both society and the family. Traditionally, the concept of "man for the field and woman for the hearth" has been implemented in life and economic activities. It is

uncommon for men to participate in housework, and their participation is much less frequent than the participation of women (Hwang, 2000). During the growing process, men are constantly affected by gender role stereotypes, and these stereotypes are enhanced again and again (Chu, 2003). For example, the caregiver roles of husbands and sons are affected by different social expectations (Harrias and Long, 1999). The difficulties faced by male caregivers and the meaning of male caregivers may be different from those faced by female ones. Male caregivers' accurate understanding of their wife's condition is significantly lower than that of female caregiver's understanding of their husband's condition (Carlson et al., 2001).

Some studies have found that there is a correlation between gender and the mental health of caregivers (Colgrove et al., 2007). Many studies have shown that the distress of female caregivers is higher than that of male ones (Matthews, 2003). However, some research results have shown that there is no difference in the distress between male and female caregivers (Kim and Carver, 2007). Some studies have even shown that the esteem of male caregivers is higher than that of female ones. Compared with female caregivers, male ones are more willing to view caring experience as part of their self-esteem, and they may also develop higher self-esteem in such a process (Kim et al., 2007). Self-esteem and distress are important predictors for the caregivers' quality of life (Kim et al., 2006). A higher quality of life is correlated with lower caregiver burden, less use of emotional-focused coping, and higher social support (Wagner et al., 2006). When husbands provide their wives with psychosocial care, they suffer from higher caregiving stress (Kim et al., 2006). Therefore, husbands need more assistance to provide their wives with psychosocial care. The frequency of the provision of tangible care has a significant effect on avoidance and gender. Husbands' higher avoidance is associated with less frequent emotional care. Husbands with higher attachment anxiety provide care less frequently, and the patients' poorer mental status is associated with higher difficulty in care. Higher avoidance is associated with higher difficulty. Unsafe attachment quality will intervene with caregiving, which is only observed in husbands (Kim and Carver, 2007).

From the above literature, it seems that the problems encountered by male caregivers are not as urgent as those encountered by female ones where assistance is required. These results may lead professionals to not pay enough attention to male spouses. However, such findings can only explain the difference between male caregivers and female ones, and cannot conclude that male caregivers do not encounter difficulties or need assistance. For example, in terms of care needs, the level of need for assistance from the husband will vary according to the task, ranging from the lowest 6.7% (toilet) to the highest 63% (shopping; Wagner et al., 2006). When males perform the role of caregivers under traditional cultural influences, the stress affects their lives. They particularly need assistance with the psychological and social aspects of assisting their wives.

Data synthesis found that there are few studies on nursing intervention and the supportive care needs

provided for the spouses of female patients with cancer (Petrie et al., 2001). There is needed for more studies on the topic of male spouses, as a reference for the provision of assistance. In order to find the ways to provide appropriate care to the male spouses of metastatic cancer patients, it is necessary to probe into the subjective experience of male spouses. The purpose of this study was to explore the lived experiences of male spouse of patients with metastatic cancer.

Materials and Methods

Research Design

A qualitative research design with an in-depth interview method was used to gather information on the subjective aspects of the experience of being a male spouse of patient with metastatic cancer. The semi-structured interview guideline was created after discussions with three doctoral prepared researchers specialized in qualitative study and cancer care. Before conducting the data collection, a pilot study was processed to confirm the appropriateness of the interview guideline.

Sample and Setting

Purposive sampling was used based on the following criteria: (1) more than 18 years old; (2) male spouse of metastatic cancer patient; (3) no obvious cognitive impairments; (4) ability to communicate or express clearly in Mandarin or Taiwanese and (5) consent to participate in this study. Participants were drawn from the oncology outpatient department in a teaching hospital in northern Taiwan. The location for interviews, chosen by the participants, was either in the privacy room at the hospital or in their place of residence, whichever was the most comfortable and relaxing for them. Nine male spouses aged 31-78 (with an average age of 61 years) of metastatic cancer patient were recruited.

