ILLNESS EXPERIENCE AND COPING WITH GYNECOLOGICAL CANCER AMONG NORTHEAST THAI FEMALE PATIENTS

Amornrat Ratanasiri[1], Pimpawun Boonmongkon[2], Preecha Upayokin[2], Prasit Pengsaa[1]
and Vanchai Vatanasapt[3]

[1]Department of Community Medicine, Khon Kaen University, Khon Kaen 40002, Thailand;
[2]Department of Medical and Health Social Sciences, Mahidol University, Nakhon Prathom 17310, Thailand; [3]Cancer Institute, Srinagarind Hospital, Khon Kaen 40002, Thailand

Abstract. This quantitative and qualitative study describes the illness experience and the coping mechanisms of cervical cancer patients. Interviews were performed with 208 cervical cancer patients to determine their health seeking behavior and illness beliefs. Most began their treatment at local health services and district hospitals, and sought treatment in up to four different places before coming to the University Hospital. Most of the respondents were not sure about the cause of cervical cancer, and waited to see their symptoms before seeking treatment. Most perceived their condition as at an early stage. The qualitative research consisted of interviews with 79 selected patients and identified stigmatization from family and community members, problems with sexuality, and varied belief in meaning and causation of the disease. Many of the problems faced were coped with because of support from husbands, family and the community. It is recommended that better recording of patient data would allow a better follow-up service, and improved information for relatives would help them to understand the patient's problems, with both of these contributing to a better recovery environment for patients.

INTRODUCTION

Apart from threatening the life of the patient, cancer also causes psychological damage during treatment. It induces severe stress, loss of self-esteem and low morale of patients (Srimoragot, 1994) as well as extending its malign influences to causing social and economic problems. It costs a great deal for treatment, estimated at more than 4-10 times that of other diseases (American Cancer Society, 1988).

Cancer is the third highest cause of death for Thai people. There are 80,000 new cases and 17,000 who die of this disease each year (Ministry of Public Health, 1996; Hangsubcharoen, 1996). The National Cancer Institute of Thailand reports that 63.2% of cancer patients in Thailand are women and most of those women have gynecological cancer (National Cancer Institute of Thailand, 1994).

Gynecological cancer is one of the most serious public health problems in the world with the main gynecological cancers, cervical, breast and ovarian, causing morbidity with severe suffering and a high mortality (Ronald, 1990). Of these three cancers, cervical cancer is the most significant disease affecting women's health all over the world (Chutidumrongphan, 1996; Chugiart, 1996). There are more than 450,000 new cases each year and 350,000 of these are found in the developing countries (WHO, 1986). Cervical cancer also ranks highest among women's cancer cases in Thailand (Ministry of Public Health, 1996). There are 5,000-6,000 new cases each year and the incidence rate is 24/100,000 (Pengsaa, 1995). In Khon Kaen Province of Thailand, the data reported at the Cancer Unit, Srinagarind Hospital shows that female cancer patients suffer cervical cancer the most, with mortality rates from 1988-93 of 20, 31, 35, 41, 44 and 45/100,000, respectively. Most of these patients came to hospital at a final stage (Pengsaa, 1995).

The basic treatments for cervical cancer at Srinagarind Hospital are surgery, radiotherapy, combined treatment or supportive treatment. Invasive cancer that has spread into other organs and needs surgery will require hospitalization. General counselling for gynecological cancer is performed while the patients receive treatment at this hospital. Unfortunately however the counselling neither includes one-on-one advice nor stresses problems such as trauma and side-effects encountered in specific cases. Most of the cancer patients suffer

---

Correspondence: Dr Amornrat Ratanasiri, Department of Community Medicine, Khon Kaen University, Khon Kaen 40002, Thailand.
Tel: 66-43-348-391; Fax: 66-43-243-104; E-mail: amorat1@kku.ac.th

psychological distress associated with the disease such as pain, anxiety, stigma, sexual dysfunction, deformation, perception of illness severity, fear of death, influence on quality of life and effect on family members especially children (Krumm and Lambiertit, 1993; Luker *et al*, 1996). Cervical cancer also affects patients' sexual lives and how they view themselves sexually. Some women find it difficult to regain their sexual feeling (Steinberg and Robinson, 1995). After surgery, they may feel they have lost femininity and sexuality. This problem needs individual counselling about how to live with their disease.

This paper documents how women in the northeast of Thailand experience and cope with cervical cancer and its impacts on both them and their families in various ways.

