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**THE INFORMATIONAL NEEDS OF WOMEN
WITH CERVICAL CANCER**

*A thesis presented in partial fulfillment of
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ABSTRACT

Women diagnosed with cervical cancer are confronted with enormous physical and emotional distress. Information plays a significant role in these women's coping process, enabling them to understand their situation, make adjustment in life and erase their feelings of isolation, and stigmatization. So far, little research has been done in New Zealand to study the information need profile of women with cervical cancer, and the extent to which they are satisfied with the information. The present study offers insight into cervical cancer patients' informational needs, their level of satisfaction with information, and the current ways of information delivery in the region.

Twenty cervical cancer patients from the greater Auckland region and eleven health professionals were recruited for this evaluative study. Semi-structured face-to-face interviews were used to collect data from both patients' and health professionals' perspectives. Results show areas of high informational needs among the participants, and suggest that emphasis should be placed on providing sufficient information in the areas with deficits, such as the causes of cancer, life expectancy, changes in sexual function, how other people live with the disease, and where to get information when needed. Evaluating the participants' use of informational sources reveals that they obtained information from a variety of sources. Some information services, such as patient counseling and support services, the Cancer Society and the oncology district nursing services were helpful but under-utilized by the patients.

Overall, the study shows that most patient participants were satisfied with the information provided by health services in the region. However, the existence of gaps between information needs and satisfaction in certain areas, and the reports of multiple barriers in patients' access to information, indicate that the informational needs of women with cervical cancer had not been adequately met. The findings stress the importance of individual assessment, care coordination and close collaboration among service providers. To provide patients with easily accessible, clearly defined, and readily available information was a recurrent theme in the participants' recommendations to information services in the region.

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TABLE OF CONTENTS

	Page
Acknowledgements	iii
Chapter 1: Introduction	1
1.1 Background of the study	2
1.2 Aim of the study	5
1.3 Structure of the thesis	7
Chapter 2: Literature Review	9
2.1 Patients' informational needs	9
2.2 Sources of information	15
2.3 Barriers to information	16
Chapter 3: Method	19
3.1 Research questions	19
3.2 Participant selection	20
3.3 Data collection	21
3.4 Interview schedule for patient participants	23
3.5 Interview schedule for health professional participants	24
3.6 Data analysis	26
Chapter 4: Results I: Patient Participant Interviews	27
4.1 Demographic characteristics	27
4.2 Informational needs and levels of satisfaction	30
4.3 Sources of information and degrees of helpfulness	34
4.4 Barriers against patients' access to information	38
4.4.1 Participants' knowledge of the informational sources	38
4.4.2 Participants' access to information	40
4.4.3 Difficulties in asking questions	41
4.4.4 Difficulties in understanding the information provided	44
4.4.5 Inconsistent and inaccurate advice to the participants	46
4.4.6 Special needs of new immigrants or people who know little English	46
4.5 Recommendations to the informational services	47

Chapter 5: Results II: Health Professional Interviews	53
5.1 Key informant information	53
5.2 Patients' informational needs	54
5.3 Sources of information for patients	59
5.3.1 Sources within hospital	59
5.3.2 Sources in community	60
5.4 Barriers against patients' access to information	61
5.4.1 Patients' knowledge of the informational sources	61
5.4.2 Patients' access to information	62
5.4.3 Patients' difficulties in asking questions	63
5.4.4 Patients' ability to understand and communicate with health providers	65
5.4.5 Inaccurate and inconsistent advice to patients	67
5.4.6 Barriers against Maori patients' access to information	68
5.5 Recommendations to the informational services	71
Chapter 6: Discussion	74
6.1 Informational needs	74
6.2 Sources of information	76
6.3 Barriers to information	80
6.4 Participants' recommendations	84
6.5 Limitations of the study	86
Chapter 7: Conclusion	89
Appendices:	92
Appendix I: Interview schedule for patient participants	93
Appendix II: Interview schedule for health professional participants	99
Appendix III: Patient participant information sheet	104
Appendix IV: Health professional participant information sheet	107
Appendix V: Participant consent form	110
Appendix VI: Binomial test of proportions	112
References	113

LIST OF FIGURES

	Page
Figure 4.1: Age distribution of patient participants	28
Figure 4.2: Ethnic origin of patient participants	28
Figure 4.3: Education level of patient participants	29
Figure 4.4: Patient participants' overall level of satisfaction	33
Figure 4.5: Sources of information and degrees of helpfulness	36

LIST OF TABLES

	Page
Table 4.1: Patient participants' informational needs and levels of satisfaction	32
Table 4.2: Patient participants' additional information needs and levels of satisfaction	33
Table 4.3: Sources of information and degrees of helpfulness	35
Table 5.1: Key informant information	54
Table 5.2: Information cervical cancer patients requested frequently from key informants (Responses to the 16 items listed in the interview schedule)	55
Table 5.3: Information cervical cancer patients requested frequently from key informants (Additional information supplied by key informants)	56
Table 5.4: Information that the Oncology specialists frequently provided to cervical cancer patients	57
Table 5.5: Information that the nurses in hospital frequently provided to cervical cancer patients	57
Table 5.6: Information that the nurses in community frequently provided to cervical cancer patients	57
Table 5.7: Information that the patient counselors frequently provided to cervical cancer patients	58
Table 5.8: Information that the Maori health workers frequently provided to cervical cancer patients	58

CHAPTER 1: INTRODUCTION

The term “cervical cancer” became familiar to the New Zealand public in 1988, when *The Report of the Cervical Cancer Inquiry* was released and attracted huge public interest. In the report, Judge Cartwright reveals details of the inquiry into allegations concerning the treatment of cervical cancer at the National Women’s Hospital and recommends urgent implementation of a nationally planned population-base cervical cancer screening program (Cartwright, 1988). This report was adopted by the Government of New Zealand at the time and a nationwide cervical cancer screening campaign began in late 1989. According to the latest figure released by the Ministry of Health (1998), 83% of eligible women in New Zealand were enrolled on the National Cervical Screening Program and had had a cervical smear in the previous 5 years, by the end of 1997. The significant improvement of cervical screening coverage in the country attributed to the reduction of cervical cancer incidence and mortality in recent years.

Each year in New Zealand, around 230 women are diagnosed with cervical cancer, and 85 women die from the disease (Ministry of Health, 1998). By the time they reach 75 years of age, the chance for New Zealand women to develop cervical cancer is approximately 1 in 91. New Zealand women of recent generations have an increased risk of developing cervical cancer due to changes in their sexual behaviour. The cervical cancer incidence in the country is highest among women aged 40-69. The latest available data on cervical cancer incidence and mortality by ethnicity indicates that Maori women have high incidence and mortality rates. Between 1993 and 1995, the annual average incidence for Maori women was twice the national rate at 22.4 per 100,000 women. In 1996, the mortality rate for Maori women was more than 3 times higher than the rate for all New Zealand women. Reducing the incidence and mortality rate of cervical cancer in Maori women is a health target in New Zealand (Ministry of Health, 1998)

In my five-year service in the Gynecologic Oncology field, I was inspired by many touching stories of women with cervical cancer fighting for survival, and striving to

lead a normal family and social life. Most patients were middle-aged, and had children to raise and/or a career to pursue. They faced a great deal of distress in their daily life but fought their disease bravely. My experiences in Gynecologic Oncology nursing led me to recognize that information was of paramount importance in women with cervical cancer. They needed information to understand their situation, deal with the emotional disturbances caused by the diagnosis, and be better prepared for living with the illness. So far, little research has been done to study this group of women's information need profile. Consequently, inconsistency in information delivery, and difficulties in satisfying patients' requirement for information were noticed. Research to assess the needs of information among cervical cancer patients in the region and examine the ways of information delivery to patients was in need to inform clinical practice and improve the quality. This was the primary intention for conducting the research.

In this chapter, the background and the aim of the research are introduced, followed by a description of the thesis.

1.1 Background of the Study

Being diagnosed with cancer is an event that evokes enormous physical and mental distress. Acquisition of information about various aspects of cancer and life with the illness is a very important coping mechanism for cancer patients. Findings from previous research suggest that cancer patients need information regarding their disease concerns, personal concerns, family concerns and social concerns (Derdiarian, 1987a). A number of recent studies have investigated cancer patients' use of, and preferences in information sources. They indicate that cancer patients received information through a variety of sources, and patients preferred a combination of verbal and written communication (Hinds, Streater & Mood, 1995).

Studies on the needs of cancer patients repeatedly stress the importance of correct and sufficient information. However, the existence of information barriers and the reality that information does not always reach the intended target are frequently reported (Grahm, 1996; Kavanagh & Broom, 1997; T. Thompson, 1990). The impact of emotional and physical stress on cancer patients creates learning difficulties. Time

pressure and poor level of facilitative communication during consultation also hinders cancer patients from expressing their concerns. Previous research on communication shows that cancer consultation is mainly clinician-dominated and patients are given little space to initiate discussions based on their own needs (Ford, Fallowfield & Lewis, 1996). The provision of information not based on patient's learning needs, individual difference, and level of understanding is often noted and found against cancer patients' proper understanding of their disease and treatment.

Among various types of cancer, cervical cancer is one relatively common in younger adults and often associated with patients of low socioeconomic status (L. Thompson, 1990). Women who are diagnosed with cervical cancer often feel anxious, confused and powerless. They require information to understand their condition, lower their anxiety and participate in treatment decisions. Emotional disturbances such as fears, guilt, altered body image, loss of female identity and uncertainties of the future, are particularly common among cervical cancer patients. Many of them experience intense need for information not only to clarify what is happening to them, but also to erase their feelings of isolation and stigmatization.

There are two common types of cervical cancer: squamous cell carcinoma and adenocarcinoma. Squamous cell carcinoma accounts for 85% of all cervical cancer (Ministry of Health, 1998). It usually develops after a long and asymptomatic pre-malignant state. The Papanicolaou (Pap) smear is most effective for the diagnosis of abnormal cell changes in the pre-malignant state and therefore prevent it from further developing into squamous cell carcinoma. As a result of its long pre-malignant state, the possibility of early detection and the availability of effective treatment for its pre-malignant lesions, cervical cancer is seen by many as a preventable disease (L. Thompson, 1990). The exact cause of cervical cancer is unknown. Its development seems related to some risk factors such as the human papillomavirus (HPV) infection of the cervix, smoking, having sexual intercourse at an early age and having multiple sexual partners. Even though women who developed cervical cancer may not necessarily have any of these risk factors, the feelings of guilt and the stigma of having a disease caused by their own behaviour are prevalent among women with cervical cancer.

Cervical cancer can be microinvasive or invasive. At the microinvasive stage, the cancer cells have not spread more than 5mm into the tissues of the cervix. At the invasive stage, the cancer cells may spread into the deeper tissues of the cervix, part of the vagina, the lymph glands, other areas in the pelvis, and other organs (Anti-cancer Council of Victoria, 1996). The common symptoms of cervical cancer include vaginal discharge, irregular bleeding, pelvic or back pain, and excessive tiredness, but some women are symptom free. The diagnosis of cervical cancer requires histology evaluation of a tissue sample and treatment options are determined by its histology and disease stage (L. Thompson, 1990). The two main types of treatment for cervical cancer are surgery and radiation. Chemotherapy has only limited use in the treatment of cervical cancer. The Surgical treatments, ranging from a cone biopsy, to a total hysterectomy or a radical hysterectomy, are usually limited to patients with early disease. Side-effects of surgical treatments vary but may include symptoms of menopause, wound infection, postoperative bowel and bladder dysfunction, and lymphoedema. Radiation therapy, consisting of external radiotherapy and intracavitary radiotherapy, can be used at all stages. Normally in radiation therapy, external beams to the pelvic area are applied a few minutes daily for 4-6 weeks, followed by an intra-cavitary cesium implant for up to 72 hours. The implant needs to be inserted via the vagina and under anaesthesia. Patients under the treatment are required to be in isolation for the whole length of time. The side-effects of radiotherapy include skin problems, tiredness, loss of appetite, bowel and bladder problems, and depression. The use of surgery combining with postoperative radiation may improve survival for patients with positive lymph nodes (L. Thompson, 1990). However, this approach increases the rates of bowel and urinary tract complications.

Management of patients with recurrent or advanced disease is difficult. Symptomatic treatment and palliative support may be the only options. Therefore, early diagnosis and treatment are critical to patient survival. Patients with negative nodes will have approximately a 90% survival rate at 5 years (L. Thompson, 1990). Approximately 35% of patients with invasive condition will have recurrent or persistent disease following therapy (L. Thompson, 1990). Intensive follow up is required in the first couple of years as most patients with recurrent disease present with symptoms during this period. Even though most women with cervical cancer can now survive the disease, many have to live with the distressing and possible long-term effects of their

treatment. They need continuing informational support over an extended period of time.

At the time of the research, all public patients with cervical cancer living in the greater Auckland region were cared for by the Gynecological Oncology Services at the National Women's Hospital in Auckland. The gynecologic oncologists in the hospital were responsible for making the diagnosis, carrying out surgical treatments and patient follow up. Visiting oncologists from the Auckland Hospital were part of the consultation team in the services, and they were mainly responsible for patients' radiotherapy and chemotherapy. Patients who required surgical treatment were admitted to the Gynecologic Oncology Ward of National Women's Hospital, while those who needed radiotherapy and chemotherapy went to the Oncology Department at Auckland Hospital. The external radiotherapy was usually given at the Oncology Outpatient Clinic of Auckland Hospital, and the intracavitary radiotherapy required inpatient treatment for several days at the Oncology Ward of Auckland Hospital. All cervical cancer patients were followed up by the Gynecological Oncology Services at National Women's Hospital.

Multiple health care information services were available to cervical cancer patients in the greater Auckland region. In hospital, they had access to specialized information provided by doctors, nurses, social workers, counselors, psychologists, and cultural support health workers. While in the community, the support from their General Practitioners (GPs), district nursing services, the Cancer Society community liaison nursing team and local hospice services was available to them if needed. The Auckland Division of the Cancer Society also provided a telephone informational service and a reference library service for the public.

1.2 Aim of the Study

Within the broad context of health care and nursing practice, an increasing emphasis on the development of scientific bases for clinical practice has been seen in recent years. Many leading nursing professionals urge nursing research to close the gaps between practice and research, and to test the links between interventions and outcomes. In light of these directions, this research intended to focus on meaningful

clinical questions, to generate knowledge for improved quality and effectiveness of clinical practice, and to provide empirical evidence with regard to the impact of nursing actions on their health care clients.

With the increasing complexity of cancer care, oncology nurses need to identify what is essential to inform patients and what ways of information delivery make a difference in patient outcomes. Various studies concerning the informational needs of cancer patients were published in the USA, the UK, Australia and South Africa. Similar studies, especially studies on the informational needs of cervical cancer patients in New Zealand have not yet been reported. Currently, there is little evidence indicating what types of information cervical cancer patients in New Zealand perceive as most valuable, and the extent to which patients are satisfied with the informational support they receive. The overall aim of this research was to help local oncology care providers to recognize the informational needs of women with cervical cancer, identify barriers hindering patients' access to information, and evaluate the current ways of information delivery. This research will provide the needed information for those who are involved in the planning and delivery of health services for women with cervical cancer in the greater Auckland region.

This research used the method of formative evaluation. It was conducted at the National Women's Hospital in Auckland between 1998 and 1999. It aimed at identifying the informational needs of women with cervical cancer in the greater Auckland region, from both the patients' and health care providers' perspectives. Twenty cervical cancer patients and eleven health professionals participated in the study. This research had the following objectives:

1. to assess the informational needs of women with cervical cancer in the region;
2. to evaluate the availability and helpfulness of local sources designated to meet these needs;
3. to identify barriers which exist in information delivery and hinder those women from gaining access to the information they need.

Based on these objectives, three main research questions were formed (outlined in Section 3.1, p. 20). The outcome of this study will contribute to the knowledge

development of cancer care, inform oncology nursing practice and have positive input into the improvement of quality of life for cervical cancer patients in New Zealand.

1.3 Structure of the Thesis

The thesis is presented in seven chapters. The first chapter is **Introduction**. In this chapter, the research topic, its background, its objectives and its likely implications are introduced. The chapter also provides an overall description of the thesis.

The following chapter is **Literature Review**. This chapter reviews the recent literature with regard to cervical cancer patients' informational needs. It provides a comprehensive review with focuses on cancer patients' informational needs, sources of information and barriers to information. Relevant research findings and possible trends are highlighted throughout the chapter.

Chapter 3 is **Method**. In this chapter, the research questions, and the methods used to answer these questions, including participant selection, data collection, interview schedules and data analysis, are described in detail.

Chapter 4 is **Results I: Patient Participant Interviews**. In this chapter, patient participants' demographic characteristics, patient participants' informational needs and levels of satisfaction, patient participants' sources of information and their degrees of helpfulness, barriers against patient participants' access to information, and finally, their recommendations to the informational services in the region, are all outlined. This chapter focuses on the cervical cancer patients' perspective.

Chapter 5 is **Results II: Health professional Participant Interviews**. The responses from health professionals (key informants) who provided care for cervical cancer patients in the region, are presented in this chapter. This chapter covers key informants' basic demographic data, their views on cervical cancer patients' informational needs, their views on the sources that provided information for cervical cancer patients, barriers they noticed in information delivery, and their recommendation to the information services in the region.

Chapter 6 is **Discussion**. The results from both patient and health professional interviews are compared and discussed in this chapter. The findings from previous research are incorporated in the discussion. This chapter also examines limitations of the study and indicates directions for future research.

The final chapter is **Conclusion**. In this chapter, the thesis is drawn together with a summary of the findings and their implications for nursing practice.

CHAPTER 2:

LITERATURE REVIEW

In this chapter, the existing knowledge basis of the areas being investigated in the study is examined. The chapter presents relevant literature findings in the following areas: 1) patients' informational needs; 2) sources of information; and 3) barriers to information.

