
ORIGINAL ARTICLES

Spouse caregivers of terminally-ill cancer patients as cancer patients: A pilot study in a palliative care unit

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ABSTRACT

Objective: It is known that families of terminally-ill cancer patients show levels of emotional and functional disruption and are called “second order patients,” however, little is actually known about the health problems of family members, especially in terms of cancer.

Methods: This study reviewed the family histories of terminally-ill cancer patients in a palliative care unit and investigated cancer related health problems of the spouses of terminally-ill cancer patients.

Results: We investigated the past medical history of 125 spouses of terminally-ill cancer patients and found that five spouses had a past medical history of cancer. In these five spouses, the duration of illness, present status of treatment and physical condition were reviewed from the database. Of these five spouses, three patients continued to attend an outpatient clinic regularly for checkup and one patient was hospitalized for nephrectomy. Two spouses did not have physical symptoms that made them unable to provide direct care for the terminally-ill spouses, while three could not provide care because of their own physical symptoms derived from cancer.

Significance of results: Our findings indicated that some of the spouses of terminally-ill cancer patients are not only “second order patients” but also “cancer patients.” Our findings also suggest that some spouses of terminally-ill cancer patients might experience distress both as a cancer patient and as a spouse and may need care both as a cancer patient and as a spouse.

KEYWORDS: Cancer, Caregiver, Spouse

INTRODUCTION

Recent studies demonstrated that family members of the cancer patient, as well as the cancer patient, show as much or even higher psychological distress (Kissane et al., 1994; Northouse et al., 1995). There are several reasons for psychological distress among family members. The family of the cancer patient is expected to provide patient care. There are shared

responsibilities for decision-making, providing concrete care-giving, meeting the financial and social costs, maintaining stability, and adapting to change. In addition, some family caregivers are involved in direct patient care. These responsibilities place both physical and emotional burdens on the family members. It has been shown that spouses demonstrate levels of emotional and functional disruption as great or greater than the patient's, and that these problems often worsen with time, independent of the patient's mood or health (Kaye & Gracely, 1993). Based on these findings, family members of the cancer patient are called “second order patients” (Lederberg, 1998).

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Health problems of the caregivers have a very important influence on their ability to meet these demands and it is reported that caregiving affected the physical health of spouse caregivers (Teel & Press, 1999). Some caregivers may be physically weak or sick, and some may demonstrate symptoms of cancer. If the caregiver is also a cancer patient, the caregiver may also experience psychological and physical distress both as a cancer patient and as a caregiver. However, little is known about the health problems of caregivers also experiencing cancer.

As a first step to investigate the distress of a family care giver with cancer, we reviewed the family histories of terminally-ill cancer patients in a palliative care unit and investigated the cancer-related health problems of the spouses of terminally-ill cancer patients. It is known that approximately 70% of primary family caregivers are spouses (Ferrell et al., 1991) and we thought that health problems of spouses would affect the style of caregiving in the family.

MATERIALS AND METHODS

All terminally-ill cancer patients admitted to the palliative care unit of Kanagawa Cancer Center between August 2002 and January 2004 were researched along with their family members, as potential participants in this study. In most cases, patients were admitted to the palliative care unit for end-of-life care.

All patient data are recorded in the database, including age, sex, marital status, tumor locations, and treatment. Family histories of cancer, including site, duration, and present cancer treatment, are also recorded in the database for family care. Data are obtained from the patient's charts and/or interviews conducted by physicians and nurses as part of the routine care for patients and families.

RESULTS

During the study period, 159 patients were admitted to the palliative care unit. Regarding the spouses of these 159 patients, 34 (21%) were widowed or divorced. We investigated the remaining 125 patients and their spouses. The spouses were 94 males and 31 females. The average age was 63.8 ± 10.9 years with a range of 35 to 92 years.

Of the 125 spouses, five (4%) had a medical history of having cancer. The clinical characteristics of these five spouses are summarized in Table 1 and the case histories of the five spouses are as follows.

Case reports

Case 1

A 62-year-old female, had breast cancer fifteen years earlier, underwent mastectomy, and a fifteen-year disease-free period followed. She was not currently receiving regular checkups for breast cancer.