METHODOLOGY

This study combines quantitative, qualitative and descriptive research, using interviews to collect quantitative data. The study design was based on a conceptual model as shown in Fig 1.

The sampling process for the quantitative and qualitative study groups is shown in Fig 2. There were 208 patients for the quantitative study who were interviewed in 1998, while there were 79 patients and key-informants for the qualitative study who were interviewed in 1999.

The research sites were five villages in each of rural and urban areas, and the city of Khon Kaen. There were 2-4 visits to each patient's village. In-depth interview was used in each visit to the 79 patients, while key-informant interviews were performed with the patients' family members, village leaders and neighbors to gain information about family and social reaction to the patient, community beliefs about the disease, the community's social and economic structure and government and private health services.

Data processing and analysis

Quantitative data: The quantitative data was processed by coding data and using SPSS PC$^+$ (Statistical Package for the Social Sciences/Personal Computer Plus) for analysis. Descriptive statistics were presented as percentages.

Qualitative data: Tape recordings were transcribed into written field notes. The researchers checked missing data, inconsistencies and mistakes in recording data from field work.

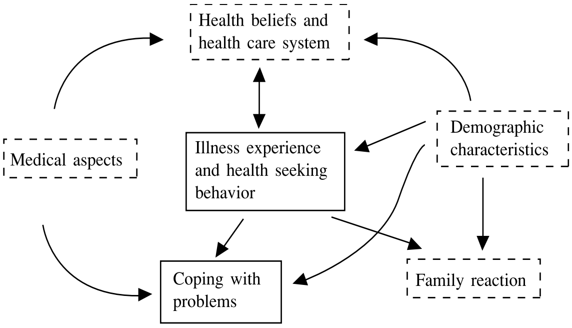

Fig 1–Conceptual model used in this study.

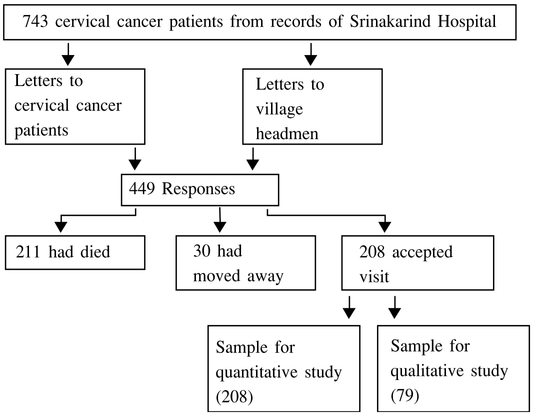

Fig 2–Sampling for study group.

Data was open coded from the field notes of the interviews to produce concepts that seemed to fit the data. The codes follow topics of interview guidelines:

1) Setting (*eg* : demographic characteristics, existing health care resources).

2) Definition (*eg* : what this patient believed about the disease causation).

3) Perspective (*eg* : perception of illness severity, family reaction to illness).

4) Activities (*eg* : pattern of health seeking behaviors or illness experiences).

5) Events or specific happenings (*eg* : symptoms before seeking treatment).

6) Strategies (*eg* : coping mechanisms and adaptation to problems).

All ideas were examined and certain ones selected (*eg* : to seek emic perspective to document folk analysis) to check whether to accept or reject folk explanations about concepts of death, stigmatization, sexuality, and belief of disease causation. The data were then worked into an organized and understandable unit.

RESULTS

Basic information about the cervical cancer patients, their health seeking behavior and Khon Kaen health care resources are summarized in Table1.

The treatment behavior (Table 2) seen in this study can be summarized in five patterns. The pattern found most commonly (83.4%) was pattern 1 (Fig 3), in which the patients waited to observe symptoms before being advised to go for treatment, and then worked through the health system until arriving at the University hospital.

In pattern 2 (7.6%) the patients have severe symptoms, and so are taken directly to a hospital, finally having follow-up treatment at the University hospital. In pattern 3 (3.8%), patients are seeing a doctor before having symptoms, and the doctor advises them to go to a district hospital or other hospital. In pattern 4 (2.5%) patients choose to have treatment in another province because of stigma. In pattern 5 (2.5%) the patients receive treatment in another province before coming to University hospital.

Table 1
Cervical cancer patients' demographic characteristics, illness experiences and health-seeking behavior and health care resources in Khon Kaen Province.