2.1 Patients' Informational Needs

Cancer patients need information across all phases of their cancer experience, proceeding from the time when the diagnosis is given, to treatment, convalescence, and cure or recurrence (Adams, 1991; Grahn, 1996). Studies on the needs of cancer patients indicate that acquisition of information about the various aspects of their disease is a coping mechanism and one of the major areas of importance for patients (Adams, 1991; Grahn, 1996; Gotay, 1984; McLoughlin & Oosthuizen, 1996; Northouse, 1989; Ream & Richardson, 1996).

Lazarus & Folkman's (1984) theory of stress and coping provides a foundation for the development of recent theories specifying the nature of cancer patients' informational needs. One example of such theories is the informational needs of patients with a recent cancer diagnosis developed by Derdiarian. Derdiarian (1987a) proposes that information seeking is a fundamental and active coping mode in patients with a recent diagnosis of cancer. The theory also indicates that information is needed for cancer patients to define the harms, the threats and the resources. A lack of information about the immediate and future implications of cancer will prohibit their anticipatory and effective adjustment to their situation.

Studies reflecting cancer patients' experience support the above theory. A descriptive study assessing the adjustment concerns of patients and husbands after a mastectomy indicated that information, emotional support, attitude, and religion were the factors

that helped them cope with the illness during this time (Northouse, 1989). Another study assessing the experiences and coping mechanisms of patients with early stage cervical cancer or pre-cancer and their partners, and patients with advanced breast or gynecological cancer reports that to seek more information was one of the most frequently mentioned coping strategies for their fear of cancer (Gotay, 1984). An Australian study identifying priorities of psychosocial needs among cancer patients receiving treatment in Western Sydney ranks “getting information” together with “family” and “dealing with emotional stress” as the top priorities of psychological needs among cancer patients (Liang, Dunn, Gorman, & Stuart-Harris, 1990). It concludes that access to information is one of the principal areas of psychosocial intervention for cancer patients.

Literature in recent years shows an increasing emphasis on the provision of information to enable patients participating in treatment decisions and exercising self control. Ream & Richardson (1996) state that the diagnosis of cancer together with its treatment often induce feelings of powerlessness and helplessness, and diminish cancer patients’ sense of mastery. They believe that information can foster cancer patients’ perception of control, enhance self-efficacy and therefore promote their psychological well-being. Grahn’s (1996) theory also acknowledges that cancer patients need information to exercise control, make sense of the experience, and promote an understanding of events throughout the course of cancer. Grahn suggests that information-seeking behaviour does not only provide cancer patients with knowledge needed to deal with illness related problems, but also with ways of managing the situation. Both Grahn’s and Ream & Richardson’s theories indicate that information-seeking is an important step of patient participation and it also helps cancer patients to re-establish control over their changed situation.

The roles of information in facilitating patients’ adaptation to cancer treatment and changed life style are repeatedly highlighted in the literature. A study on cancer patients’ perception of the functions of information before and after radiotherapy reports that treatment related information creates appropriate expectation and reduces psychological distress (Hinds, Streater & Mood, 1995). Ream & Richardson (1996) concludes that information results in more self-care behaviors being initiated, lower anxiety scores and less disruption in patients’ daily activities after a review of all

studies using control groups to evaluate the effects of informational interventions for cancer patients receiving chemotherapy or radiotherapy. In patients undergoing radiation treatment, “understand the experience”, “be mentally prepared” and “relieve anxiety” are the most frequently reported reasons of why information was useful (Fieler, Wlasowicz, Mitchell, Jones & Johnson, 1996). Congruent to the above reports, the study of Hinds et al. (1995) on cancer patients’ perception of why information is important before and/or after radiotherapy shows that “participation”, “preparation” and “anxiety reduction” are the three main categories.

With the trend to move the care of cancer patients from an inpatient basis to an outpatient basis and to shorten hospital stays, patients have a greater need for self-care information and information on community resources for support, counselling and supplies (Adams, 1991). The most significant areas where cancer patients have a need for information and support in the community during the rehabilitation and continuing care phase have been identified as the fear of recurrence, living with compromise, economic and social shunning, and dealing with uncertainty and dying (Adams, 1991).

In addition to investigation of the importance cancer patients place on getting information across all phases of their cancer experience, there are a large number of studies on their specific informational needs. According to Derdarian (1987a), cancer patients have four main categories of concerns soon after diagnosis: 1) disease concerns, about physical survival such as diagnosis, tests, treatments, and prognosis; 2) personal concerns, about physical well-being, psychological well-being, job/career, and plans/goals; 3) family concerns, about spouse and significant others; and 4) social concerns, about social relationships and contacts. A study of these categories of concerns confirms that the nature of their information needs is in congruence with the needs previously described by Derdarian (1987b). The results of the study also reveal that women required more information about their prognosis, about psychological well-being and about family; and young adults (18-35 years of age) and adults (36-55 years of age) tended to need more information related to job/career relationships.

A cross sectional survey of 250 cancer patients in west Scotland shows that almost all cancer patients (96%) wanted to know their diagnosis, most wanted to know about the

side effects of treatment (94%) and the chance of cure (91%), and a majority of the patients (79%) wanted as much information as possible (Meredith et. al., 1996).

Another study involving 200 cancer patients in South Africa reports that 75% of the respondents would like to receive detailed information about reasons, possible side effects and ways of minimizing the side effects of all treatment methods (McLoughlin & Oosthuizen, 1996). The study also indicates that over 80% of the respondents wanted to be informed about the possible success rate of treatments in their specific cancer, and 78.5% of the respondents wished to be informed about the prognosis and survival rate.

Fieler et al. (1996) conducted a study on informational preferences of 134 cancer patients undergoing radiation therapy and reports that “what side effects would be, when to expect them and how long they would last”, “how treatment kills cancer cells” and “how to deal with side effects” are on top of the patients’ preference list.

There has been an increased research interest in the informational needs of breast cancer patients in recent years. A number of studies indicate that women with breast cancer had high informational needs and they mainly wanted information about the stage of disease, likelihood of cure and treatment options (Bilodeau & Degner, 1996; Galloway et al., 1997; Graydon et al., 1997; Loveys & Klaich, 1991). A study examining the specific informational needs of 105 women with breast cancer reports that at the newly diagnosed stage, the top three priority information needs were information about the likelihood of cure of breast cancer, information about how advanced the disease was and how far it had spread, and information about the different types of treatment; and at the follow up stage (a mean of 21 months from diagnosis), the most important information needs were the likelihood of cure and the risk of family developing breast cancer (Luker, Beaver, Leinster & Owens, 1996).

Despite the increasing number of studies directed towards the informational needs of women with breast cancer, there is relatively little investigation specifying the informational needs of women with cervical cancer. However, the results discussed above have provided valuable understanding of the informational needs of cancer patients in general. A review of the literature notes that a few descriptive studies

involving mainly cervical cancer patients have revealed some informational needs related specially to the group. A study assessing the experiences and coping mechanisms of 112 individuals including patients with early stage cervical cancer or pre-cancer, patients with advanced breast or gynecological cancer, and their partners reports that the fear of cancer diagnosis, progression and recurrence, future ability to bear children, general emotional disturbances, and effect of illness on patient's job were the most common causes of concerns among early stage cervical cancer or pre-cancer patients (Gotay, 1984). The fear of cancer diagnosis, progression and recurrence, restrictions on activities, side effects of treatment, worry about family's future and general emotional disturbances were the most common causes of concerns among advantage stage breast or gynecological cancer patients.

A retrospective study of 105 patients who had undergone major gynecological surgery for cancer of the cervix or vulva reports that a high proportion of the participants had not had sufficient information on the after-effects of the operation, how they would feel and the physical effects (Corney, Everett, Howells & Crowther, 1992). The other areas where patients requested additional information were identified as the illness itself, recurrence rate, amount of pain afterwards and preparation for radiotherapy.

Another study of 83 women treated by surgery or radiotherapy for early stage cervical cancer reveals that the majority of the participants felt they needed more information about the cause of cancer, the risk of recurrent disease, and how to help themselves recover from treatment and to deal with their sexual relationship (Cull et al., 1993). Many women in this study also reported that their partners had very little information about their disease and treatment, resulting in their inability to discuss the women's central concerns (Cull et al., 1993).

There is evidence that younger woman with gynecological cancer would like their partner to be given information on general issues, after-effects of operation and effects on sexuality (Corney et al., 1992). Although women's partners normally play an important role in providing support for the patients, and their desire for information is no less than that of women diagnosed with cancer, their need for information regarding the women's disease is frequently overlooked by the health services (Meissner, Anderson & Odenkirchen, 1990). Adams (1991) urges health providers to

include partners in discussions of diagnosis and treatment in order to provide opportunities for them to ask questions and to increase the chances that both patients and partners understand treatment instructions.

The importance of providing information on the effects of treatments on cervical cancer patients' sexual function is highlighted in the literature with the results from Corney et al. (1992) indicating that 76% of the previously sexually active women had encountered sexual problems in the first year after the operation, and results from Cull et al.(1993) indicating that almost half of the sexually active women reported deterioration in their sexual function relative to what they regarded as usual for them prior to the appearance of cervical cancer symptoms. Women who were treated for cervical cancer have reported persistent vaginal changes that compromised sexual activity and resulted in considerable distress (Bergmark et al., 1999). There is evidence suggesting that the care of, and information available on, sexual dysfunction and rehabilitation for women with gynecological cancer is often not sufficient (Cartwright-Alcares, 1995; Robinson, Scott & Faris, 1994).

Finally, to follow up on cancer patients' satisfaction with the information provided is also an area warranting research attention as difficulties in satisfying individual requirement for information have also been reported (Gramble, 1998; Steptoe, Sutcliffe, Allen & Coombes, 1991; Wiggers, Donovan, Redman & Sanson-fisher, 1990). The study of Wiggers et al. (1990) on cancer patients' satisfaction with care indicates that great importance was given to the provision of information and the communication skills of doctors by patients in the study. A large number of patients were satisfied with the information from specialists about progress, but few patients were satisfied with the information about treatment benefit/side effects and the information about symptom control at home. Interestingly, Steptoe et al., (1991) report that patients who were completely satisfied with the information provided were not better informed in terms of factual knowledge but had a more avoidant coping style towards their illness. This finding suggests that satisfaction with communication in medical settings is not simply the matter of communication skills and the provision of adequately structured information, but also related to other factors such as the patients' tendencies to cope with stress (Steptoe et al., 1991).

2.2 Sources of Information

Information about cancer and related matters can be communicated to patients through a variety of sources and media. A number of recent studies have investigated cancer patients' use of, and their preferences in, information sources. These studies suggest that cancer patients preferred verbal communication and a combination of verbal communication and written material (Bilodeau & Degner, 1996; Hinds et al., 1995; McLoughlin & Oosthuizen, 1996). Their results also indicate that medical specialists were the most frequently mentioned source of information for cancer patients. Nurses, general practitioners, other patients, family/friends, pamphlets, women's magazines, news media (i.e. newspapers, television and radio programs) were the other frequently mentioned sources of information (Hammick, Tutt & Tait, 1998; Luker et al., 1996; Meredith et al., 1996).

Studies comparing cancer patients' major sources of information at the newly diagnosed stage with those at the follow-up or post-treatment stage show that patients' major sources of information may change over time as a result of the role changes of health professionals and the shift in the content of information desired at different stages of the disease (Hinds et al., 1995; Luker et al., 1996). The study of Hinds et al. (1995) shows a higher percentage of patients cited nurses and other patients as major sources of information in the post-treatment sample than that in the pre-treatment sample. Luker et al. (1996) report that information sources at the time of diagnosis centered around the health care team in hospital and the pamphlets provided, while further from diagnosis, few professional sources were utilized and the use of media sources such as women's magazine, television and radio programs for information was significantly increased.

The benefit of a cancer information help-line as a valuable resource for both cancer patients and their support persons is supported by the literature. Carlsson, Strang & Lindblad (1996) claim that telephone help-lines not only supply information to patients, relatives and the general public at their own premises, but also function as a link between people with needs and appropriate health services. A few large-scale overseas studies involving cancer patients and relatives who called the cancer help

lines for information reveal that the help-lines had a huge demand for information such as treatment options, side effects, rehabilitation, biology, specialists and dealing with anxiety (Carlsson et al., 1996; Love, Wolter & Hoopes, 1985; Manfredi, Czaja, Buis & Derk, 1993). A lot of patients wanted to be knowledgeable when discussing treatment plan with their doctors, and the information received from the help lines satisfied their needs for preliminary or secondary information (Manfredi et al., 1993). There is also evidence that the phone calls to the help-lines often developed into supportive dialogues and met the patients or their relatives' psychosocial needs (Carlsson et al., 1996).

Medical books/journals, audiotapes and audiovisual material, regular newsletters to oncology patients, personal letters to patients outlining the content of their consultation with doctors, and patient support programs were also reported as effective or preferred sources of information in the literature, but have not been widely used and evaluated (Bilodeau & Degner, 1996; Damian & Tattersall, 1991; Hagopian, 1996; Hinds et al., 1995; Luker et al., 1996; McAlpine & Jones, 1994).

2.3 Barriers to Information

It is repeatedly noted in the literature that barriers to information existed and cancer patients sometimes found it difficult to get the information they required. Among these barriers, a lack of quality communication between clinicians and patients, and time pressure during consultation are cited frequently (Cull et al., 1993; Meredith et al., 1996; Kavanagh & Broom, 1997; T. Thompson, 1990). Clinician communicative dominance, ignoring or interrupting issues raised by patients, leaving little space for patients to absorb information or applying no facilitative effort for patients to initiate discussion are also reported as communication barriers (Ford et al., 1996; Kavanagh & Broom, 1997; Roberts, Cox, Reintgen, Baile & Gibertini, 1994; Wilkinson, 1991).

Further to the above, a lack of comprehension of information provided due to the use of technical language or jargon in medical consultation creates cognitive barriers. Kavanagh & Broom (1997) report that women with abnormal cervical smears often find it hard to understand their abnormality and treatment as they are unable to see

their cervix and the abnormality often has little symptoms that the patients can recognize or observe. Studies in New Zealand show that a high number of Maori and Pacific Island women in the country reported little knowledge of the term “cervix” and the human reproductive system (Grace, 1985; Macdonald, 1992; Ma’ia’I, 1992). As a result, many women rely on lay understandings of the medical terms in absence of adequate discussion and explanation.

Other barriers such as emotional barriers (e.g. fear, embarrassment), and socio-economic barriers (e.g. the perceptions that doctors and nurses are overworked with little time to spend, the cultural or class differences between doctor and patient), may also result in patients’ reluctance to initiate communication (Luker et al., 1995; Macdonald, 1992; T. Thompson, 1990; White, 1995). In contrast to these barriers, there is evidence that the context of a caring doctor-patient relationship is perceived by cancer patients as the most encouraging factor in inducing effective communication (Roberts et al., 1994).

Cimprich (1995) claims that the demands of a life-threatening illness, and the multiple factors related to cancer and its treatment increase the risk of cognitive dysfunction, concentration problems and attentional fatigue in cancer patients. Cancer places intense demands on patients’ mental and cognitive capacity over a prolonged period of time (Cimprich, 1993). Women with cervical cancer are reported suffering psychosocial and physical difficulties including depression, anxiety, irritability, insomnia, fatigue and pain (Kulhara, Parmanand, Ayyagari & Nehra, 1988; Srivastava, Rai, Agrawal & Srivastava, 1987; Steginga & Dunn, 1997). A growing number of articles support the notion that concentration and memory difficulties in patients with cancer are pervasive (Cimprich, 1993; Cimprich, 1995; Cull et al., 1996; T. Thompson, 1990). Many patients have difficulties in understanding and retaining the information provided. Good timing in provision of information and efforts to attend to patients’ physical and emotional responses to the illness are critical to ensure the information reaches the intended target (Grahm, 1996).

Recent literature indicates that increasing attention is now placed on the individualized approach in patient education. Research shows that cancer patients who receive individualized intervention gained more information and were more satisfied

with that information (Derdiarian, 1989). Cancer patients' learning needs, learning capability, motivation and readiness should first be established to avoid the paternalistic manner in information giving (Grahn, 1996). It is noted that the content and detail of information that patients need may require changes from time to time as a result of the difference in primary function of information for each patient and time period (Hinds et al., 1995). The influence of individual coping style on cancer patients' informational needs was also studied and the results indicate that tailoring information to cancer patients' coping styles produced positive outcomes (Miller, 1995; Steptoe et al., 1991).

The above review provides a background understanding of the nature and elements of cancer patients' informational needs, what sources they used to obtain information and where the barriers to information situated. The inadequacies in, and problems with information and informational support available to women with cancer are illustrated. The scarcity of research on the informational needs of women with cervical cancer, in particular the informational needs of woman with cervical cancer in New Zealand, necessitates an assessment of local cervical cancer patients' informational needs and an evaluation of the delivery of information to those patients. This research intended to fill this knowledge gap and provide a theoretical foundation for service providers to plan and deliver quality informational services to cervical cancer patients in the region. The next chapter will discuss the method used for this research in detail.

CHAPTER 3:

METHOD

Formative evaluation was the method used for this research. According to Turner, Dehar, Casswell & Macdonald (1992), evaluation which uses research methods for the purpose of assessing and improving the adequacy of human services, organizations or programs is a specific type of applied research. The authors describe formative evaluation as “the collection and feedback of information relevant to programme planning and operation, for use in developing and improving the programme as it is designed and implemented” (Turner et al., 1992, p.8). The key assumption of formative evaluation is that people use information to improve what they are doing, thus the desired results of a formative evaluation are recommendations for improvement (Patton, 1990). Conducting need assessment is a major activity in formative evaluation, and it should include all relevant parties in the assessment (Turner et al., 1992). This study focused on assessing the informational needs of women with cervical cancer in the greater Auckland region, evaluating their use of the available informational resources, and identifying the possible barriers to the effective delivery of information to them. The research participants in this study consisted of both cervical cancer patients and health professionals who cared for them.

This chapter outlines the methods used to undertake this research. It covers research questions, participant selection, data collection, interview schedules and data analysis. Ethical issues, and the reliability and validity of the study tools are also discussed.