Data Collection and Analysis

Permission for this study was obtained from the Research Committees at the National Taipei University of Nursing and Health Sciences and a teaching hospital, located in Northern Taiwan. Before the formal closure of patient recruitment, researchers had two weeks of oncology outpatient field observations in the hospital to familiarize themselves with the treatment environment and the possible participants. While the patients completed their outpatient treatment, potential participants were approached and given written information that explained the study.

Interviews lasted approximately 60 minutes each. During the interview process, the male spouses were encouraged to express their feelings and their experiences. Interviews were audio-taped with the participant's permission and were transcribed verbatim immediately after the interview. The first author continued to collect data until all the authors were assured that saturation was achieved, that is, data collection was ended when no new themes emerged from the participants' narratives and the data were repeating (Streubert and Carpenter, 2011). In addition, during each interview, the interviewer recorded

the participant's nonverbal behaviors, any special events that occurred and thoughts derived from the interview. Content analysis (Graneheim and Lundman, 2004) was used to analyze the data in this study.

Trustworthiness

Trustworthiness of the data was established by using the criteria of Lincoln and Guba (1985): credibility, transferability, dependability and confirmability. Open-ended interviews were used to verify participants' responses and participants were asked to validate findings to establish credibility. The typed transcripts were carefully checked by listening to each tape again to ensure the accuracy of the transcripts. Using of few controlling conditions, variations in sampling analysis of a large volume of qualitative data established transferability. Dependability was validated using a peer review analyzing process. Three doctoral prepared researchers who specialize in cancer care and qualitative studies, completed the data analysis of the verbatim text alone and then cross-examined the analysis.

Ethical Considerations

Besides written information provided during recruitment, the purpose and process of the study, including the participant's right and protection of identity, were discussed and a signed consent form was obtained prior to the interview. During the interview, when participants raised sensitive issues and information, support was provided and maintenance of confidentiality reassured. During the data collecting process, the participants were allowed to request termination of the interview and deletion of the recorded data for any reason. In addition, to protect the identity of the participants, the researchers used letters (A to I) instead of the participants' real names in presenting the documents or reports of this study.

Results

Content analysis of the interview revealed five themes: (1) suffering and struggling, (2) difficult to focus on communication and interaction, (3) shouldering the responsibility, (4) cherishing the love between husband and wife; and (5) enabling each other to live better.

Suffering and Struggling

The male spouses of patient with metastasis cancer experienced the physical and psychological distress with the uncertainty of wife's illness. It is frustrated that he didn't know how to help his wife when his wife suffer from the disease and treatment, at that time, he also didn't receive any help from others. Suffering and struggling was also the result of concrete influences on their own lives. Other than sleeping poorly or sleeping in separate rooms, couples seldom going out together. The participants said:

"I cannot sleep well..... I am the right one to take care of her all day long." (D) *"I didn't know what to do to help her, and when I felt helpless I did not get help."* (I)

Difficult to Focus on Communication and Interaction

Being as the husbands of metastatic cancer patients,

the participants felt difficult to communicate and interact with their wife in talking about having cancer, sharing the suffer feeling, and expressing the caring. They felt very difficult to talk about having cancer and related issues to their wife. They also felt difficult to understand the thoughts of their wife. The husbands' ways of expressing caring and love were not expected and understood by the wife, it made them felt being misunderstood as well. For example: the participant B said:

"Breast cancer is for women. The first time I went to the outpatient department, I didn't think I needed to go into the clinic with her, and later she was very upset, saying that I didn't care about her at all. But she's a patient! I have never getting cancer, there are some ideas of hers that I just can't understand." (B)