Demographic characteristics of patients
- Married and living with husband (67%) or widowed (21%).
- Primary (39%) or lower secondary education (27%).
- Currently (55%) or previously (19%) a farmer.
- No income (27%) or less than 2,000 baht/month (35%).
- Able to afford treatment costs at least partly (71%).

Medical aspects
- Abnormal menstruation or bleeding (49%) and leukorrhea with bad smell (34%).
- Believed they had stage 1(55%) or unstaged (39%) cancer.

Illness experiences and health seeking behavior
- Went for treatment within 2-7 days (68%) or waited more than 30 days (26%).
- Delayed treatment because the symptoms were not severe (67%) and did not delay because of work (64%).
- First told husband (48%) or children (23%) about their problem.
- Did not know the cause of cervical cancer (71%).
- Had no health card during treatment (57%).
- Received treatment regularly (78%).
- Is now healthy with no symptoms (46%) or is receiving treatment and is healthy (33%).

Health care resources in Khon Kaen Province
- Health volunteers – One or more trained health volunteers per village.
- Drug and grocery stores – Selling paracetamol, penicillin, herbal medicine etc.
- Health stations – One per big village manned by midwives or nurses.
- Private clinics – About 100, manned by a doctor.
- VD Clinic – Provides pelvic examinations and laboratory work.
- District hospitals – 19, each with 30-60 beds and 2-4 doctors. Pap smears.
- Maternal and Child Health Center – Gyne doctor + about six trained nurses.
- Private hospitals – 6 providing pap tests and cervical cancer management.
- Provincial hospital – 3-4 doctors + nurses. Pap smears etc.
- University hospital – Treatment of cancer + complicated cases.

Table 2

Places where patients sought treatment for their cancer, their reasons, the treatment method and its result.

Treatment no.	Reason for seeking treatment here	Place where treatment sought					Did not seek treatment	Treatment method	Result of this treatment
		Local health service	District hospital	Provincial hospital	Central hospital	University hospital			
1	Near house 40% Referral 38%	12%	25%	15%	14%	16%	0%	Others 62% Self-medication 22%	No treatment 27% Treatment/healthy 14% Treatment/unhealthy 12%
2	Referral 41% Doctor's ability 23%		7%	8%	14%	50%	12%	Others 29% Radiotherapy 22% Combined 16% Surgery 13%	No symptoms/healthy 25% Treatment/healthy 24%
3	Doctor's ability 49% Referral 18%			5%	7%	32%	49%	Combined 16% Radiotherapy 14%	No symptoms/healthy 11% Treatment/healthy 19%
4	Referral 18%				7%	10%	79%	Others 12%	Healthy 8% Others 8%

Community health beliefs on the cause of cervical cancer

The data are from in-depth interviews with the 79 patients and 77 key-informants in the study. The popular beliefs on the causes of cervical cancer are:

1) Eating taboo food (*eg* raw fish) or receiving toxic substance (13%).

2) Husband infecting the wife through extra-marital sex with an unclean woman/ prostitute and then transferring fungus or germ to his wife (7%).

3) Bad *karma* caused by the patient's personality (4%).

4) Heredity since relatives had died from cancer (3%).

5) Infected uterus associated with poor hygiene (3%).

6) Tumor growing inside the uterus causing abdominal pain which becomes cancer (3%).

7) Not sure, but think:
  a) It can be cured (13%).
  b) Should ask someone about the disease (9%).
  c) It can be transmitted (8%).
  d) It is a terrible illness (8%) etc.

Patients' beliefs on the cause of cervical cancer

1) Poor hygiene from working in a dirty place and dirt entering body from a rice field/fish pond or from urination without washing, or from dirt transferred to body by the poor hygiene of their husbands (11%).

2) Husband infecting the wife (10%).

3) Bad *karma* (9%).

4) No follow-up after delivery or not having *Yuu Fai* (traditional practice to dry out uterus) or working too hard (8%).

5) Heredity (6%).

6) Eating taboo foods (6%).

7) Not sure, but think:
  It is a terrible illness (34%).
  It should be concealed (5%) etc.

Family reaction to the patient

Husband and wife relationship: There were 3 different ways that husbands reacted to their wives illness:

a) Sympathetic and supportive *eg* taking the patient to see a doctor or buying some medicine, encouraging the patient to rest and taking over household tasks, showing concern and attending to the patient while sick, and voluntarily ceasing sexual relations.