3.1 Research Questions

This research intended to capture the experience and knowledge of the participants as related to their own informational needs or the informational needs of their clients with cervical cancer. The three research questions were:

1. What information do patients with cervical cancer who live in the greater Auckland region need and how satisfied are they with the information they have received?
2. What kind of sources do patients with cervical cancer get information from and how helpful are these sources in providing them with the information they need?
3. How do cervical cancer patients and health care providers in the region see the current ways of delivering information to cervical cancer patients? Are there any barriers hindering the patients from gaining access to the information they need?

Methods used in participant selection, data collection and data analysis were designed to answer the above research questions based on ethical concerns, the research time frame and the limits of resources. Approvals to conduct the research were obtained from the National Women's Hospital, the North Health Ethics Committee and the Massey University Human Ethics Committee. Ethical issues regarding recruitment, consenting, data collection and data use are incorporated in the following sections.

3.2 Participant Selection

The research participants were women with cervical cancer who lived in the greater Auckland region, were capable of giving informed consent, and had been diagnosed with cervical cancer for at least 6 months at the time of interview; and health professionals who cared for cervical cancer patients in the region. Convenience sampling method, the use of the most readily accessible samples, was used to recruit 20 cervical cancer patients and 11 health professionals for the study (LoBiondo-Wood & Haber, 1994). Since all participants were current patients or employees of the Oncology services in the region, their identities were carefully protected. No tape recording was used in the interviews and the information provided by the participants was used exclusively for this study.

Cervical cancer patient participants All 20 patient participants were recruited at the Gynecologic Oncology clinic of the National Women's Hospital between 1998 and 1999. They were recent patients of the clinic at the follow up stage of their care, had no apparent distress or cognitive deficits at the time of recruitment, and were

identified by the clinic staff during their clinic visit. Adverts for the study and patient participant information sheets (Appendix III) were given to eligible patients while they were waiting to be seen by doctors in the clinic. Those willing to participate had the research explained to them in detail by the researcher, and an interview arranged either in a private area of the hospital or at their own home at a convenient time. All participants were given the opportunity to ask questions and time to consider their decision. A written consent (Appendix V) was obtained before the beginning of each interview. The participants were assured that taking part in this study was voluntary and they could decline or withdraw from the research at any time and that would in no way affect their future health care.

At the time of being interviewed, all patient participants had been diagnosed with cervical cancer for at least 6 months and therefore had a reasonable amount of contact with and understanding of the informational services for cervical cancer patients in the region. Nineteen participants had good understanding of English and could answer all interview questions independently. One participant used a qualified hospital interpreter during the interview.

Health professional participants (key informants) Potential key informants were identified and approached by the researcher. Eleven health care professionals including Oncology specialists, Oncology nurses working in the Gynecologic Oncology ward or community, cancer patients counselors and Maori health workers were recruited. A number of General Practitioners were also approached but they had limited numbers of cervical cancer patients currently under their care and therefore were not suitable to be key informants. Verbal invitation and a written information sheet (Appendix IV) were given to each of the potential informants for consideration before their consent to the study. No health professional declined the invitation. The interviews took place at private places of their choice, mostly at their own office or home.

3.3 Data Collection

Data collection was conducted by the researcher through semi-structured face-to-face interviews with all study participants. Interview schedules for both patient participants

and health professional participants were prepared and included standardized questionnaire-type questions in the early part and semi-structured discussion in the later part of the interview to enable systematic and flexible data collection (see Appendix I & II). The information from the participants was mostly obtained in a conversational style. The participants were encouraged to share their experiences and opinions freely and openly within the subject areas. Neutrality and impartiality were maintained by the researcher throughout the interviews.

All participants were assured of anonymity and confidentiality due to the possible disclosure of sensitive information regarding care providers and service management in the interviews. The researcher recorded the participants' responses to the interview questions on the interview schedule sheets which had no identification of the study participants. Important comments were written down *verbatim* under the relevant sessions. Enough time was allowed for recording and clarifying unclear answers with the participants. The interviews took 30 to 60 minutes, and during that time the patient participants' physical and mental condition was monitored closely. No rescheduled interviews were needed.

A high percentage of Maori participants were recruited to the study. Maori patients and health providers had been consulted on issues of data collection before the study to assist with Maori participation and ensure cultural appropriateness. The guidelines on health research involving Maori provided by the Health Council of New Zealand was followed throughout the research process.

The reliability and validity of the study tools had been tested before they were used in the study. The interview schedules for both health care professionals and cervical cancer patients were developed from previous research findings relating to the informational needs of cancer patients and in consultation with local experts in the Gynecologic Oncology field. A number of people including health professionals, a Maori health researcher and lay people assessed the interview questions for readability, relevance and accuracy in the wording of items. Interview questions were pre-tested with both cervical cancer patients (including a Maori patient) and health professionals to ensure acceptability of the format, clarity of the content and appropriateness of the questions.

3.4 Interview Schedule for Patient Participants

The interview schedule for patient participants consisted of four parts: demographic and diagnosis related details; information needs and levels of satisfaction; sources of information and degrees of helpfulness; and barriers to information (see Appendix I). The first three parts were standardized questions and the last part was semi-structured discussion.

Part I collected patient participants' age, ethnicity, education level, area of living, year of being diagnosed with cervical cancer, ways of being diagnosed and treatments for the cancer.

Part II had three questions concerning the participants' informational needs and levels of satisfaction. In Question 1, the participants were asked to respond to 16 items of information relevant to their cancer diagnosis. The 16 items listed in Question 1, referring to cancer patients' health and social needs, were the most commonly asked questions suggested by the literature or advised by the experts in the Oncology field. The participants answered either YES or NO to each item to indicate if they had wanted or not wanted to find out the information related to the item. If they answered YES to an item, they were then asked to rate their level of satisfaction with the information they had received (related to that item) on a four-point scale: 1- quite dissatisfied, 2- mildly dissatisfied, 3- mostly satisfied and 4- very satisfied.

In Question 2, the participants were asked to provide any further information they had wanted to find out and to indicate their levels of satisfaction with the answers received using the same 4-point scale.

In Question 3, the participants were asked to rate their overall level of satisfaction with the cancer information they had received.

Part III had two questions related to sources of information and their degrees of helpfulness. Question 1 asked the participants to report their usual sources of health information, and Question 2 concerned the sources which had provided the participants with the information related to their cancer diagnosis and the degree of

helpfulness of each of those sources. Fourteen commonly known sources in the region, such as GPs, Oncology specialists, nurses in the hospital, etc., were listed under Question 2. The participants indicated if they had or had not received any cancer related information from each of those sources and added additional sources if they had received cancer related information from them. The degree of helpfulness for each of those sources was rated by the participants on a 3- point scale: 1- they did not help much, 2- they helped somewhat, and 3- they helped a great deal.

Part IV intended to find out if the participants had experienced any problems which were barriers to the information they needed. This part was semi-structured with 7 leading questions for the discussion. The first two questions were designed to reveal problems in access to the informational sources by assessing the participants' knowledge of the sources (Question 1) and their perception of the availability of the information (Question 2). The next four questions intended to identify communication barriers by asking whether the participants had experienced any difficulties in asking questions (Question 3 & 4) or in understanding the information provided (Question 5); and whether they were confused by inconsistent or inaccurate information (Question 6). The last question (Question 7) sought to find out the patient participants' overall experience regarding their use of information services and their recommendations to the delivery of information to cervical cancer patients.

3.5 Interview Schedule for Health Professional Participants

The interview schedule for health professional participants (key informants) consisted of participant information (gender and position in health care), cervical cancer patients' informational needs, sources of information and barriers against patients' access to information (see appendix II). Part I was given to the key informants to complete at the beginning of the interview and Part II took the form of a semi-structured discussion with 7 leading questions.

Part I had 3 questions concerning the informational needs of patients with cervical cancer. Question 1 had 16 items of cervical cancer patients' informational needs, identical to the items listed in the Patient Participants' Interview Schedule. The key

informants were asked to respond to each item with either YES or NO to indicate if they had or had not been asked that information by their patients with cervical cancer. If they answered YES to an item, they were then asked to specify the frequency of being asked that item on a 4-point scale: 1- seldom, 2- sometimes, 3- often and 4- very often.

In Question 2, the key informants were asked to report other information (apart from the 16 items listed in Question 1) that they were asked by cervical cancer patients. They were also asked to specify the frequency of the information being asked using the same scale.

In Question 3, the key informants were asked to report other information (apart from the 16 items listed in Question 1) that they had provided to cervical cancer patients without being asked because it was important for their patients to know. They were also asked to specify the frequency of that information being provided using the same scale.

Part II intended to find out the helpfulness and accessibility of the informational services in the region, and possible barriers to cervical cancer patients' access to information from the key informants' perspective. This part had 7 leading questions, corresponding to the questions asked in patient participant interviews to ensure that the same subjects were discussed but from a different perspective. Question 1 concerned the most helpful and accessible sources of information for cervical cancer patients in the region. Question 2 asked about their cervical cancer patients' knowledge of the informational sources. Question 3 questioned whether the key informants had noticed any barriers to cervical cancer patients' access to information. Question 4 asked whether their cervical cancer patients had difficulties in asking questions. Question 5 asked whether their cervical cancer patients had difficulties in understanding the information provided. Question 6 questioned whether the key informants had noticed any inconsistent or inaccurate information to cervical cancer patients. The last question asked for the key informants' thoughts on the existing ways, and sources, of information delivery to cervical cancer patients in the region.

3.6 Data Analysis

The research data collected from the interviews was analyzed using both quantitative and qualitative methods. The quantitative data was summarized using basic descriptive methods such as frequency distribution and percentage to describe patient participants' needs of information, their levels of satisfaction with the information, their use of informational sources, and the helpfulness of those sources rated by patient participants. The Binomial test of proportions was also used to determine the statistical significance of the informational needs identified by patient participants in the study. In addition, an analysis was conducted to 1) compare the patient participants' needs for information with their levels of satisfaction to determine if their needs had been adequately addressed, and 2) to compare the patient participants' needs for information with the informational needs of cervical cancer patients identified by key informants in the study to determine if cervical cancer patients' informational needs had been adequately recognized by their service providers.

The qualitative data from the interviews was analyzed using content analysis methods including listing, ranking, labeling, grouping, identifying patterns and summarizing ideas. The aim was to put together coherent answers to relevant research questions by cross-case analysis. The analysis began with listing simple answers, labeling notes to search for patterns, and grouping the data together to form categories. The interview schedules were used as descriptive analytical frameworks to summarize answers from different participants to common questions, and to analyze different perspectives on central issues. To ensure the quality of data analysis, special attention was paid to test rival explanations and to search for negative cases (Patton, 1990). Cross-checking of findings to reduce bias by comparing different types of data (quantitative against qualitative) and perspectives (patients' against health professionals') were made possible in data analysis due to the use of multiple data triangulation.

This chapter summarizes the key assumptions of formative evaluation, outlines the research questions of the study, and describes the methods used in data collection and analysis. The following two chapters will detail the results from data collection. Chapter 4 will present the findings from patient participant interviews and Chapter 5 will present the findings from health professional participant interviews.

CHAPTER 4:

RESULTS I:

PATIENT PARTICIPANT INTERVIEWS

In this chapter, the main source of information, patient participant interviews, are analyzed and presented under five major headings:

- *Demographic characteristics*, covering the demographic information of patient participants;
- *Informational needs and levels of satisfaction*, presenting the findings of what information patient participants needed after they were given the cancer diagnosis and their levels of satisfaction with the information they had received;
- *Sources of information and degrees of helpfulness*, reporting the common sources of cancer information for patient participants and their degree of helpfulness;
- *Barriers against patients' access to information*, revealing the barriers that hindered patient participants' access to the information they needed;
- *Recommendations to the informational services*, presenting the patient participants' views on how the services could better serve the informational needs of women with cervical cancer.

4.1 Demographic Characteristics

The patient participants were asked to supply demographic data such as age, ethnic origin, education, residential area, year of being diagnosed with cervical cancer and the types of treatment they had. This information is summarized as follows:

Age

The age of patient participants ranged from 25 to 75, with an average age of 49 (see Figure 4.1) . One participant was aged < 30, two were aged 31 - 40, eleven were aged 41 - 50, two were aged 51 - 55, and four were aged > 61.

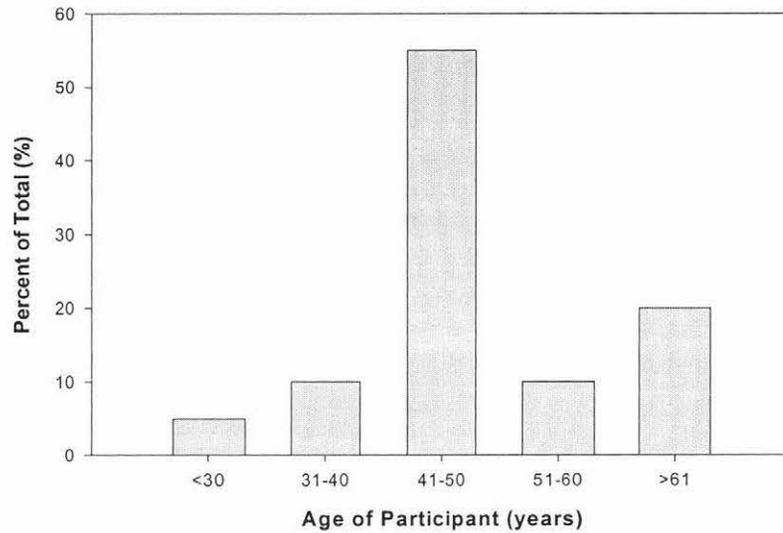


Figure 4.1: Age distribution of patient participants

Ethnic Origin

Of the 20 patient participants, 11 were European, 6 Maori, 1 Samoan, 1 Tongan, and 1 Asian (see Figure 4.2). Apart from the Asian woman, all participants had good understanding of English.

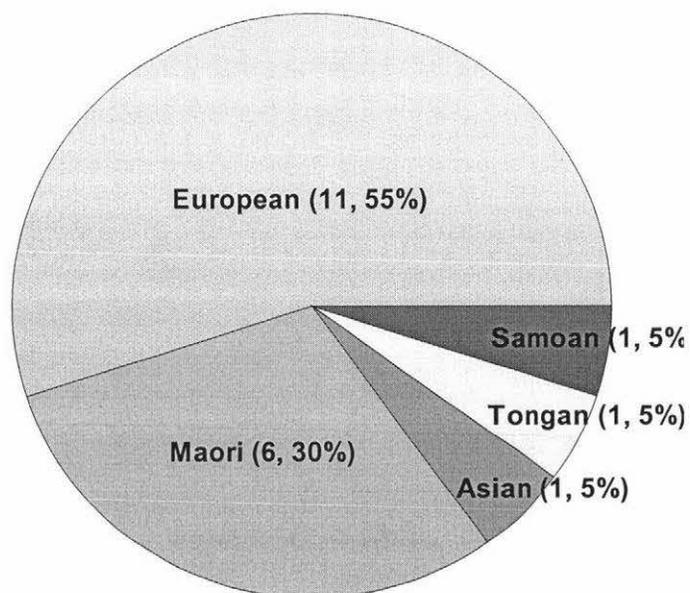


Figure 4.2: Ethnic origin of the participants

Education

A majority of patient participants (15) had Secondary education as their highest level of qualification. Three participants had tertiary education. Two participants had only primary education (see Figure 4.3).

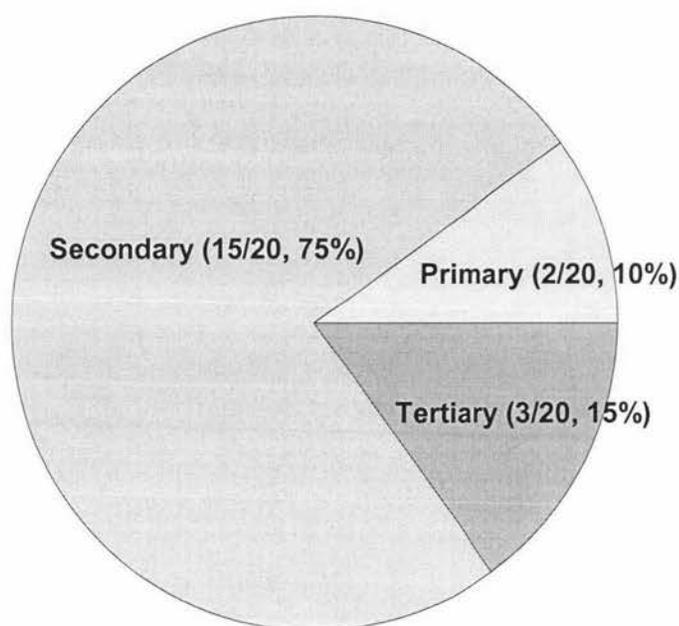


Figure 4.3: Education level of patient participants

Residential area

All patient participants lived in the greater Auckland region. Fifteen (75%) lived in the urban areas, and five (25%) lived in the rural areas.

Year of being diagnosed with cervical cancer

All patient participants in this study were recent outpatients of the gynecologic oncology services at the National Women's Hospital. Of the twenty participants, eighteen (90%) were diagnosed with cervical cancer within 3 years prior to the interviews being conducted (between the years of 1996 and 1998), the other two were diagnosed 3 and 5 years prior to the interviews being conducted (in 1995 and in 1993). Over half of the participants (55%) were diagnosed with cervical cancer after

symptoms presented, 20% of them were diagnosed through an occasional checkup and 25% of them were diagnosed through a regular cervical smear.

Type of treatment

Of the twenty participants, six had surgery only, ten received radiation therapy or radiation therapy combined with chemotherapy, and the other four had both surgery and radiation therapy.

4.2 Informational Needs and Levels of Satisfaction

Questions concerning patient participants' informational needs and levels of satisfaction were asked in the questionnaire part of patient interview (see Appendix I). The participants' responses to the questions are summarized in Tables 4.1, 4.2 and Figure 4.4.

Table 4.1 presents the participants' responses to 16 items concerning common questions relevant to their informational needs and their levels of satisfaction with the answers. Of the 20 participants, 19 responded to these items. One participant who attended the interview with an interpreter, had difficulties with understanding the items, and therefore was not asked to respond to the items.