Shouldering the Responsibility

This theme clearly showed that when the male spouses took care of their wives, they relied on themselves and reminded themselves that they needed to be brave and be responsible. They believed that it is unnecessary to discuss the wife's illness, and that no one else could help, not even the gods. They took care of their wife by themselves, and when they got problems, they found the solution by themselves. There was even one husband being worried that his wife's nasal gastric tube had moved out. He worried that his wife would not receive enough nutrients; therefore, he inserted the nasal gastric tube back on his own. Even though it was hard work to take care of their wives, they expressed the attitudes of the male spouses that taking care of their wives was their responsibility, as well as something they must face bravely. They said:

"Being her husband, I have to be brave and face it (problems). If my wife can live for a few more years, of course, I support her life and take care of everything. Otherwise, who is going to take care of her?" (F)

Cherishing the Love Between Husband and Wife

The participants believed that it was necessary to make their wives feel at ease, and that anything could make their wives feel at ease was worth doing. They accommodated each other in daily living. They believed that the relationship of couple is unique, interdependable and unreplaced. They highly value the love and responsibility each other. The participants said:

"If I got sick she would take care of me too! It is fated that husbands and wives need to sacrifice and take care of each other! ...I loved her since she was young until now, how could I stop taking care of her when she is old and sick? I do not allow myself for not taking care of her." (G)

Enabling Each Other to Live Better

The participants used various ways to let themselves and their wives live better, including sincerely take care of treatment related activities and daily living. Except western medicine, they tried to find several kinds of alternative medicine to keep hope. They also sought religious support to reinvigorate themselves and their spouses. The husbands not only took care of their wives but also had to adjust their own mindsets. They believed that being a husband of metastatic cancer patient, experiencing

the suffering is fated. They understood that sadness is not forever, they tried to deal with them peacefully. The participants said:

"I often talk to my wife: 'You got this disease, but don't be sad, don't be upset. You have to feel fortunate, because I buy you whatever you want to eat, I'll take care of whatever you want, or if you go to the bathroom or something, I'll take care for you.'" (C)

Discussion

Being as a male spouse of metastatic cancer patient is a unique hardship. The results of this study showed that the male spouses of metastatic cancer patients have deep feelings of suffering and struggling about their wives' illnesses, and they also feel difficulties in communication such as talking about the cancer with their wives. Even though they are in difficult contexts they demonstrate their abilities and responsibilities as spouses, and they cherish the life experiences formed by such suffering and responsibility.

In this study, the husbands felt difficult to express themselves and unwilling to discuss their negative emotion. In the process of socialization, male is requested that talking must be concise and got the point (Chu, 2003). According to Levant (1992), traditionally, men have been educated to become strong and silent, expressing their love by doing tangible things for others, but they rarely use language to express their feelings. Male caregivers emphasize responsibility, dealing with the problems of caring for the family rationally, and they are quite limited in the personal expression of inner feelings (Lee et al., 2006). Men reported great self-silencing than women, they didn't talk their own needs, put it in order to facilitate coping. Men talked positioned self-silencing as a normal aspect of masculinity. In the past, they do not express vulnerability (Ussher and Perz, 2010). However, in this study, we found that this situation blocked the opportunity for understanding between the couple, and affected their communication through language.

Rabin et al. (2009) found that the spouse of cancer patient know his partner's condition very well, especially on her quality of life. However, the results of this study showed that the husbands did not think they could understand how their wives thought. In this study, one of the husbands did not think it was necessary to go into the clinic with his wife, and she was very troubled by this action. Husband and wife have divergent ideas of caring behavior, and the husband felt a sense of frustration. In the past, men were used to thinking in male parochialism ways about the treatment of women. However, their actions may not have conformed to women's needs. If men do not listen to women's feeling and thoughts, they may feel frustrate or angry that their good will or care does not receive approval (Bih, 2003). Thus, it is important to assist male spouses in talking about themselves, talking about their own feelings, thoughts, and actions, and talking about their difficulties. Other than talking, they can also understand the behaviors expected by their wives, so that when sharing the tenderness and sadness of life, there can be more of the tenderness and less of the sadness.