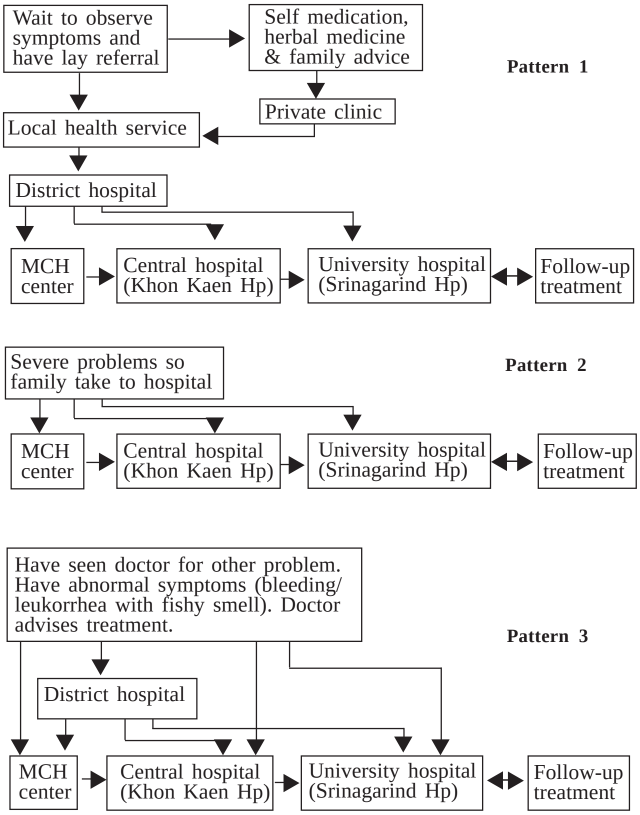

Fig 3–The main patterns of health seeking behavior observed.

b) Mixed, indifferent or negative reactions *eg* general indifference and lack of attention and support, and a continuation of expectations of sexual intercourse despite the woman's pain. Two couples separated during treatment.

c) Not supportive because they did not know about their wife's illness so the wife needed to avoid sex.

Daughter and mother relationship: Daughters reacted in 3 ways to their mother's illness:

a) Positive reactions and supportive behavior *eg* buying medicine, taking to see doctor, encouraging to rest or taking over household tasks, asking about symptoms and attending to the patient personally while sick.

b) Negative reactions and non-supportive behavior *eg* avoiding contact.

c) Supportive behavior with fear *eg* fearing disease but still supportive.

Problems and coping mechanisms

The most common problems the patients encountered and the strategies and factors relating to their resolution were:

a) Fear of death. Religious beliefs about bad *karma* helped the patients to cope, and family support was an important factor leading to reduced fear of death.

b) Economic problems. These were overcome by the family working harder, or by receiving or borrowing money from relatives. The family and relatives' support was important.

c) Perceived self stigmatization/social rejection. Patients coped by revealing their illness, or by going away and concealing it. Family and community support helped.

d) Sexual relations. The patients discussed the problem with their husbands, or concealed it and avoided sex. The gender role of the patient and the husband's support were important.

DISCUSSION AND CONCLUSIONS

This study of illness experience and coping with cervical cancer was conducted to describe the women's health seeking behavior and the way they coped with their disease. Illness experience and coping mechanisms of cervical cancer patients are shaped by the level of stigmatization attached to the illness experience in terms of sexual relationships with their husbands, beliefs in the meaning and causation of cervical cancer as well as the health care system being utilized. There are patterns of illness experience, health seeking behavior and coping processes for psycho-social problems and economic problems.

Most of the respondents in the ethnographic study had severe bleeding and leukorrhea with a fishy smell before they told their husbands, or their children, or their relatives, and then sought treatment. Family members and/or neighbors took them to hospital. Most of the patients were not sure about the cause of their disease but thought that this disease is very severe and leads to death. After they knew that they had cervical cancer they decided to receive treatment immediately, usually at the hospital near their house, and went later to the provincial hospital or university hospital because the doctor advised them.

There were 5 different patterns of health-seeking behavior observed, but the most common was to wait to observe symptoms, have self medication, and tell family members, especially husbands, children and relatives, and then to go to see health staff or doctors at public or private health services which are very near their houses.

The respondents had psycho-social problems and economic problems *eg* fear of death, perceived self stigmatization/ social rejection, and also had problems with sexual relations. They needed to cope with these. Some patients did not succeed in coping with these problems, but some did. Family support; financial support from the family members, or relatives, or neighbors, understanding from husbands, family members, and community members helped them to cope. It is very fortunate that the community members feel pity for these patients rather than stigmatize them.