As shown in Table 4.1, all 16 items were of interest to the participants. The item of most interest (No. 7) concerned the likelihood of cure, and the item of least interest (No. 10) concerned complementary therapies.

Statistical methods were used to determine the significance of the findings presented in Table 4.1. The questions required the participants to give either a YES or a NO answer. The probability of choosing a YES or a NO answer is 1:1. Therefore the null hypothesis: there is no statistical difference between the group answering YES and the group answering NO is 50% ($H_0: p = 50\%$, Binominal test of proportions).

The H_0 will be rejected at the 5% significance level when the test statistic exceeds 2. This will be the case whenever $p > 0.5 + 2 \times 0.115 = 0.73$ ($n = 19$, $se = 0.115$). For a

YES response to be statistically meaningful without ambivalence, p should be ≥ 0.73 . Of the 16 items, ten of them (No. 1, 3, 4, 5, 6, 7, 8, 12, 14 and 16) had a YES response of over 73% ($p > 0.73$), indicating that the participants wanted the information (see Table 4.1). The rest of the six items had a YES response of between 42% to 68% (did not reach the required p value), therefore did not have enough statistical evidence to support that they were the information wanted by the participants. For the information on the test statistic, see Appendix VI.

The participants' levels of satisfaction with information related to their needs were reflected by the total numbers of participants who reported satisfaction and dissatisfaction with the information they had received. In Items 3, 6, 7, 8, 9 and 11, over 80% of the participants who had the informational needs reported satisfaction. In Items 4, 12, 13, 14, 15 and 16, between 60% and 80% of the participants who had the needs reported satisfaction. And for Items 1, 2, 5 and 10, less than 60% reported satisfaction (see Table 4.1).

Table 4.1: Patient participants' informational needs and levels of satisfaction

Items of Informational need	No.(%) reported the need (n = 19)	Level of satisfaction			
		No.(%) reported very satisfied	No.(%) reported mostly satisfied	No.(%) reported mildly dissatisfied	No.(%) reported quite dissatisfied
1. What caused my cancer?	16 (84*)	5 (31)	2 (13)	7 (44)	2 (13)
2. How common is cervical cancer?	9 (47)	2 (22)	3 (33)	0 (0)	4 (44)
3. What is the up to date information of my condition?	18 (95*)	12 (67)	5 (28)	1 (6)	0 (0)
4. How is the cancer going to progress?	14 (74*)	6 (43)	4 (29)	3 (21)	1 (7)
5. How long have I got to live?	16 (84*)	5 (31)	3 (19)	4 (25)	4 (25)
6. What are the treatment options?	18 (95*)	12 (67)	4 (22)	2 (11)	0 (0)
7. What is the likelihood of cure after the treatment?	19 (100*)	9 (47)	7 (37)	2 (11)	1 (5)
8. What will happen to my body during and after the treatment?	18 (95*)	8 (44)	7 (39)	2 (11)	1 (6)
9. will I pass my disease onto my partner or family members?	10 (53)	8 (80)	0 (0)	0 (0)	2 (20)
10. What are the complementary methods of cancer therapy?	8 (42)	2 (25)	1 (13)	4 (50)	1 (13)
11. Will cervical cancer or its treatments affect my appearance?	13 (68)	8 (62)	4 (31)	1 (8)	0 (0)
12. Will cervical cancer or its treatments affect my sexual health?	18 (95*)	5 (28)	7 (39)	5 (28)	1 (6)
13. How is my lifestyle going to change with the cancer and its treatment?	12 (63)	2 (17)	6 (50)	3 (25)	1 (8)
14. How do other people live and cope with cancer?	14 (74*)	3 (21)	6 (43)	2 (14)	3 (21)
15. Is there any financial or domestic support available for cancer patients?	11 (58)	4 (36)	3 (27)	3 (27)	1 (9)
16. If I have any queries of health problems, whom can I talk to or get help from?	15 (79*)	7 (47)	3 (20)	4 (27)	1 (7)

(* indicates that the percentage has statistical significance, Binomial test of proportions)

Table 4.2 outlines additional questions the participants had and their levels of satisfaction with the answers received.

Table 4.2: Patient Participants' additional informational needs and levels of satisfaction

Additional information wanted by the participants	Level of satisfaction
1. Can I have children after the treatment?	Very satisfied
2. Contraceptive needs	Very satisfied
3. Anesthetic options and the safety of the surgery	Very satisfied
4. Is cervical cancer curable?	Very satisfied
5. Is there any new development in cervical cancer treatment?	Mildly dissatisfied
6. What are some of the support services for younger cancer patients?	Quite dissatisfied
7. How to prevent some of the long term side effects caused by the treatment, e.g. lymphoedema and bowel problems?	Quite dissatisfied

Figure 4.4 shows the participants' overall level of satisfaction with the cancer information they had received. Of the 20 participants, 16 (80%) reported being very or mostly satisfied, and 4 (20%) reported mild dissatisfaction.



Figure 4.4: Patient participants' overall level of satisfaction

4.3 Sources of Information and Degrees of Helpfulness

This part concerns patient participants' usual sources of health information, the sources which had provided the participants with the information related to their cancer diagnosis and the helpfulness of these sources to the participants.

Usual sources of general health information

All 20 patient participants stated that their General Practitioners (GPs) were their main source of general health information. The elders of the family, friends with health knowledge, the media, a nurse-led health clinic, experiences in the health care fields, and talks given by health professionals in church groups were also reported.

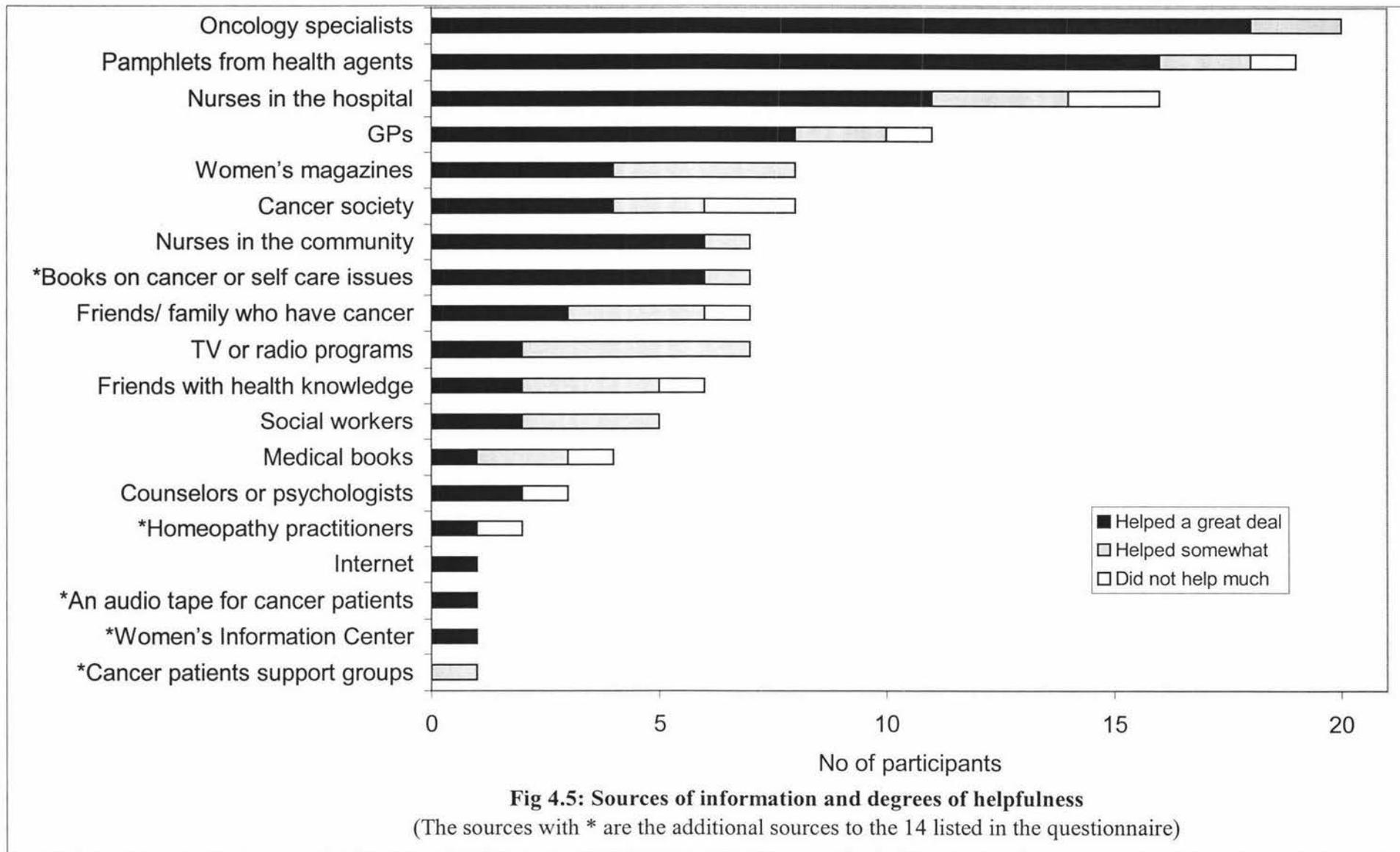
Sources of cancer related information and their degree of helpfulness

Table 4.3 and Figure 4.5 present a list of informational sources that had provided cancer information to patient participants, starting from the most commonly mentioned one to the least commonly mentioned one. Both the table and the figure also list the numbers of patient participants who rated the helpfulness of these sources.

Table 4.3: Sources of information and degrees of helpfulness

	Source	No. (%) used the source (n=20)	No. rated <i>helped a great deal</i>	No. rated <i>helped some- what</i>	No. rated <i>did not help much</i>
1	Oncology specialists	20 (100)	18	2	0
2	Pamphlets from health agents	19 (95)	16	2	1
3	Nurses in the hospital	16 (80)	11	3	2
4	GPs	11 (55)	8	2	1
5	Women's magazines	8 (40)	4	4	0
6	Cancer society	8 (40)	4	2	2
7	Nurses in the community	7 (35)	6	1	0
8	*Books on cancer or self care issues	7 (35)	6	1	0
9	Friends/ family who have cancer	7 (35)	3	3	1
10	TV or radio programs	7 (35)	2	5	0
11	Friends with health knowledge	6 (30)	2	3	1
12	Social workers	5 (25)	2	3	0
13	Medical books	4 (20)	1	2	1
14	Counselors or psychologists	3 (15)	2	0	1
15	*Homeopathy practitioners	2 (10)	1	0	1
16	Internet	1 (5)	1	0	0
17	*An audio tape for cancer patients	1 (5)	1	0	0
18	*Women's Information Center	1 (5)	1	0	0
19	*Cancer patients support groups	1 (5)	0	1	0

(The sources with * are the additional sources to the 14 listed in the questionnaire)



From the results, *oncology specialists, pamphlets from health agents, nurses in hospital and GPs* are the four most commonly mentioned sources (Items 1 - 4). Their degrees of helpfulness were also highly rated by patient participants.

Women's magazines were mentioned frequently by the participants as an informational source (Item 5). Those people stated that they liked to read stories of how other people fought against cancer. They found those stories extremely encouraging to their situation. They also liked to see other cancer sufferers' appearance and to learn some helpful tips of self caring from the reports in the magazines.

The Cancer Society had been used by 40% of the participants as a source for information (Item 6). Some other participants stated that they knew the Cancer Society funded cancer research and provided domestic supports to cancer patients, but were not aware of its function as a source of cancer information in the community.

Nurses in the community, including district nurses, hospice nurses, cancer society community liaison nurses, and nurses in community clinics, had provided information related to the cancer diagnosis to many participants in the study (Item 7). Their degrees of helpfulness were rated very highly by those who had received information from them.

Books on cancer or self care issues were also suggested in this study as a common and helpful source for the participants to obtain information (Item 8). Those participants reported that topics on cervical cancer, self care for cancer patients, positive thinking, nutritional and dietary information, general health maintenance and *the report of the cervical cancer inquiry* (Cartwright, 1988) had provided them with the information they needed.

Many participants in the study revealed that they had talked to and gained information from *friends or family members who had cancer* (Item 9). They stated that there was always something which they could relate to themselves from those people, and they believed that some useful tips could only come from other cancer patients.

Thirty-five percent of the participants had gained information related to their disease from *TV and radio programs* (Item 10). They reported that they obtained useful information from TV documentaries and radio talk-back programs.

Friends and family with health knowledge, social workers, medical books, counselors or psychologists were mentioned by a number of participants as sources of cancer related information (Items 11 - 14). Other reported resources were *homeopathy practitioners, the Internet, taped information for cancer patients, the Women's Information Center* (at National Women's Hospital) and *cancer patient support groups* (Items 15 - 19).

4.4 Barriers Against Patients' Access to Information

The results in this and the following section were based upon the content analysis of the qualitative data obtained from the interviews with patient participants. Statements presented here are supported by comments made by the participants in the interviews (italics or with quotation marks). The barriers against patient participants' access to the information they needed have been summarized as follows.

4.4.1 Participants' knowledge of the informational sources

Most patient participants were able to name at least one source where they could get help if they had any queries regarding their cancer diagnosis after their initial consultation with a specialist. General Practitioners and the nursing staff at the oncology ward of the National Women's Hospital were the two most commonly mentioned sources that the participants would seek information from if they had problems regarding their cancer diagnosis.

A number of participants also mentioned that they would talk to the Cancer Society community liaison nurses or ring up the phone-line provided by the Cancer Society. The informational support provided to cancer patients by the Cancer Society could be seen in these comments:

I was given a Cancer Society booklet. I rang them up and got more helpful information and pamphlets.

We have a Cancer Society nurse working in the area. She gives us the information and support we needed.

The 0800 number they [the Cancer Society] offered was so helpful, like a lifeline, providing all kinds of help. I said to them that I wanted to talk to someone who had the same operation as the one I was going to have, and they arranged for me to meet a patient.

“To ring up the nurses at the oncology clinic of Auckland Hospital”, “to read up on books”, “to talk to other patients”, “to give the specialist a call”, “to talk to friends with medical knowledge”, “to talk to other specialists” and “to visit the Women’s Informational Center [at National Women’s Hospital]” were also mentioned by the participants as ways they would use to get information.

However, some participants showed a lack of good knowledge of where they could get help and whom they could talk to. A number of participants did not know about the informational services provided by the Cancer Society and many said that they were not sure how to contact the doctors if they had further questions after the consultations. Their helplessness is seen in the following response:

I wasn’t given any contact numbers. I didn’t know who to talk to. I tried to ring the hospital but my call was passed on from one person to another. I felt so helpless in those early days. I really wanted to be able to talk to somebody and have my questions answered.

The participants’ lack of understanding of some informational services was also noted when a participant talking about her desire for information related to her sexual relationship with her husband. She was aware of the service for sexual health counseling but was reluctant to seek help from it. She stated in the interview that she was not comfortable approaching a counselor for information because the term counseling frightened her. She was afraid that the counselor might intrude on her privacy and “pull things out” of her past. Her misinterpretation of the service put her off using the available source for information.

4.4.2 Participants' access to information

When patient participants were asked if they felt that getting the information they needed was difficult, 65% of them answered "NO". While the majority did not feel that it was difficult to get the information they needed, they placed a significant emphasis on the need to ask questions. Most of those who considered getting the information was not difficult stated that they were assertive and not afraid of asking health professionals questions.

Those who considered getting the information was difficult stated that they wanted to know more but the information they needed was not readily available to them. Some also had an expectation that health services would provide them with all the things they ought to know without them asking. The following comments demonstrate the difficulties:

The information I needed was not readily available. I felt that I had to ask to get the information. The pamphlets available provided only basic information. The things I wanted to know were often not there. Health books had very little information on cervical cancer.

Now I realize that if you don't ask questions, you won't get the things you want to know.

The written pamphlets did not provide in-depth information. I wanted to know a lot more. Later I found a book on cervical cancer. I read that and understood a lot more. I don't know how I could have coped and understood my disease without reading the book.... Not enough information was coming from the hospital, or perhaps I was given some, but I really could not remember them.

Each time when I came to see the doctors, they only told me that I was all right and they did not explain things to me. I wanted to know more. They probably thought I would not understand it anyway. A few times they said to me: "We have got some pamphlets for you to read". I wasn't happy at all. I wanted them to explain things to me.... When I asked them how long I had got to live and what was my chance of cure after treatment, all they said to me was that everyone was different, and they had to wait until I finished the treatment to see if it'd worked. I mean it's the same disease for many women. Doctors must have had some ideas. How could they say they didn't know. They just wouldn't tell me.

A number of participants expressed their needs for advanced and additional information related to their illness. They reported that the information provided by health services such as information pamphlets was not deep and broad enough to

cover their desire for cancer information, and they had to search other sources for information.

4.4.3 Difficulties in asking questions

In the interviews, nearly half of the participants responded that they had felt uncomfortable asking health professionals questions related to their illness. The following were the areas that some of the participants were uncomfortable discussing:

- Changes in sexual function due to the disease or treatment, such as the safety of having sex after being diagnosed with cervical cancer, the possibility of resuming sex after surgery, and the effects of treatments on sexual relationship.
- Bladder and bowel problems
- The structure of female reproductive system or other internal organs
- Minor discomforts or things less important (e.g. vaginal discharge, ache in the pelvic region)

There were a lot of reasons why many participants felt uncomfortable asking health professionals questions related to their cancer diagnosis. The difficulties they experienced were outlined as follows:

1) Embarrassment and lack of privacy

Among the participants, there was a generally expressed feeling that discussing private parts of the body and gynecology related concerns were embarrassing, especially with male health professionals or in an environment where their privacy was less protected. However, many of them noted that this feeling was eased after they had established a relationship with their doctors. The comment below represented this feeling among the participants:

I was shy at the beginning. I was uncomfortable with discussing the private parts with doctors. I did not know them and I felt ashamed.