Case 2

A 69-year-old female, had stomach cancer five years earlier and underwent gastrectomy, then developed breast cancer four years earlier and underwent mastectomy. She was currently receiving monthly checkups at the outpatient clinic. There were no signs or symptoms of recurrence recognized during the study period.

These two spouses could provide direct care of a terminally ill cancer patient in a palliative care unit.

However, in cases 3, 4, and 5, spouses could not provide direct care of a terminally-ill cancer patient because of physical symptoms derived from cancer and ongoing the cancer treatment.

Table 1. Clinical characteristics of the spouses of terminally-ill cancer patients who also have cancer

No.	Age	Sex	Origin	Interval since diagnosis (years)	Present status	Provide direct care?
1	62	F	Breast	15	Disease-free for 15 years, not currently receiving check-ups	Yes
2	69	F	Stomach Breast	5 4	Receiving monthly checkups	Yes
3	68	M	Liver	Unknown	Almost bed-ridden, regular check up	No
4	73	F	Kidney	0	Nephrectomy recently performed	No
5	71	F	Meninges	4	Wheelchair-bound, regular check up	No

Case 3

A 68-year-old male was diagnosed as having liver cirrhosis and cancer, and could not come to the palliative care unit because he was bedridden almost all day long.

Case 4

A 73-year-old female was diagnosed as having renal cancer when her husband admitted to the palliative care unit. She was admitted to another hospital and underwent nephrectomy.

Case 5

A 71-year-old female could not walk after resection of meningioma, and her husband and her children took care of her until the husband was admitted to the palliative care unit.

DISCUSSION

During terminal illness, spouses face not only the problem of the present illness but also the forthcoming bereavement, and show signs of emotional and functional disruption. Approximately 20 to 30% of spouses of cancer patients develop psychological impairment and mood disorders (Blanchard et al., 1997). It is reported that spouse caregivers of cancer patients show as much or even higher psychological distress than patients (Northouse & Swain, 1987; Baider & Kaplan De-Nour, 1988; Northouse et al., 2000), and show a lower quality of life (QOL) than non spouse caregivers (Hughes et al., 1999). Most of the research to date has focused on the distress of the spouses of cancer patients from a family perspective (Kaye & Gracely, 1993; Kissane et al., 1994; Northouse et al., 1995). However, we demonstrated that some of the spouses are not only the spouse of a terminally-ill cancer patient, but also a cancer patient themselves, and some of these spouses are still receiving treatment and/or regular checkup for their cancer. These findings suggest that some spouses of terminally ill cancer patients should be considered not only as caregivers, but also as cancer patients. Our findings suggest that some spouses of terminally-ill cancer patients might experience distress both as a cancer patient and as a spouse and need care as both a cancer patient and a spouse.

When terminally-ill cancer patients were married to someone who had a history of cancer, the ability to provide care differed with each spouse. Some spouses were nearly disease-free and did not have physical symptoms that made them unable to provide direct care of the terminally-ill cancer patient,

while others experienced physical symptoms of cancer and could not provide care for terminally-ill cancer patients. The spouses who could not provide direct care of the terminally-ill patient sometimes experienced increased distress because of their inability to provide care for their terminally-ill spouse, and their need to request care-giving from other family members not only for terminally-ill cancer spouse but also for themselves. Further study will clarify the psychological distress in these spouses.

These spouses of a terminally-ill cancer patient also experience bereavement. It is reported that some cancer patients develop various kinds of psychological distress, including depressive disorder, manic episodes, brief psychotic disorder, and conversion disorder, after they experience bereavement (Onishi et al., 2000, 2003, 2004). In these reports, the death of close friends evoked concern for their own mortality, which led to the onset of psychotic symptoms. Several factors, such as the existence of a close relationship and financial status, are recognized as causing complications during bereavement (Beckwith et al., 1990). In these cases, the death of close family members due to cancer, together with the experience of their own cancer, likely evoked concern regarding their own death. It might be necessary to follow these spouses who experienced cancer after they were bereaved of the terminally-ill cancer spouse. Psychiatric intervention might prevent the development of these psychiatric disorders. Further study will demonstrate the psychological distress level and psychiatric interventions needed for these members.