In conclusion, the illness experiences and coping mechanisms of the psycho-social problems and economic problems are related to beliefs of disease causation, self-stigmatization and sexuality. The coping mechanisms are shaped by the level of stigmatization attached to the illness in terms of sexual relationships with their husbands, beliefs in the meaning and causation of cervical cancer, as well as the health care system being utilized.

RECOMMENDATIONS

On the basis of the results obtained in this study the following recommendations are put forward to achieve further improvement of illness experiences and coping with psycho-social and economic problems due to having cervical cancer:

1). Recording of the correct address needs to be ensured during registration, so that the health personnel or others who have the responsibility to visit patients at their houses are able to contact the patients regularly. Patients will gain moral support, and succeed in coping with gynecological cancer problems.

2). Informing the patient's family and/or the patient's relatives about the physical or mental problems of the patient which need family support will help the patient's family and/or the patient's relatives understand the patient's illness.

Suggestions for other ways to improve illness experiences and coping with gynecological cancer problems from this baseline data are as follows.

1) Usually the cervical cancer patients come to see a doctor when their illness is stage 2, 3 or 4. It would be better if information was provided to the public about how to detect this disease at an early stage by themselves, and where to go to see a doctor to receive effective treatment.

2) Most of the cervical cancer patients lived with suffering from fear of death, had economic problems, felt self stigmatization and social rejection, and had problems of sexual relations. A special counsellor could establish personal contact and good rapport with the patients and their families.

3) Involving peripheral personnel, such as the village health volunteers and professional health workers in follow-up activities, and to supervise health centers where chemotherapeutical treatment can be provided, would make it easier to visit patients, reduce travelling time and effort of the patients and their relatives, ease the load on Srinagarind Hospital and increase cost effectiveness.

4) Psycho-social problems and economic problems are very interesting. A new study should concentrate on illness experience and psycho-social problems, economic problems and coping mechanisms during three months after diagnosis and treatment, six months after follow-up treatment, one year after treatment and several years after treatment or follow-up treatment. This would explain illness experiences, psycho-social and economic problems more effectively in the different stages.

5) Doctors or health staff should be concerned about the patient's psycho-social and economic problems and should apply treatment procedures to the patients with a holistic approach.

ACKNOWLEDGEMENTS

The authors wish to thank Mr Ian Thomas, Department of Physics, Faculty of Science, Khon Kaen University, Khon Kaen, Thailand, for his assistance in editing this manuscript.

REFERENCES

American Cancer Society, Cancer facts and figures, New York: American Cancer Society, 1988.

Chutidumrongphan A. An application of the health belief model and group process to promote PAP smear attendance behavior among women in Promkiri district of Nakorn Sri Thammaraj Province. Mahidol University, 1996: Graduate Studies, MSc Thesis (Public Health).

Chugiart N. Ways of Motivating Rural Women in Dankhuntod District of Nakhon Ratchasima Province to attend PAP Smear Test. Mahidol University, 1996:

Graduate Studies, MSc Thesis (Public Health).

Hangsubcharoen M. Quality of life of patients with ovarian cancer receiving chemotherapy. Faculty of Graduate Studies, Mahidol University, 1996.

Krumm S, Lambiertit J. Change in sexual behaviour following radiation therapy for cervical cancer. *J Psychosom Obstet Gynecol* 1993; 14: 51-63.

Luker KA, *et al*. Meaning of illness for women with breast cancer. *J Adv Nurs* 1996; 23: 1194-201.

Ministry of Public Health (MOPH), Bureau of Health Policy and Planning and Division of Epidemiology Health in Thailand 1995-1996; 1996.

National Cancer Institute of Thailand, Statistics Report of Gynecological Cancer. 1994; 23.

Pengsaa P. Report of literature teview on cervical cancer. Department of Obstretics and Gynecology. Faculty of Medicine, Khon Kaen University, Khon Kaen, Thailand, 1995.

Ronald WR. The theory and practice of oncology: Historical evolution and present principles. New Jersey: Parthenose Publishing Group, 1990.

Srimoragot P. Effects of supportive counseling on perceived illness in self-esteem and morale in cervical cancer patients undergoing radiotherapy, 1994.

Steinberg R, Robinson L. Cancer risks: Women's sexual health, United States of America: Donald I Fine, 1995.

WHO, Control of cancer of the cervix uteri. *Bull WHO* 1986; 64: 607-18.