Privacy was a great concern to many participants when they discussed gynecological or sexual related concerns with health professionals. Some reported that the presence

of a number of health professionals or the presence of some relatives made them reluctant to discuss private issues.

2) The perception of doctors being too busy

The perception of doctors being too busy to spend time with patients was a common feeling among the participants. Many stated that they did not feel comfortable asking doctors “small things” or discussing “less important” concerns because they did not want to take up the doctors’ time. This theme was repeatedly emerged in the participants’ comments. Here are two examples:

They [doctors] were in a hurry. They did not seem to be able to spend time with me.... Sometimes I wished they could slow down for me.

Doctors were often very busy. A lot of things became too small to ask.... Long waiting time for the patients and the tight schedule of the doctors made the consultation short.... [Patients] hurried in, rushed out.

3) Inability to communicate and feelings of inferiority

Doctors and patients in a health care environment were often not perceived as an equal partnership. In the interviews, the participants described their perception of doctors being “big man” and using “big words”. By contrast, they saw themselves as inferior to the doctors. Many stated that doctors often talked about the expected symptoms, possible side-effects and treatment outcomes in concise terms. They wanted the doctors to be more specific, but felt “silly” to ask them to explain every thing. They were also not comfortable asking about body parts and their functions because they felt ashamed of not knowing them. The feelings of inferiority among some participants was a factor contributing to the difficulties they experienced in communicating with health professionals.

In the interviews, a number of participants reported that they found it hard to use appropriate language to communicate their queries to health professionals. Some participants regarded medical terms as the only proper language used to describe medical conditions. They thought using them was part of the health care custom. They stated that they were grateful most doctors were kind enough to explain the terms to

them to make them understand the language, but it was difficult for them to express their queries and concerns using the same words.

The participants' inability to phrase their health concerns in medical terms triggered their feelings of inferiority and weakened their confidence in communication with health professionals. Some participants reported that they were able to ask a lot more questions after they became familiar with the technical terms used to describe their condition. The following comments are some of the examples:

Doctors talk in their own language. I don't know the words to ask them questions.

They [doctors] talk in big words, I can't use the language to explain the questions I have in mind.

After I had been to the clinic a few times, I understood my body parts and the disease a bit better. I started to understand what they talked about and had more confidence in asking questions.

4) Attitudes of some health professionals

Health professionals' being impatient with patients, lacking understanding of patients' situation and not showing interest in patients' concerns had been perceived as obstacles to their access to professional advice by some participants. On the other hand, courtesy, kindness and a caring attitude produced gratitude and trust. In an interview, a participant stated that:

Attitudes of frontline health professionals or other support personnel are so important to how we feel as patients. If we see smiles in their faces or are greeted when we enter the room, we feel that they care about us as a person, not just another number. We feel that we can relax and be comfortable with asking things.... It also makes the discomfort from the treatment a lot easier to handle and overcome.

Another participant had this experience:

The doctor I saw twice in the clinic before the operation was not a people person. He was not interested in my concerns. I just didn't feel like to ask anything.... It was not because he was a male doctor. I met a few very nice male doctors before.... It's his attitude.... He was probably used to dealing with older people. He did not seem to be able to understand younger patients like me. I had a lot of concerns about my life, fertility, sexual functions, and he only talked about the surgery and treatment.... He became quite impatient with me.... I felt it really hard to discuss some practical issues with him.... At that time, I was in shock and I was also scared of him. I did not have the opportunity to

see another specialist. So when I had difficulties in communicating with him, I had no other place to go for my questions.

5) Gender difference

An issue was raised in the interviews about the gender difference between health professionals and patients as a factor contributing to their willingness to ask health professionals questions. These were the comments from the participants:

I was a bit uncomfortable talking to XX, He was a male doctor. He looked at things differently. He would not understand what a woman concerned about.

Talking to male doctors was somehow quite difficult. Lady doctors usually understood me better.

The doctor was so surprised that I was still breast-feeding my baby. I didn't feel like to ask anything more Male doctors don't always understand us. This is what we do as women. We will put the interest of our kids and family ahead of us.

Gender difference between patients and health professionals had a negative effect on some participants' access to the information they needed. Some participants had the perception that male clinicians would not understand the feelings and experiences of women with cervical cancer, and they had different understanding of women's informational needs. A number of participants stated that male clinicians focused only on curing the disease while they talked to their cancer patients. They paid less attention to detailed information, women's psychological needs and the long-term effects of the disease and treatment on women's life. Even though the women were often offered a chance to ask questions by their male clinicians, they said they were not comfortable talking about their personal concerns, such as changes in appearance and sexual life, due to their belief that male clinicians would not be interested in those concerns, or male clinicians would not understand their personal needs. Those women stated that they were generally quite keen to express these kinds of concerns to female clinicians.

4.4.4 Difficulties in understanding the information provided

A number of participants reported that they could not always understand the information provided by the health services. They often had difficulties with

understanding some technical terms. They called them “big words”. The following is an example of these comments:

Doctors speak too fast, they do not use plain English, use big words.... I always get my cancer society nurse to come to the clinic with me. So she and the other female doctor there [a nurse practitioner] can explain the doctor's words to me..

Although it was evident that doctors tended to use a significant amount of medical terms in consultation, most of the participants stated that their doctors used good, clear language to explain the terms to them. They were normally able to understand the information well after the explanation was given.

The participants' emotional state was critical to their ability to understand and remember the information provided by health professionals. Some participants reported that they had difficulties taking in the information provided by their doctors in the first few visits, when they were shocked by the cancer diagnosis. Here are some comments:

In the first few visits to the hospital, I was in deep shock. I could not take in anything.

Yes, I can understand [the information], but not when I was first given the news [of having cancer], I was in shock. I was not able to take in much ... Afterwards, I felt so hard trying to remember what I was told.

In general, the written information was well understood by the participants. Only two participants, one was a new immigrant who could not understand English and the other one who only had a few years schooling, stated that they could not understand the information pamphlets provided. The new immigrant said that the written information was good despite that it was written in English. It provided a chance for her family and friends to read it, discuss concerns and raise questions for her to ask the doctors. The other participant regarded the pamphlets as a useless way of delivering information to her.

4.4.5 Inaccurate and inconsistent advice to the participants

Most of the participants reported that the information they received was consistent and accurate except in a couple of cases: one participant had received conflicting information on hormone replacement treatment, and the other one was given different advice on the need for an examination. It was also noted, from some participants' experience, that some health professionals in the community had different understandings of the participants' need for cervical smears and limited knowledge on current treatment for cervical cancer. As a result, some out-of-date information were offered.

4.4.6 Special needs of new immigrants or people who know little English

When an Asian new immigrant was interviewed and asked if she was aware of the informational sources for cancer patients in the community, she stated that she did not know about the Cancer Society or other possible sources of information provided by health services in the community. When she had queries, she asked her friends with health knowledge or saw a doctor who could speak her language. When she was concerned about arrangements for her treatment she asked the interpreter she met in the clinic to ring up the hospital. She said she was very grateful that the hospital provided her with an interpreter for each clinic visit and gave her some pamphlets (in English) to take home. Apart from the discussion with health professionals in clinics and hospitals, this participant's health information was mainly obtained through her ethnic community. She stated that to seek information was very difficult for someone like her who knew little English and was new to the country. She relied totally on her family and friends to help.

In the interview, she further described her experience of being an inpatient during the radiation treatment. In those days, since she could only express her basic needs to nursing staff through sign language or pointing at words, the information she received was very limited. Being in the hospital alone without knowing what would happen next and why, she felt isolated and insecure. Her family wished to see more written information about the treatment procedures and about the hospital stay available to them beforehand so that the patient could have been better prepared when she came to the hospital. Even though their English was also somewhat limited, they stated that with the written information in hand, they could get help more easily.

4.5 Recommendations to the Informational Services

In the interviews, the participants were asked about their overall level of satisfaction with the informational services which had provided them with the information they needed to understand and deal with their illness. The majority of the participants were satisfied, although many had views on how the services could better serve the informational needs of women with cervical cancer. Their recommendations to the informational services in the region are outlined below.

Greater sensitivity to patients' feelings when delivering information

The following is a narrative demonstrating a typical story of a participant attending her first clinic visit:

This was her first clinic visit with a gynecologic oncologist. Before this she had already been told that she had cervical cancer. During the visit, the woman listened carefully to every word from the surgeon. The surgeon explained to her the procedures of her operation. She did not take in much. All she wanted to hear at that time was something such as "Once you have the operation, you can ...". By the end of the consultation, she still could not get what she was hoping to hear, not even something similar to indicate that she could live after the surgery. She was totally disappointed. She thought that she had the big "C" and would die soon. She wanted to know how soon, whether it would be on the operation table or after the operation. She was speculating the whole time while she was there listening to the words coming from the surgeon. Since the surgeon had not mentioned once about the arrangement after her surgery, she believed deeply that she would not have the chance to live long after that operation.

Many participants who had limited medical knowledge had believed that cancer (the "C" word) meant a terminal condition. The women needed careful explanation about the nature of their disease and thoughtful reassurance when the information was delivered to them.

Some participants indicated that they needed to feel secure during consultations. They did not want their emotional needs being overlooked by health professionals in information delivery. Two further examples were recalled by the participants:

After the operation, they told me that my pelvic nodes were inflamed. So I had to go through radiation treatment. It was all too much for me, especially when the bad news was not delivered in a supportive manner. It was very hard to take.... I still remember that moment. I was coming out from the shower,

wrapped in towels, with tubing still connected to my body. A nurse was walking me back to my bed. That was the time when they all walked in to the room and told me the news that my cancer had spread to the pelvic nodes.

I was admitted to the hospital with heavy vaginal bleeding. A young doctor in the ward came to me and said that "You have cancer". I was so shocked. I was totally not prepared for that. I had no idea of what was wrong with me and it wasn't a nice way to break the news.

In these two instances, information in relation to the patients' diagnosis and condition was not delivered to them in a supportive manner. The participants wanted health professionals to be more sensible to patients' emotions and to understand the significance of each of their words on patients' feelings.

Information to be readily available

The need for information to be readily available to patients was expressed by a number of participants as they said they often had no idea of what to ask their doctors or felt awkward asking some questions. In the following four cases, the participants reported retrospectively that they should have been given the information they needed or the information should have been explained to the level they could take in and remember:

I received information, but was often not able to understand them. I had to ask the doctor to explain it to me. Sometimes I consented to a treatment, but I did not know how it would actually affect my body. When the treatment did not go as easy and well as I expected, and when I got sicker than I had been before the treatment, I wished I had been told more about how it worked and how successful it would be. I want doctors to be honest with their patients.

When I was told that my cancer hadn't been cured after radiation treatment, I was very angry with the doctors. I was devastated and planned to overdose myself. They should have told me the truth earlier. I expected the disease would go away after the treatment...

My first biopsy was done without my knowledge. I had not been told that I would have one, and I did not know that I had one until I rang them up to report that I was bleeding. I could not remember signing any consent form at all. The procedure had not been explained to me. I was bleeding afterward. I hadn't been told this would happen and I did not know what to do ...

[I was] not happy about not being given the up-to-date information of my body. The doctors kept saying to me that I was alright, but I did not know what had happened or would happen to me. I had

not been told that I would have diarrhea after radiation treatment. I had so much trouble and I did not know that was caused by the radiation. The [internal] radiation treatment was a lot harder to handle than I expected. I wanted them to tell me how it worked and how it was done before I started the treatment.

The above four participants needed information to understand their condition and treatment. They also wanted health professionals' honesty and patience. Some participants stated that they did not realize the importance of asking and understanding the information until they had problems later with their treatment. Some of them simply did not know what to ask beforehand because they had no idea of what to expect.

A number of participants stated that they often felt awkward asking health professionals information that was not directly related to their clinical condition or information about the alternative services. Questions such as where to find additional information, where to get a second opinion, what numbers to ring if they had problems, whether or not they could seek alternative therapies and self-care issues were some of the things they did not feel appropriate or comfortable to bring up. They often did not want to give health professionals an impression of being "silly", asking too much, not trusting what the clinicians have said or taking up too much clinical time. The participants said they were generally happier to ask questions if health professionals initiated these kinds of discussion or if the topic was already mentioned in the pamphlets for patients.

The following comment represents the views of some participants:

I want to see more information written in booklets, such as the sexual side of things, the effects of treatments, and the information on diet during radiation treatment. Written information helps patients understand things better. It is easier for patients to find the answers of some silly questions in these booklets than to ask health professionals.

Some participants also suggested the health services provide easily accessible informational support to cervical cancer patients. They stated that they preferred to contact a health profession who knew them and understood what they had been through when they had queries or needed to talk to someone. A few participants stated

that they felt it comfortable and helpful to ring up and talk to nurses in hospital who knew them as persons and understood their needs. Many participants had positive experiences with the nursing staff in the oncology field, and believed that nurses were very knowledgeable health professionals.

A participant recalled the help she received from a nurse working in the clinic:

It was a big help to me that a nurse I met in the clinic rang me up at home to tell me the results of the biopsy and informed me of the possibility of needing a hysterectomy before my appointment with the specialist. I was so much better prepared and knew what to expect and ask during the visit to the hospital. I was so grateful that the nurse gave me the information I wanted and talked to me on the phone. They [nurses] are very knowledgeable people in the area.... It was so nice to have a nurse checking on patients. It is always easier to talk to a nurse and ask about anything.

Some stated that it would be an assurance to them if they knew they had someone whom they could contact for information, and someone who was taking responsibility for their needs.

Anticipatory information for treatment and recovery

A important issue raised by a number of participants was that they often missed out being provided with anticipatory information, the information which would have prepared them for problems happening during and after their treatment. According to those participants, information such as changes in emotion, symptoms of menopause, wound infection, bowel problems, slow resuming of bladder function, and the likelihood of having long-term lymphoedema, was too “small” and “insignificant” to be mentioned to them either in the clinic or on the ward. They stated that they wanted the information so that they could take precautions. They also suggested having anticipatory information in pamphlets, so they could refer to it when problems occurred in later days.

A number of participants reported similar experiences with the internal radiation treatment. They said that they did not know what to expect when they left home for the treatment, and found that the experience was very difficult to handle.

This is the experience of a 25-year-old participant:

I was quite upset and in shock when I went to have radiation treatment through the vagina. I had to stay in isolation for several days, with no privacy and sometimes up to six people inside the room watching the procedure, so unpleasant.... They kept asking me: "Why are you crying, where does it hurt?".... I guess it may not be too much for older women. But for me, it was so terrible.... I remembered I had been told about the procedure before the treatment, but it was different. When I was there, nothing could have prepared me for it. It was so traumatic.

A 75-year-old participant shared the same view:

The process of treatment [internal radiation treatment] should be explained to patients. I was so upset and frightened by the experience, staying in a room by myself and not able to move for 2 days. Perhaps patients should be advised to talk to a nurse beforehand, or to go and look at the place before the scheduled treatment so that they know what to expect.

The internal radiation treatment was described by the participants as a traumatizing, frightening and almost intolerable experience. They repeatedly stressed the need for good orientation to be offered by the service to ensure that patients were well informed of the procedure. For those who needed the treatment, some participants suggested a "compulsory" visit to hospital beforehand as they said many would overlook the importance of being prepared before they went for the treatment.

Setting up a patient network

Many participants stated that they wanted the opportunity to talk to other cervical cancer patients. They liked to exchange information when they underwent treatments together, such as sitting in the waiting area for radiation therapy or staying on the ward for surgical treatment. Some of them suggested setting up a patient network so that they could support each other. The following is an example of such suggestions:

Patients will benefit from talking to other patients who have been or half-way through the treatment, especially for Maori patients, or those who are frightened by the treatment, or those who are afraid of asking doctors questions. I wished I had the chance to talk to other patients about some self-care techniques while I was having radiation treatment. I am happy to talk to others what I have learned now, such as to drink plenty of water before radiation treatment, lie down for a while after I get home from the hospital, and use some chemical-free cleansing products and shampoo.... Nurses do not necessarily have the experience to tell their patients about these.... I suggest setting up a system where

patients who would like to help and talk to other patients, and live in the same area, can put down their names and phone numbers. I really want to see that happen.

Informational support for family members

Some participants stated in the interviews that women in general, were quite altruistic even when they were sick. They said that they worried a great deal over the feelings of their spouse and children. If more informational support could be offered to their family, they could focus more on their own well being. Those participants suggested providing opportunities for spouses to discuss issues of concern with clinicians, families to visit the hospital before the treatment begins, and community nurses to talk to the spouses and children at home (in one-on-one sessions or in support groups). Most participants agreed that the availability of support and informational services for their family could significantly lower their level of stress.

In the above recommendations to the informational services, patient participants stressed the need for health professionals to understand their feelings when the information was delivered and the difficulties they had in getting information they needed. They particularly needed more anticipatory information to support them through treatment and recovery. In addition, they also wanted the health services to support patient networking and to provide information for their family members.

In summary, this chapter reports the demographic details of patient participants, the participants' informational needs and their level of satisfaction, the participants' use of local informational sources and their degree of helpfulness, the barriers against the participants' access to cancer related information, and the participants' recommendations to the informational services. The following chapter will present the findings from the health professional interviews.

CHAPTER 5:

RESULTS II:

HEALTH PROFESSIONAL INTERVIEWS

The second source of information, health professional (key informant) interviews, are analyzed and presented in this chapter. Paralleling the previous results chapter, the findings from this source are presented under five headings:

- *Key informant information*, covering basic demographic data of the health professionals participated in the study;
- *Patients' informational needs*, listing the cancer related information which the key informants were frequently asked by, or provided to, cervical cancer patients;
- *Sources of information for patients*, reporting some helpful and accessible sources of information for cervical cancer patients in the region;
- *Barriers against patients' access to information*, identifying a number of barriers hindering patients' access to cancer related information;
- *Recommendations to the informational services*, outlining the key informants' views on how the services in the region could better serve the informational needs of women with cervical cancer.

5.1 Key Informant Information

Eleven health professionals who cared for cervical cancer patients in the Auckland region at the time of the study, participated in the research as key informants. Nine female and two male health professionals were recruited. Their positions in the health care system for cervical cancer patients are listed in Table 5.1.