In this study, for facing the difficulty of having a wife

with metastatic cancer, participants used to take everything on their own shoulders. The husbands usually faced problems by themselves. This may have been a result of the husband's helplessness, and it may be a stereotyped of how he has dealt with problems in the past, but this threatened the patient's safety and quality of care. Some studies found that both men and women's attitudes toward seeking professional help are positive, and there are no significant differences in gender in terms of usage difficulty (Liou, 2008). However, men needs longer time to think about whether using professional psychological institution than women do (Chang and Chen, 2004). Thus, men do not reject seeking help, but their actions for seeking help are not active and aggressive. Men delay seeking help or are unwilling to seek help because of masculinity norms, stereotypes, traditional values (Galdas et al., 2005; Addis and Mahalik, 2003). Hasson-Ohayon et al. (2010) found that friend is the most important support for the male partner. Getting together male's support group may be benefit strategy.

Other than caring for wives, husbands also encourage themselves to be brave. Traditionally, men are the pillars of the family, should be problem-solving, logical thinking, and risk-taking (Levant, 1992). Thus, husbands are capable, self-confident, and willing to take risks, as well as able to complete all care responsibilities on their own. The care ability of male spouses can also improve the lives of the couple. Even though the process is hard work, they can view their relationship with a cherishing attitude. If, someone would actively intervene and provide assistance to male spouses and ease their suffer, the spouses and the cancer patients would be able to have better life.

In conclusion, this study demonstrated how male spouse experienced physical and psychological sufferings when their wife suffered from metastatic cancer. Particularly, the physiological difficult is not so suffering to them as psychological distress is. Traditionally, masculine independence has been considered as the counterpart to feminine dependence. Males suffer because of the pursuit of masculinity, and the formation and breaking of gender role stereotypes is a cyclical process (Chu, 2003). If it is possible to add some new elements for male caregivers when they are being the husband of metastasis cancer patient, maybe there could be some changes to the cycle of stereotype. This study found that in the experiences of males with wives who are metastasis cancer patients, including suffering, empathy, and love for the wives, as well as rational problem solving; this is real life. Following the perspective of postmodernism, people should learn to respect the characteristics differences of genders.

Future studies can combine gender and genetic traits to provide more individualized care services, to find the ways that are easiest for male spouses to express their feelings, or to conduct studies on nursing intervention for communication between married couples.

Health care professionals should be more active to understand the needs of male spouses. Being as a husband of metastatic cancer patients, the male spouses felt suffering and struggle in facing the illness of their wives. However, they had difficult to express their feelings. Levant (1992) believed that while men express emotions, they do it selectively. For instance, anger is an emotion that is

commonly seen in men. Thus, men do not lack the ability of expressing emotions, but are affected by the traditional concepts of gender differences. In addition, while men do not actively seek help, they also do not reject it. Thus, health care professionals should be more active to understand the needs of male spouses.

Health care professionals should assist male spouses to enhance the abilities to provide care. Husbands believe that the relationship with their wives is irreplaceable; thus, taking care of his wife cannot be done by others. When communicating with male spouses, it is not necessary to ask men to show help-seeking behavior like women, or to erase the masculine ideas. Smith et al. (2008) mentioned that for those who can't give up masculinity, it may be important that support them with appropriate method being with masculinity. For instance, following the spirit of shouldering responsibility, health care professionals should assist male spouses to hold the arrangement of care. This will not contradict personal beliefs, and on the other hand it will provide cancer patients and their spouses with optimal care, so that male spouses will not feel helpless.

Health care professionals should encourage the male spouses to express their emotions. Health care professionals should provide opportunities for the husbands to understand more about their wives' diseases and thoughts enthusiastically. They should also encourage the husbands to express their emotions in ways they feel comfortable with. In addition, health care professionals should also assist and properly act as a bridge of communication between husbands and wives.

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