This study has several limitations. First, we investigated the spouses of terminally-ill cancer patients only. Other family members that care for terminally-ill cancer patients while demonstrating cancer symptoms were not included in the study. Second, this study was performed at only one palliative care unit of a cancer center hospital. Therefore, our data cannot claim to be representative, and institutional bias may have confounded the findings. Third, in this study, as 21% of the terminally-ill patients were widowed or divorced, the exact prevalence of spouse caregivers with cancer themselves who are providing for a terminally-ill cancer patient was not investigated. Fourth, our study design was retrospective and we could not investigate the psychological distress of these spouses.

In conclusion, we identified terminally-ill cancer patients in a palliative care setting with spouses who were also experiencing cancer. Medical staff should be aware that some family members of terminally-ill cancer patients are also experiencing cancer and may feel distress both as a cancer pa-

tient and as a caregiver. Further study will clarify the psychological distress level and indicate appropriate interventions for these families.

REFERENCES

- Baider, L. & Kaplan De-Nour, A. (1988). Adjustment to cancer: Who is the patient-the husband or the wife. *Israel Journal of Medical Science*, *24*, 631–636.
- Beckwith, B.E., Beckwith, S.K., Gray, T.L., et al. (1990). Identification of spouses at high risk during bereavement: A preliminary assessment of Parkes and Weiss' Risk Index. *Hospice Journal*, *6*, 35–46.
- Blanchard, C.G., Albrecht, T.L., & Ruckdeschel, J.C. (1997). The crisis of cancer: Psychological impact on family caregivers. *Oncology*, *11*, 189–194.
- Ferrell, B.R., Ferrell, B.A., Rhiner, M., et al. (1991). Family factors influencing cancer pain management. *Postgraduate Medical Journal*, *67*, Suppl 2, S64–9.
- Hughes, S.L., Hurder, A.G., Weaver, F.M., et al. (1999). Relation between caregiver burden and health related quality of life. *Gerontologist*, *39*, 534–545.
- Kaye, J.M. & Gracely, E.J. (1993). Psychological distress in cancer patients and their spouses. *Journal of Cancer Education*, *8*, 47–52.
- Kissane, D.W., Bloch, S., Burns, W.I., et al. (1994). Psychological Morbidity in the families of patients with cancer. *Psycho-Oncology*, *3*, 47–56.
- Lederberg, M.S. (1998). The family of the cancer patient. In *Psycho-Oncology*, Holland, J.C. (ed.). New York: Oxford University Press.
- Northouse, L.L., Dorris, G., & Charron-Moore, C. (1995). Factors affecting couples' adjustment to recurrent breast cancer. *Social Science Medicine*, *41*, 69–76.
- Northouse, L.L. & Swain, M.A. (1987). Adjustment of patients and husbands to the initial impact of breast cancer. *Nurse Research*, *36*, 221–225.
- Northouse, L.L., Mood, D., Templin, T., et al. (2000). Couples' patterns of adjustment to colon cancer. *Social Science Medicine*, *50*, 271–284.
- Onishi, H., Miyashita, A., & Kosaka, K. (2000). Manic episode associated with bereavement in a patient with lung cancer. *Supportive Care in Cancer*, *8*, 339–340.
- Onishi, H., Onose, M., Yamada, T., et al. (2003). Brief psychotic disorder associated with bereavement in a patient with terminal stage uterine cervical cancer: A case report and review of the literature. *Supportive Care in Cancer*, *11*, 491–493.
- Onishi, H., Kamijo, A., Onose, M., et al. (2004). Conversion disorder with convulsion and motor deficit mimicking the adverse effects of high-dose Ara-C treatment in a post-transplant acute myeloid leukemia patient: A case report and review of the literature. *Palliative and Supportive Care*, *2*, 79–82.
- Teel, C.S. & Press, A.N. (1999). Fatigue among elders in caregiving and non-caregiving roles. *West Journal of Nurse Research*, *21*, 498–520.