Table 5.1: Key informant information

A. Oncology specialists	1. Gynecology/ Oncology specialist
	2. Gynecology/ Oncology specialist
B. Nurses in hospital	3. Oncology nurse practitioner
	4. Nurse working on a Gynecologic Oncology ward
	5. Nurse working on a Gynecologic Oncology ward
C. Nurses in the community	6. Oncology district nurse
	7. Cancer Society community liaison nurse
D. Patient counselors	8. Cancer patient counselor / Social worker
	9. Clinical psychologist
E. Maori health workers	10. Maori health manager
	11. Maori community health worker

5.2 Patients' Informational Needs

Key informants were asked to identify the information requested by their cervical cancer patients from a list of items (identical to the list presented to patient participants), and to supply additional information that cervical cancer patients requested from them and the information that they provided to patients. In this chapter, only the information which was frequently requested by or provided to cervical cancer patients were reported.

Table 5.2 & Table 5.3 list a total of 30 frequently asked questions. Some of them are clinically focused and were often referred to doctors and nurses. Some were socially or psychologically focused and were often referred to patient counselors. Maori health workers reported that Maori patients had some common concerns. Questions 11-14 in Table 5.3 were the questions asked frequently by Maori patients. Tables 5.4 – 5.8 present 22 items of information that key informants frequently provided to cervical cancer patients.

Table 5.2: Information cervical cancer patients requested frequently from key informants (Responses to the 16 items listed in the interview schedule).

Information requested	Reported by Key informants *				
	A	B	C	D	E
1. What caused my cancer?	√	√	√	√	
2. How common is cervical cancer?	√	√	√	√	
3. What is the up-to-date information of my condition?	√	√	√	√	
4. How is the cancer going to progress?	√	√	√	√	
5. How long have I got to live?	√	√	√	√	
6. What are the treatment options?	√	√	√	√	
7. What is the likelihood of cure after the treatments?	√	√	√	√	
8. what will happen to my body during and after the treatment?	√	√	√	√	
9. Will I pass my disease onto my partner or family members?				√	
10. What are the complementary methods of cancer therapy?		√	√	√	
11. Will cervical cancer or its treatments affect my appearance?		√		√	
12. Will cervical cancer or its treatments affect my sexual health?	√	√	√	√	
13. How is my lifestyle going to change with the cancer and its treatment?	√	√	√	√	
14. How do other people live and cope with cancer?		√	√	√	√
15. Is there any financial or domestic support available for cancer patients?		√	√	√	√
16. If I have any queries of health problems, whom can I talk to or get help from?		√	√	√	√

* **Key informants A:** Oncology specialists; **Key informants B:** Nurses in hospital; **Key informants C:** Nurses in the community; **Key informants D:** Patient counselors; and **Key informants E:** Maori health workers.

Table 5.3: Information cervical cancer patients requested frequently from key informants (Additional information supplied by key informants).

Information requested	Reported by Key informants *				
	A	B	C	D	E
1. Issues related to fertility	√	√			
2. Information on hormone replacement therapy	√	√			
3. How to control pain and discomfort?		√			
4. Will I get cancer somewhere else?		√			
5. How long do I need to keep coming back to the hospital for follow up?		√			
6. Are the treatments I had normal for cervical cancer?			√		
7. Are the symptoms I experienced common to others?			√		
8. Why me? Am I responsible for my illness? Could I have done anything?		√		√	
9. How can I communicate and get support from my partner /family?				√	
10. How can I deal with the guilt that my partner's sexual needs cannot be meet?				√	
11. How does the hospital deal with the body parts?					√
12. How much family support is permitted on the ward?					√
13. When is a chaplain available in the hospital?					√
14. What is the possibility of being looked after at home?					√

* **Key informants A:** Oncology specialists; **Key informants B:** Nurses in hospital; **Key informants C:** Nurses in the community; **Key informants D:** Patient counselors; and **Key informants E:** Maori health workers.

Table 5.4: Information that the Oncology specialists frequently provided to cervical cancer patients

Key Informants	Information provided to cervical cancer patients
Oncology specialists	1. Patient information pamphlets with the information on cervical cancer and proposed treatment
	2. Patient's clinical condition
	3. Treatment options, and pros and cons of the selected option

Table 5.5: Information that the nurses in hospital frequently provided to cervical cancer patients

Key Informants	Information provided to cervical cancer patients
Nurses in hospital	1. General knowledge of cervical cancer
	2. Information on radiation treatment, e.g. side effects, skin care and diet
	3. Information on hormone replacement therapy, e.g. benefits, risks and alternative remedies
	4. Information related to the control of pain and other symptoms

Table 5.6: Information that the nurses in the community frequently provided to cervical cancer patients

Key Informants	Information provided to cervical cancer patients
Nurses in the community	1. The support services available to cancer patients in the community, including services from the Cancer Society and the Oncology district nursing team
	2. The Cancer Society patient information pack and booklets on cervical cancer
	3. Self care issues
	4. The availability of sexual health counseling

Table 5.7: Information that the patient counselors frequently provided to cervical cancer patients

Key Informants	Information provided to cervical cancer patients
Patient counselors	1. Financial and other benefits available to patients
	2. Information on home help and other practical issues for patients living at home
	3. The importance of acknowledging feelings and ensuring the feelings being heard
	4. The effects of the illness on relationship with other people in the family
	5. Sexual changes throughout treatment e.g. artificial menopause, vaginal changes and libido issues
	6. How to deal with partner's concern about resuming sexual relationship
	7. How to deal with changes in body image

Table 5.8: Information that the Maori health workers frequently provided to cervical cancer patients

Key Informants	Information provided to cervical cancer patients
Maori health workers	1. The arrangement for follow up after being discharged from hospital
	2. The intention of Maori health workers to maintain contact with and provide continuing support to Maori patients in the community
	3. The support services available to Maori patients in both hospital and community
	4. How to ask health professionals questions and the importance of asking questions.

5.3 Sources of Information for Patients

The key informants were asked in the interview about their thoughts on the available informational services for women with cervical cancer. This section presents their opinions based on their experience in the field and their frequent contacts with cervical cancer patients.

5.3.1 Sources within hospital

The following informational sources for cervical cancer patients were identified by the key informants as the most helpful and accessible sources within hospitals:

- gynecologist or oncologist consultation
- written pamphlets prepared for cervical cancer patients
- staff in the Oncology wards
- patient counseling and support services

Gynecologist or Oncologist consultation was usually the first opportunity for patients with cervical cancer to get specialized information regarding their diagnosis and treatment. However, according to the key informants, the initial consultation was normally a distressing moment for cervical cancer patients. As a result, patients were often only able to take in a small amount of information and ask a few questions. Therefore to give patients written information was necessary to consolidate their understanding of the condition. Patients also needed advice on where and how to ask more questions after the consultation. To advise patients to ring up nurses on the oncology ward, or to refer patients to patient counseling service and support services were suggested by the key informants. The following are examples of their comments:

Oncologist consultation is the initial time for patients to receive information regarding their diagnosis and treatment. The time is often limited and patients normally can not take in the information explained.... I always tell them that they can ring up the ward and talk to the nurses, but I really think there should be a nurse who has the designated role to answer their queries.... It is difficult for them [cervical cancer patients] to ask more questions after the consultation or the ward round.

Written pamphlets are important for patients to understand different kinds of surgeries and treatments. They are especially useful for people who speak foreign languages. They can digest the information more fully at home after the consultation.

5.3.2 Sources in the community

According to the key informants, the most helpful and accessible informational sources in the community:

- General Practitioners (GPs)
- Cancer Society
- District Oncology nursing team

If patients required more in-depth information, the Cancer Society library, women's book shops or healthcare book shops, and the Women's Informational Center at the National Women's Hospital were suggested.

Key informants extensively discussed how community resources could be better utilized to meet patients' informational needs. They revealed that community resources were often either not well known to or poorly used by patients. Health professionals in the community were frustrated that they were not able to have access to all those who needed community health services because the services relied on professional referrals.

The oncology district nursing service is accessible and convenient to cancer patients. It is very hard for many people to just simply go out and search for information. Oncology district nurses do come to their home to address their concerns. However, the district nursing service relies on referrals made by hospitals. Hospitals hold all the information of cancer patients. They should have a special role created to liaise with community health and to look after all cancer patients' informational needs.

Not all of them know about our service [the Cancer Society's community liaison nurse team]. We probably have missed out quite a number of patients who needed the service but have not been referred to us or other community teams.

The key informants generally agreed that the Cancer Society was one of the most helpful and accessible informational resources for cervical cancer patients. However, some comments with regard to patient's use of this source were made in the interviews:

The Cancer society is not well known to the public. The word "cancer" frightens people. The general public do not know that they can ring up the Cancer Society if they have queries. The Cancer society should promote its service in the community, especially with answering questions and so on.

The Cancer Society provides informational service to patients. It has a library available to the public and has community liaison nurses to do home visits. The Cancer Society should promote its service for both the well and the sick regularly on newspapers and TV. At the moment, it is not well received.

The Cancer Society's function as a resource center for both the well and the sick in the community has not been well recognized by the public. Key informants would like to see its function as an informational source for cancer related health information in the community being promoted and advertised more frequently through the news media or other channels, so that it could become a well known and well accepted resource for either cancer sufferers or the general public.

5.4 Barriers Against Patients' Access to Information

The possible barriers against cervical cancer patients' access to the information they needed, from the perspective of key informants, are summarized as follows:

5.4.1 Patients' knowledge of the informational sources

Currently the care for cervical cancer patients with regard to their informational needs was fragmented. The key informants revealed that their patients knew some informational sources but often had not received complete and sufficient guidance on where to ask questions and how to get help. The lack of knowledge concerning the available sources of information was relatively common among those who did not need to be hospitalized or had not yet been admitted to a hospital for treatment.

Not everyone of them knows where to get help. For example, the Cancer Society's information phone line is not well known.... They should have been given a list of contact numbers.

There is not enough information for patients in the community. Once they are admitted to the ward, they are given a lot more information. However for those who do not need to be in, or have not yet been admitted to the ward, information is limited.

The above comments indicate that there were not enough measures to ensure systematic assessment, implementation and follow up with regard to cervical cancer patients' informational needs.

5.4.2 Patients' access to information

The key informants stated that women with cervical cancer faced enormous stresses in life, trying to battle their sickness, to cope with treatment schedules and to balance family life, career, finance, and so forth. They revealed that patients' access to informational services was often limited by the time and energy they had left for themselves. Going through booklet after booklet for information and trying to contact the right person who could discuss and answer their queries seemed too much for many of them. The key informants repeatedly stressed the need for patients to be given a simple list of contact names who have the necessary knowledge and are available to meet patients' informational needs. The appointment of a nurse specialist to work in the service was suggested.

Women [with cervical cancer] in today's life situation have a lot of stress.... They often do not have time to care for themselves or look after their own health problems. That is why they have no time or energy to go through piles of information booklets and to find out where they can get more help. It may be helpful if they are given a list of telephone numbers or have the informational services more accessible to them by giving them the name of a person who can find answers to all their questions and assist with their informational needs.

[I] suggest develop a role for an oncology nurse, not a clinic nurse, she has to have oncology knowledge. Patients can then ring up the nurse after the doctor's consultation and ask for the information they want. This nurse may provide patients with accurate information and liaise with the oncologists.

Most community health services in the region relied on professional referrals to gain access to patients. Cervical cancer patients were referred to those services when they had special needs and those needs were recognized by their care providers. This process was viewed by some informants as a barrier to patients' access to necessary information. In the current system, hospitals held patient information but failed to communicate or liaise adequately with community health services. Some key informants urged to strengthen the links between hospitals and community health services.

Hospitals hold all patient information. They have control over referring patients to a lot of community services. To ensure patients getting access to community health services for information,

communication and liaison between hospital and community health services should be improved and strengthened.

At the moment, the care for cervical cancer patients is fragmented. Continuity of care is poor.... Both doctors and nurses are not having enough time to discuss and repeat information to patients.... There is not enough contact with patients in the community.... A role to link between hospital care and community follow up is needed, i.e. the role of an oncology nurse practitioner.

Some patients' lack of self responsibility to seek help was also identified as a barrier to their access to the information they needed.

I normally cover most of the important issues and give them pamphlets to read. However, patients also have the responsibility of asking questions if they do not understand something or if they have concerns.

Some key informants further pointed out that more efforts should be made to encourage patients to participate in therapeutic decision making and to exercise self control over their health situation.

5.4.3 Patients' difficulties in asking questions

As revealed by the key informants, embarrassment, guilt or a sense of shame often stopped women with cervical cancer getting help from health professionals or other informational sources. A lot of patients felt uncomfortable describing their symptoms or queries related to their disease in front of male doctors. The lack of privacy and opportunity made it harder for patients to disclose their sexual concerns to health professionals.

It is a private part of the body, some people hide the disease from family and friends. This stops them from getting help or getting information.

The presence of male doctors, student doctors or doctors they don't normally know and trust, may hinder patients from discussing some private symptoms and concerns with doctors.

Some key informants revealed that patients' being afraid of asking too much would upset health professionals, especially doctors, had a considerable effect on their willingness to ask questions. Doctors were often perceived as the "God" in health care

delivery. Some patients felt that they had little control over their health situation. They had no power and they relied so much on health professionals and the services. Consequently, they needed to be a “good” patient and accept medical advice without questioning.

Patients normally feel less threatened to talk to nurses than to doctors. They perceive doctors as the God. They use technical words and they hold the power and control.

The hospital environment and culture make patients feel that they have very little power and control.... They are afraid of the consultants. They are also afraid of asking too much from nurses. They feel that they have no power to challenge the system of health care delivery.... They have no choice but to follow instructions and be passive.

A key informant mentioned that some women did not ask questions because they did not want to face the answers. Another informant revealed that stress in life often put patients off wanting to know more about their illness.

Some women have fears in their mind. They do not want the information because they don't know if they can cope with the answers.

Stress due to social situation and family burden puts people off. They often don't have the energy to deal with any complicated information.

Many key informants believed that cultural beliefs or practice had contributed to some patients' unwillingness to ask questions.

Patients from Asian culture do not like to talk about cancer,.Pacific Islanders like to keep the disease as a private matter to themselves.

Some cultures only allow men to speak for women in the family. Women communicate to health professionals through men, such as husbands or brothers, and they also like to deal with emotional problems within the family.

Women in some cultures are brought up to be shy. They find it extremely difficult to talk about private issues. In some cultures where men are used to speaking for women, men ask questions for their wife.

The key informants also noted that some patients were under pressure from their cultural or religious community to abandon conventional cancer treatment. This pressure became a barrier to their access to necessary information from the mainstream health providers.

Some people from the Pacific island cultures are very religious. They would rather to leave their body to the god and let the god to heal their disease.

For some Polynesians, there is pressure coming from their church groups or community groups to go with traditional medicine and alternative treatments.

The key informants reported that sexual concerns were the most difficult issue for cervical cancer patients to discuss with health professionals. The other difficult issues for patients with cervical cancer to ask about included financial supports, hospice care and issues surrounding death such as how to deal with the fears, and so forth. Family conflicts, according to the key informants, were often a hidden issue. Women with cervical cancer needed information and counseling to deal with changed family dynamics but often felt reluctant to seek professional help. In order to ensure patients receiving enough information on these issues, some key informants suggested having the information available in writing, and that health professionals initiate the discussion at appropriate times.

5.4.4 Patients' ability to understand and communicate with health providers

According to the key informants, patients' inability to fully understand the information provided was a challenge to quality information services. The use of medical jargon in consultation was seen by some key informants as a barrier to patients' understanding of the information provided, in particular, a barrier to those who have a low level of literacy or limited knowledge of their body structure.

Language is a huge barrier [for patients whose first language is not English] as most written materials are in English, and quite often, their consultation with health professionals relies on family and friends to interpret.

Hospital jargon is often used by health professionals. Patients are often not able to understand them. It is also quite difficult for some of them to ask questions.

Another barrier noted by the key informants was that some health professionals had a tendency to speak to their patients in general terms rather than being specific to individual case or disease process. Some patients had difficulties with relating generality to their own situation or condition. Some intended to gauge the severity of their condition using cues from the conversation. Confusion and misinterpretation often happened as a result.

Patients sometimes misinterpret the meaning of the information given by their doctors because the doctors talk to them in general terms, not specific or clear enough for them to understand it.

Doctors often talk about generality rather than specific cases. Some doctors do tend to use technical words to describe things to patients. Those who is likely to need help should have a nurse with them during the ward round or clinic visit.

Key informants also recognized that patients' emotional and physical status are two important factors affecting cervical cancer patients' readiness for and understanding of the cancer information they needed. The following are some comments:

I have noticed that patients don't normally take in much information during the consultation when the diagnosis is told, or after the operation when we try to tell them the findings and treatment options.

A lot of women can not articulate what information they want or need due to anxiety, withdrawal, anger, and sometimes aggression towards health professionals.

Often Maori patients do not take in what the doctors say to them because they have not yet sunk in and accepted that they have serious health problems.

According to these key informants, shock and denial related to the cancer diagnosis were common to patients in the early days of receiving the news and often delayed their access to necessary information. Fears and anxiety of having cervical cancer also affected their ability to concentrate and comprehend. Aggression and resentment towards health professionals happened sometimes and undermined patient's relationship with their health providers. Patients' poor physical condition such as being in pain or suffering from side effects of the treatment, often affects their ability to take in and remember information. As a result, the key informants stressed that information to patients should be simple, precise and relevant to the stage where

patients were at. The key informants also highlighted that important information to cervical cancer patients must be given in different ways, more than one time, and reinforced by different people. The following are their comments on how information should be delivered.

Not [able to understand the information provided] when they are given the diagnosis. Most of them are in shock and disbelief.... Information should be kept simple at the beginning.... Information should be reinforced at a later stage.

The information giving to patients should be simple and precise. Not to give too much irrelevant information. Timing and time are quite important too.

[Health professionals] should adjust the way information is given to patients such as to slow down, to repeat, to give written information, and to give information in more than one forms.

5.4.5 Inaccurate and inconsistent advice to patients

Key informants did not believe inaccurate and inconsistent information to patients was a common issue. However, new treatments and changes in care structure outdated information constantly. Some information given out by GPs and referring gynecologists was noted to be inaccurate, and some reading materials were found out-of-date.

Inconsistent advice to patients was not commonly noted. There was no suggestion of a consistency problem between professional groups such as doctors versus nurses in information delivery.

They are mostly similar information. Giving inconsistent and inaccurate information to patients sometimes happens to junior doctors or nurses. It is not a problem between groups such as doctors versus nurses. They are mostly individual problems due to the lack of training or up-to-date information.

We have tried to eliminate that [inconsistent advice to patients] by having a multidisciplinary meeting on each individual case. So we come up with just one decision and we discuss the same thing in front of the patient.... We should all work as a team along with the decision made in the multidisciplinary meeting.

Inconsistent information to patients was often caused by different opinions within the health care team. A multidisciplinary team approach to eliminate differences between members of the healthcare team was successful in creating consensus within the team and “taking away argument from patient’s bedside”. By having multidisciplinary discussion on each case, the health care team came up with a single treatment plan. All members were informed of the plan and would give patients advice accordingly. However, this approach had also drawn criticism from some key informants as the decisions were medically led with little involvement of patients and their bed-side care givers.

Developing clinical pathways and guidelines with multidisciplinary involvement was another measure currently being examined in the area. The informants were positive about this measure.

Patients with cervical cancer often wanted to know about the statistics related to the disease and treatments, but had little understanding of what the numbers meant. Statistical information was an area likely to cause confusion in information delivery. One key informant noted that statistics were sometimes explained to patients differently with contradictory interpretation.

...a lot of contradictions with different statistics, which patients have no understanding of and rely on the explanation given by health professionals.

5.4.6 Barriers against Maori patients’ access to information

Maori health workers and other key informants were consulted over the issue of barriers against Maori patients’ access to the information they needed. A number of barriers had been identified.

The language used by health professionals to provide cancer information was viewed as one of the major barriers to Maori patients’ access to information. Some key informants reported that a number of Maori patients had difficulties in understanding the information provided verbally or in writing. To address this problem, they suggested that health professionals use “plain English” in all forms of consultation, and provide written information with the “language level of a 12-year-old”. Many also

stressed the need for nurses or Maori health workers to follow up on Maori patients after medical consultation.

The other barrier hindering Maori patients' access to health information, according to Maori key informants, was that many Maori patients tended to "hold back" when they were confronted with health problems. Maori patients often did not take a further step to ask questions or to clarify the information given to them. This, as described by the Maori key informants, was due to "the fears they had in mind with medical professionals" and "the embarrassment of discussing their body".

Maori patients are whakama (shy) in general. They see their body as a private part of them. Exposing the body is a violation in their beliefs. So they are usually quite uncomfortable with discussing health care issues with those whom they did not know well.... Male doctors make a lot of Maori women uncomfortable discussing health problems related to private parts.

According to Maori key informants, the other reason "holding back" Maori patients from discussing their health concerns was that they were generally afraid of being asked to go to hospital or stay in hospital. Hospital was a foreign place for Maori patients. They would not want to be kept in an unfamiliar environment and isolated from their family and social support. A lot of them had negative experiences with hospitalization and believed staying in a hospital would actually affect their health.

They [Maori patients] fear that they would be asked or kept in hospital. They often associate hospital with ill health. They fear the isolation in a hospital where family support is kept away. They believe hospital will actually bring their health down.

The key informants revealed that Maori patients' access to information was often a matter of whether or not they felt comfortable using the informational services available to them. Maori patients would choose not to have contact with a health service if they were not given the feelings of security and control. Care providers' knowledge and attitude towards Maori culture had also been identified as a barrier. The following comments show that Maori patients' feelings of being understood, accepted and cared for were crucial to their willingness of communicating with health professionals and seeking information from health sources.

A lot of them [Maori patients] know where to get help, but it is a matter of feeling comfortable or not.

Maori and Pacific Islanders need more understanding and support from the staff and the hospital due to their cultural differences. Attitudes of health professionals and their knowledge of other cultures can become barriers to patients' access to information. Some patients felt that they were accused of being responsible for their sickness by health professionals.

Hospital is a foreign place for Maori patients. They often want to know what is expected to be a "good" patient in a hospital ward. Doctor-patient relationship is critical to whether they would feel comfortable or not to communicate with doctors and to ask questions.

Inadequate resource for effective delivery of health information to Maori patients both in hospital and community was another barrier identified.

I have noticed the lack of connection for information in the community. We need Maori nurses who can do patient follow up in the community. It will be helpful to set up a unit which provides home visits for Maori cancer patients after they leave the hospital.

There is not enough commitment from health service providers. To be able to deliver health information effectively to Maori people, hospitals should allocate more resources to employ Maori health professionals, to train hospital staff, to develop policy, and to enhance staff's commitment to Maori health.

Allocating resources for health workers to establish regular contacts with Maori patients in the community was urged by the key informants following their reports that Maori patients had difficulties gaining access to information in the community. In addition, they also urged health services to further their commitment to Maori health.

5.5 Recommendations to the Informational Services

The key informants' opinions on the current services and ways of delivering health information to cervical cancer patients were sought in the interviews. Their views on how the services could better serve the informational needs of women with cervical cancer have been summarized in the following aspects:

Measures to ensure effective delivery of health information to cervical cancer

The key informants suggested that the oncology services in the region should develop policy or apply measures to ensure:

- 1) important information being delivered to patients repeatedly and in more than one form;
- 2) simple access to specialized care information for patients after they leave hospital;
- 3) adequate patient need assessment and follow up by appointing a designated nurse specialist or care coordinator who sees patients routinely in the clinic or on the ward; and
- 4) patients being referred to community health services early and promptly.

More resources to be put into the informational services for women with cervical cancer

The key informants stressed that more resources should be put into the following areas in order to develop better informational services for women with cervical cancer:

- 1) providing patients with adequate counseling and emotional support;
- 2) attracting more female gynecologists to work in the oncology field;
- 3) improving the communication and counseling skills of health professionals who care for cancer patients; and
- 4) providing more update training for health professionals in the community, e.g. GPs and district nurses.

Close collaboration and liaison between service providers

As revealed by the key informants, patients with cervical cancer often needed to go through a number of services all with different specialties. A lack of continuity in patient management and care fragmentation were repeatedly reported, indicating the needs for developing efficient channels for communication and liaison among different services. The creation of oncology nurse specialists or case managers who follow patients through different services and liaise among services was recommended by a number of key informants.

The oncology clinic to become a major informational service for women with cervical cancer

Many key informants pointed out that patients' clinic visits were an important opportunity for information delivery, needs assessment, emotional support, prompt referrals to support services and patient education. Some claimed that patients would benefit from an oncology clinic staffed by knowledgeable oncology nurses. A suggestion was made to attach the clinic to the oncology ward and rotate ward staff to work in the clinic. This suggestion was based on the consideration that it required nurses with an oncology specialty to inform patients and give out practical advice during patients' clinic visits.

Promoting the concept of hospice care

Hospice specialized in all areas of palliative care, not only in terminal care, but also in pain management and symptom control. Hospice care promoted the concept of living positively and creatively with dying. Some key informants revealed that many patients with advanced cervical cancer, rejected the information on hospice services early in their care, because they had little understanding of the services hospice offered. Since dying was not a normal subject in both medical and social discourse, those patients' fears and anxiety were often trapped in silence. Patients with advanced cervical cancer and their families relied on the efforts of health professionals whom they trusted to help them voice their negative feelings over dying and to promote the concept of hospice care in advance. The key informants stated that providing those patients with the information early would enable them to receive good hospice care and have a better quality of life at the end stage of their life.

Facilitating patient networking

Suggestions such as developing support groups for cervical cancer patients and inviting those who have gone through the treatment to meet new patients were mentioned by some key informants based on their assumption that patients could benefit from talking to each other and listening to other's experiences. However, some opposed the idea because they believed that patients might pass on information without understanding the clinical differences between patients with the same disease. They also worried that some unnecessary information might bring confusion to patients and some negative information might cause undesirable effect on patients' emotional status. Nevertheless, this approach warranted careful consideration and further studies to determine both its risks and benefits to cervical cancer patients.

The results outlined in this chapter are from the perspective of health care providers. They cover the demographic information of the key informants, the informational needs of cervical cancer patients, some helpful and accessible informational sources, and the key informants' recommendations to the informational services in the region. In the next chapter, the findings from both patient interviews and health professional interviews will be examined, compared and discussed in detail.

CHAPTER 6:

DISCUSSION

This chapter discusses the results of the study and highlights their significance. Relevant issues reported in the literature are also compared and incorporated in the discussion. Four aspects of the results are presented: 1) informational needs, 2) sources of information, 3) barriers to information, and 4) participants' recommendations. Finally, the limitations of the study are examined.

6.1 Informational Needs

As anticipated, women with cervical cancer living in the Auckland region had informational needs similar to those of cancer patients described in the literature. The variability in the needs of information was also consistent with the findings from previous studies and included information related to disease, personal, family and social concerns (Derdiarian, 1987a). According to patient participants, the areas of highest informational need (95-100%) were related to: 1) the likelihood of cure after treatments, 2) the effects of treatments on the body, 3) the effects of treatments on sexual health, 4) treatment options and 5) up to date information of their condition. Other areas of high informational need (74-84%) were: 6) the causes of their cancer, 7) life expectancy, 8) the likely progression of the disease, 9) how other people live and cope with cancer, and 10) where to get help when needed. These results are congruent with data obtained from health professional participants.

Overall, the results of this study indicate gaps between the patient participants' informational needs and their level of satisfaction with the information existed in the areas of: 1) the causes of cancer, 2) life expectancy, 3) the effects of treatments on sexual health, 4) how other people live and cope with cancer and 5) where to get help when needed.

Information on the causes of cancer and life expectancy was identified by both patient and health professional participants as areas of high informational need, but had the lowest patient satisfaction rates (44% & 50%). This might be expected due to the limited understanding of the disease and the unpredictable nature of cancer. How to satisfy patients' informational need on both issues continuously poses a challenge to all health professionals who care for cervical cancer patients. It was suggested in this study that some doctors had a tendency to speak to patients in general terms rather than being specific when asked about these issues. An example was given by a patient participant, who was told "not to worry" without any specific information given to her when she asked about her prognosis. This kind of answer was perceived by patients as information gate-keeping. Similar findings were reported previously by Kavanagh & Broom (1997). In the present study, patient participants' perception of not being able to get direct answers from health professionals on issues related to the cause of their illness and life expectancy may in some ways contribute to their dissatisfaction on these areas of informational need.

Informational need concerning sexual health has not been well met in the current structure of information delivery. The results indicate that information on the effects of treatments on sexual health was needed by almost all patient participants (95%). However, the in-depth discussions with both patient and health professional participants revealed that cervical cancer patients felt most uncomfortable asking questions relating to sexuality due to reasons such as the lack of privacy, feelings of embarrassment, gender difference between themselves and their care providers, and cultural beliefs. The under-utilization of patient counseling services was also found in the study. The low participant satisfaction rate suggests that some cervical cancer patients may have the questions in mind but do not seek help from health professionals. Measures such as preparation of information in writing, opportunities for discussions on sexual health issues, and encouraging more cervical cancer patients to use sexual health counseling service were suggested by the participants. The need of providing information on sexual health for cervical cancer patients and difficulties in satisfying the patients' need concerning sexual health have been reported in the literature (Corney et al., 1992).

How other people live and cope with cancer and where to get help when needed were also areas of high informational need and low patient satisfaction. So far, these two areas of informational needs have not attracted much attention in the literature. Some patients commented in the interviews that such questions were too small to ask doctors during consultation. Putting in place a system to ensure patients having easy access to information and support patient networking may address these needs.

As this study is partly retrospective, it would be an assumption that patient participants had not been informed in the areas of low satisfaction through various communication channels. The dissatisfaction shown in the study may result from poorly structured information being presented, or information being delivered in an insufficiently comprehensible way, or at ^{an} inappropriate time.

Nevertheless, both quantitative and qualitative data shows that overall, the patient participants were mostly satisfied with the information they had received and the services which had provided informational support for them. This high level of overall satisfaction reflects the particular efforts made by all members of the oncology team who care for cervical cancer patients in the region.

However, as previously reported in the literature, greater satisfaction with information did not always reflect higher levels of factual knowledge, and the satisfaction with information was often positively correlated with the satisfaction with care in general (Stephoe et al., 1991). It is possible that patient participants' report of overall satisfaction with information in this study may partly result from a social desirability effect, i.e. they were satisfied with their care in general and wished to report positively on the team that cared for them.

6.2 Sources of Information

The results of the study show that patient participants obtained cancer related information from a variety of sources and most of those were helpful in some ways. Congruent with the findings from previous research, this study indicates that oncology specialists, pamphlets from health agents, nurses in hospital and GPs were the main

sources of cancer related information for patient participants, and they obtained information from both verbal communication and written materials (Hinds et al., 1995; Luker et al., 1996).

Health professional participants identified specialist consultation, written pamphlets, staff on the gynecologic oncology ward, and patient counselling and support services as the most helpful and accessible sources for cervical cancer patients in hospital. These findings were consistent with the data from patient participants except the use of patient counseling and support services. Only 40% of the patients in the study reported they had gained information from social workers, patient counselors or psychologists. The value of social support and counseling for cervical cancer patients has been highlighted by previous research on the psychosocial and sexual outcomes of treatments for gynecological cancer (Corney et al., 1992; Cull et al., 1993). Cervical cancer patients' unresolved feelings of anger and blame, the possible loss of reproductive ability, sexual dysfunction following treatments and the effects on their marriage were some of the distressing factors reported in the literature. A change in care orientation with more emphasis on the women's emotional and social needs should be considered.

Patient counseling and support services, including social workers, cancer patient counselors, clinical psychologists and Maori health workers, were free services available to cervical cancer patients in hospital. They helped patients to understand their situation and reduce distress, provided patients with information on financial and domestic supports, and liaised between patient, whanau, health professionals and community services. A clinical psychologist who specialized in sexual health counseling was available to help cervical cancer patients in relation to their sexual functioning during and after treatments. All these counseling and support services were offered to cervical cancer patients with or without referrals from doctors and nurses. The information on these services was normally available on the oncology wards or in clinics. However, some patients in the study revealed that they had no knowledge of these services, and some stated they knew the services but chose not to use them. The findings indicate that more efforts should be made to enhance patients' awareness and understanding of the services and to examine the availability of these services to cervical cancer patients.

According to health professional participants, the most helpful and accessible informational sources in the community for cervical cancer patients were GPs, the Cancer Society and district oncology nurses. The responses from patient participants revealed that all the above sources in the community were very helpful but only relatively accessible. For example, only 35% of the patient participants had received information from nurses in the community but all those who received information from this source reported that the information had helped them. The results suggest that these resources in the community should be widely introduced and made more accessible to cervical cancer patients in the region. However, concerns regarding a low referral rate of cervical cancer patients to community health services as a result of insufficient assessment of patients' informational needs and the lack of adequate liaison between hospitals and community health services, were expressed by the informants in community health. They urged the hospital team to improve their referral system and to strengthen the links between hospital and community health services.

The under-utilization of community resources for cervical cancer patients is a cause of concern because continuing informational support for patients is important after they have been discharged from hospital care. Giving the information at appropriate time is regarded as crucial to patients' understanding of the information (Adams, 1991; Hinds et al., 1995). The hospital team commented that they could only give the amount of information their patients could cope with and concentrate on at the diagnosis and treatment stage, when they had to encounter enormous physical and emotional distress. The shortening of patients' hospital stay also put pressure on the hospital team to provide cervical cancer patients with adequate information related to management of the after effects of treatment and long-term self-care issues. The finding that not enough cancer related information was provided to cervical cancer patients outside the hospital environment, may be attributed to GPs and other community health providers deferring responsibility for providing specialized information to the hospital team and not recognizing cervical cancer patients' increasing need for informational support from community resources. If this is the case, then the gaps between hospital and community care should be addressed with more communication and close collaboration between the hospital team and

community services. Efforts to increase the knowledge base of community health providers on issues related to cervical cancer care in the community and to improve the availability of community health resources to cervical cancer patients are necessary to ensure that they are able to meet cervical cancer patients' informational needs further from the time of diagnosis and treatment.

Three quarters of patients in the study reported that they had gained useful information from the media including women's magazines, TV and radio programs. This result is consistent with the findings from previous research and shows that the media is a powerful source especially for general information related to cancer, cancer sufferers and new developments in cancer treatment (Luker et al., 1996). One of the major informational needs identified by patients in this study was that cervical cancer patients wanted information on how other people live and cope with cancer. The media may be a main provider for this information.

Another source that cervical cancer patients could get this information from was other cancer patients. Forty percent of patient participants had gained information from friends/family who had cancer or cancer patients support group. Many discussed in the interviews that they would like the opportunity to have contact with or to support other cervical cancer patients. This is congruent with the findings from the study of patients undergoing surgery for gynecological cancer conducted by Corney et al. (1992). They reported that a third of their study subjects felt that patients should be given the opportunity to talk to someone who have had that operation, and many would be prepared to do this for other women. A close look at the available channels for this kind of information exchange between patients, there was no patient support network set up for cervical cancer patients in the region apart from the general cancer patient support groups organized by the Cancer Society. Even though some health professionals had conservative views regarding patients passing on information, a system to facilitate informational support among cervical cancer patients should be carefully considered by the service providers in the region.

The Women's Informational Center at the National Women's Hospital was valued by some health professionals in the interviews but had only been used by one patient participant who reported it helped her a great deal. It was a relatively new service

provided by the hospital. A variety of information on issues related to women's health was gathered in one place for the convenience of the public. This service provided women and family with both verbal or written information of their needs. The staff there assisted the public to get access to information from various sources including the Internet. The results of the study indicate that many cervical cancer patients had no knowledge of this new source of information or had not yet used it for information. The value of this informational service to women with health concerns should be promoted to both cervical cancer patients and health professionals.

At the time of this study, only one patient had used the internet to obtain cancer related information and reported satisfaction. Using this source may become a new trend for cervical cancer patients to get information in the future. One health professional reported that she did not support patients using the Internet as the information there was broad and some would be quite irrelevant to the treatments available here. The relevance and helpfulness of the Internet information for cervical cancer patients warrants further research.

Overall, the above findings on sources of information are mostly consistent with both the reported useful sources of information for breast cancer patients in England (Luker et al., 1996) and the reported preferred sources of information for radiotherapy treated cancer patients in Canada (Hinds et al., 1995). By way of comparison, nurses in hospital were perceived by a larger percentage of patient participants in the current study to be a useful source of information. This may suggest that nurses caring for cervical cancer patients in the region were in a better position to respond to their patients' informational needs and provide them with timely information. Unfortunately, the sample size is relatively small, therefore, conclusions are not generalizable.

6.3 Barriers to Information

Qualitative interview data from both patient and health professional participants revealed that cervical cancer patients in the region had knowledge of some informational sources but often had not received complete and sufficient guidance on

where they could ask questions or obtain the information they needed. Currently the care for cervical cancer patients with regard to their informational needs was fragmented. Patient participants complained that the information they needed was not readily available to them. In many cases, they said they had to ask to have the information provided to them. The health professional participants also recognized the difficulties of patients getting necessary information. They repeatedly stressed the need for patients to be given a simple list of contact names of people who had the necessary knowledge and would be available to provide information.

It was apparent that there were not enough measures in the system to ensure systematic assessment, implementation and follow up with regard to patients' informational needs. The creation of a nurse specialist's position, to fulfill the role of assessing patients individual needs on a regular basis, and giving patients easily accessible advice, was strongly supported by health professionals in the study, and recommended by previous research on the care of women with gynecologic cancer and breast cancer (Corney et al., 1992; Luker et al., 1996). With the development of this new role, patients could be better supported throughout the course of their illness and be promptly referred to the appropriate hospital and community services should they need professional assistance. If patients want more in-depth information to understand their diagnosis and treatment after specialist consultations, the nurse specialist who sees them routinely in the clinics can assist them with using resources such as libraries and the Internet. The appointment of a nurse specialist responsible for patient need assessment and ongoing support would be a positive measure to reduce system barriers and strengthen the links between the hospital team and community health services.

Communication barriers between cancer patients and health care providers have drawn much attention in the literature (Grahn, 1996; Meredith et al., 1996; T. Thompson, 1990). They were also recognized by both patients and health professionals in the study. Nearly half of the patient participants responded in the interviews that they had felt uncomfortable asking health professional questions relating to their illness. Both the patients and health professional identified sexual concerns as one of the most difficult issues for cervical cancer patients to discuss with health professionals. Addressing problems in routine clinical practice such as building

a trustworthy relationship with patients, providing a private and comfortable environment for consultations and allocating adequate time to hear patients' concerns may encourage patients to ask questions about the most difficult areas.

The other areas where cervical cancer patients normally had difficulties in asking questions were reported differently by patient participants and health professional participants. Patient participants reported bladder and bowel problems, structure of internal organs and minor discomforts. Health professional participants reported financial supports, hospice care, issues surrounding death and family conflicts. These two perspectives are not exclusive but rather supplementary to each other in providing a complete picture of what difficulties cervical cancer patients had experienced in asking their care providers questions. However the finding that none of the areas where patient participants reported were identified by health professional participants in the study suggests that those areas of patient difficulties were possibly overlooked by their care providers.

As revealed in the study, many factors contribute to cervical cancer patients' difficulties in asking questions. In common with the findings from previous research, embarrassment, lack of privacy, gender difference, not knowing how to ask questions, feelings of inferiority and not wanting to upset health professionals by asking too much or small things were the factors recognized by both patients and health professional participants. Patient participants also revealed that they perceived some health professionals being too busy to spend time with them, lacking understanding of their situation and not showing interest in their concerns. These obstacles to patients asking questions are congruent with the findings in the literature of health care communication, but had not been directly identified by health professional participants (T. Thompson, 1990). Whether they were wide-spread and long-standing problems in the services for cervical cancer patients in the region warrants further examination.

On the other hand, health professional participants revealed some barriers which had not been reported by the patients in the study. Factors such as too much stress in life, patients not wanting to face the answers to certain questions, different religious beliefs and cultural practices, and patients' lacking self responsibility to seek help or to

participate in decision making were reported as factors influencing cervical cancer patients' willingness to ask questions. These barriers may not be easily recognized and overcome by patients themselves. These will need to be addressed individually with the support of patients' care providers in order for them to get the information they need .

Cervical cancer patients' emotional and physical status were pointed out to be crucial to their ability to understand and retain the information provided by health professionals. The emotional problems were particularly common to patients at the initial stage of receiving their cancer diagnosis and these often delayed patients' access to necessary information. The health professionals in the study suggested that important information should be given to cervical cancer patients in different ways, more than one time, and reinforced by different people.

Inaccurate or inconsistent information provided to cancer patients was indicated by the literature as a major disadvantage of patients receiving information (Hinds et al., 1995; Fieler et al., 1996). In this study, inaccurate and inconsistent advice to patients was not found as a common or alarming issue. Several measures within the hospital team were in place to ensure patients with cervical cancer received accurate and consistent information.

This study reveals that some immigrants had difficulties in getting information due to language barriers or a lack of knowledge of the informational services in the region. This problem was not adequately addressed by the services for cervical cancer patients at the time of research. Those patients were left with little ongoing informational support from both the hospital and the community. Most information was provided in English, and there was not enough personalized help offered to meet those patients' individual informational needs. To provide quality informational services to new immigrants or those who can not understand English creates a significant challenge to service providers in the region. More in-depth studies to investigate the special informational needs of new immigrants and those who can not understand English are imminent in the current situation.

Several barriers against Maori patients' access to information were also identified by the health professionals in the study. They revealed that Maori patients' access to information was often a matter of whether they felt comfortable or not using the informational services available to them, including staying in hospital and asking health professionals questions. Hospital was an alien place for many Maori patients. They did not want to be isolated from their usual social support. These feelings were reflected on the information Maori patients frequently requested from Maori health workers, such as what hospitals do to the body parts, how much family support is permitted, when a chaplain is available, and whether they can be looked after at home (see Table 5.3, p. 56). Health providers' knowledge and attitudes towards Maori culture were indicated by some health professional participants as crucial factors to Maori patients' feelings of being understood, safe and in control. In addition, a lack of adequate resources for health workers to establish regular contacts with Maori patients in the community was highlighted. Practical suggestions to address Maori cervical cancer patients' special needs and to encourage their access to informational services were made by the participants in the study.

6.4 Participants' Recommendations

As indicated by both quantitative and qualitative data, this study reflected a high level of satisfaction with the current sources and ways of delivering information to cervical cancer patients in the region. However, it did highlight some problems in the system, and many participants had views on how the current services could perform better to serve the informational needs of women with cervical cancer. Those recommendations were outlined in Chapters 4 & 5.

Patient participants' recommendations indicate their need for information additional to those provided by the hospital team. They wanted to know where to get a second opinion and how to obtain information from other sources. These needs were reflected on the questions cervical cancer patients frequently put forward to nurses in the community, such as "Are the treatments I had normal for cervical cancer?" and "Are the symptoms I experienced common to others?" (see Table 5.3, p. 56). Patients did not normally pose this kind of questions to their care providers in hospital. They did

not want to be seen as challenging the opinions of their care providers. They often asked those questions in the community where they felt much more in control. Cancer patients and their family's need to know about the availability of second opinions and how to obtain them are reported in the literature. Adams (1991) points out that most cancer patients are concerned about whether their doctor is the best doctor or whether their treatment is the most suitable one in the treatment phase. Health services for cervical cancer patients may look at providing cervical cancer patients with channels and assistance for secondary and independent information to allay their distress and ensure their needs being adequately met.

The importance of providing cervical cancer patients with anticipatory information was also stressed in patients' recommendations to the services. The value of teaching patients about expected symptoms or side effects before they occur and to reduce stress during treatment by providing information on expected sensations is emphasized in the literature (Adams, 1991). The reported distress reactions associated with cervical cancer patients' internal radiation therapy highlights the need for better preparation for this kind of treatment. This finding indicates that cervical cancer patients should be prepared with accurate expectations about the sensations they will experience during the internal radiation therapy and coping techniques, in addition to the traditional ways of giving out information relating to the technical and procedural aspects of the treatment.

Patient participants also wanted health services for cervical cancer patients to provide more information for their family members. Literature reviews indicate that both the women and their partners had a strong desire for information about the cause of cervical cancer, factors influencing the risk of recurrence, and the effects of cancer treatments on their sexual relationship (Corney et al., 1992). One study reported that the women's partner often had very little information about the disease and were therefore unable to understand and discuss the women's central concerns (Cull et al., 1993). The current informational services to cervical cancer patients in the region had limited initiatives to provide informational support for family members. Based on the information from the participants, it appeared that partners of the women had not been directly offered a chance to express their concerns, nor had they sought the opportunity to attend discussions with the women's clinicians. Patient participants'

suggestions on what supports can be offered to their family were very practical and constructive (p. 52).

Health professionals' recommendations about the informational services focused on the overall structure of information delivery. Relevant issues have been discussed previously. The analysis of these issues points to the importance of applying measures to ensure that ongoing informational needs assessment becomes a routine part of patient care, and the necessity of providing easily accessible and readily available information to cervical cancer patients. In addition, an emphasis was placed on effective communication and liaison among a range of service providers in the region. Oncology literature shows that continuity of care is of paramount importance for quality cancer care (Beddar & Aikin, 1994). Cervical cancer patients interface with a wide variety of health services over an extended period of time. Close collaboration among services, care providers, and care settings is crucial to the effective delivery of information. The role of oncology nurse specialists or case managers in assessment and coordination of cervical cancer patients' informational needs was recommended by participants in the study.

6.5 Limitations of the Study

This study is a formative evaluation, which does not attempt to generalize results beyond the research population. It is important to emphasize that the findings of this study pertain to patients under the care of the public health services in the immediate years prior to the research being conducted.

Given the small sample size and the use of a convenience sampling method, the results are only preliminary. It is estimated that around 70 new cases of cervical cancer each year were diagnosed in the region between 1996 and 1998, and most of them were cared for by the public health services. This study sampled 20 cervical cancer patients and 18 of them were diagnosed between 1996 and 1998 at the National Women's Hospital. Based on this estimation, the results of this study represent close to 10% of cervical cancer patients who were diagnosed and managed by the public health services between 1996 and 1998 in the region. The sample in the

study is characterized by cervical cancer patients of different age groups and educational levels, from a variety of cultures, and living in both urban and rural areas of the region. In spite of this, the true representativeness of this sample can not be determined because data on key characteristics of the research population is not yet available.

The 11 key informants (health professional participants) cover a variety of oncology care experts and support health workers both in hospital and community. A missing perspective in this research is that of the general practitioners who play a valuable role in providing ongoing informational support for cervical cancer patients in the community. Reasons for not being able to recruit general practitioners in the study were discussed in Chapter 3.

In this study, a large amount of data was collected retrospectively and might have been influenced by other factors such as participants' ability to accurately recall previous events and some social desirability effects. The participants' responses in the interviews were recorded *verbatim* by the researcher on the interview scheduled sheets. Some detailed description of the events, or comments which might not seem relevant to the questions asked at the time of the interviews was not recorded *verbatim* and therefore can only be used as supportive data to present the findings.

Data on cervical cancer patients' informational needs was collected mainly through standardized questions using a list of informational needs reported in the literature or generated by gynecologic oncology experts. The list represented the current knowledge on cancer patients' informational needs but might not reflect the needs specific to cervical cancer patients in the region due to the scarcity of previous research on their informational needs. The finding that all the listed items were considered to reflect patients' needs by at least 42% of cervical cancer patient participants in the study demonstrates the content validity of these standardized questions. The additional informational needs reported by participants in the study are outlined in the results and warrant further investigation to determine how common they are among women with cervical cancer.

In data analysis, no correlations were suitable due to the use of a small sample size. As a result, there was no analysis of the influence of age, ethnicity, educational level, residential area, disease stage, type of treatment and year of being diagnosed on patients' informational needs and their use of informational sources. Some trends were reported but only limited conclusions can be drawn from the data. Future research on cervical cancer patients' informational needs should address these issues because the literature suggests that cancer patients' informational needs and their use of informational sources vary from person to person and over the course of the disease.

Overall, the generalizations of the results should be limited to cervical cancer patients who were diagnosed with cervical cancer and managed by the public health services between 1996 and 1998 in the greater Auckland region. Continued research to replicate these results will be valuable in expanding and validating the theoretical basis for evidence-based oncology practice and management of the informational services for cervical cancer patients in the region.

In this chapter, the results of the study are discussed in detail. The similarities and differences between the findings of this study and those from earlier research are also explored. In addition, this chapter examines the limitations of the study in relation to its generalizability, and representativeness as well as methods used in data collection and analysis. The following chapter will conclude the thesis and summarize its implications for oncology nursing practice.

CHAPTER 7:

CONCLUSION

As indicated in previous chapters, this research achieved its aims of assessing the informational needs of women with cervical cancer in the region, evaluating the availability and helpfulness of local sources designated to meet these needs, and identifying barriers which exist in information delivery and hinder those women from gaining access to the information they need. Despite a number of limitations, the results obtained from the study provide a foundation for understanding the informational needs of women with cervical cancer in the greater Auckland region.

Findings of the study suggest that emphasis should be placed on providing information to cervical cancer patients in the areas of high informational needs. These areas of needs are: 1) the likelihood of cure after treatments, 2) the effects of treatments on the body, 3) the effects of treatments on sexual health, 4) treatment options, and 5) the up-to-date information on their condition. Evaluating cervical cancer patients' use of informational sources in the region reveals that the patients obtained information from a variety of sources, and some sources in hospital and community were particularly helpful and accessible to the patients.

Overall, the results of the study indicate that most patient participants were satisfied with the information provided by health services in the region. However, gaps between the participants' informational needs and satisfaction with the information they received were found. They were mainly in the areas of: the causes of cancer, life expectancy, the effects of treatments on sexual health, how other people live and cope with cancer, and where to get help if they had queries. Multiple barriers to information were also reported hindering cervical cancer patients from gaining access to informational services, communicating with health professionals and understanding the information provided. A number of patient concerns such as changes in sexual function were identified as areas patients had difficulties in initiating a discussion with their care providers. The existence of information deficits and problems in patients' access to information indicate that meeting individual patients' requirement

for information is a continuous challenge in the care of cervical cancer patients in the region. The findings of the study highlight that the benefits from information can be maximized when measures are applied to systematically assess and address their individual requirements for information. To provide patients with clearly defined, readily available and easily accessible information was a recurrent theme in both patient and health professional participants' recommendations to informational services in the region.

The findings of this research have implications for nursing practice. More women are now living with cervical cancer for a longer period of time due to advances in cancer diagnosis and treatment. As with the care of any chronic illness, facilitating cervical cancer patients' acquisition of accurate and relevant information becomes a significant part in patient care. It enables patients to cope better with their illness and allows them to participate more actively in their disease management. In this study, nurses were identified by both patient and health professional participants as a major source of information for cervical cancer patients in the region. The finding places nurses in a key position in providing cervical cancer patients with the information they need. To meet this challenge, nurses have to adequately prepare themselves and be knowledgeable in the areas of patients' informational needs. In addition, nurses should apply intervention strategies to remove barriers and facilitate their patients' access to necessary information.

This research reinforces the perception that information is important to cervical cancer patients from both the patients' and health professionals' perspectives. It gives clear indications in what areas cervical cancer patients needed information, where the information deficits lay and why information sometimes did not reach the target group. These findings provide guidelines for nurses caring for women with cervical cancer in the region. They enable nurses to prioritize resources and focus on areas assuming high importance in terms of cervical cancer patients' informational needs. However, this does not mean that an individualized approach to address patients' informational needs is not warranted. The study highlights the importance of individualized need assessment and case by case patient management, with adequate liaison with service providers in the community. The appointment of nurses specialized in care coordination and case management was also recommended.

In light of the research findings, nurses should be aware that cervical cancer patients' informational needs extend beyond hospital care, and be prepared to offer on-going informational support that focuses on effects of treatment and self-care issues. In today's situation where the length of hospitalization is significantly shortened, it is necessary to consider extending the services of oncology nursing to meet the women's requirements of information in the community. It is also important for oncology nurses to explore alternative ways of providing efficient informational support to cervical cancer patients during the full course of their illness.

As consumers of health care services in New Zealand, patient's right to information is protected by The Code of Health and Disability Services Consumers' Rights. Informing cervical cancer patients fully and effectively continues to be a major challenge for all oncology care providers, as available resources for dealing with today's increasingly complicated care situation are limited. The findings of this research provide local health services with a focus of attention on important issues surrounding the informational needs of cervical cancer patients in the region. They have positive input into the improvement of quality of life for cervical cancer patients in New Zealand.

APPENDICES

- Appendix I:** Interview Schedule for Patient Participants
- Appendix II:** Interview Schedule for Health Professional Participants
- Appendix III:** Patient Participant Information Sheet
- Appendix IV:** Health Professional Participant Information Sheet
- Appendix V:** Participant Consent Form
- Appendix VI:** Binomial Test of Proportions

Appendix I: Interview Schedule for Patient Participants

The Informational Needs of Women with Cervical Cancer

Patient Interview Schedule

Date: _____

PART I: *Patient Information*

Age (or age range) _____

Ethnicity _____

Education level _____

Area of living _____ urban rural

When were you diagnosed with cervical cancer _____

How did you find out you have cancer?

from regular smear

from occasional checkup or smear

from presenting to your doctors with symptoms

What treatments have you completed or are you currently undergoing?

PART II: *This part is to find out what some of the things you wanted or want to know after you were given the cancer diagnosis, and how satisfied you are with the information you have received.*

1. Have you ever wanted to find out the following information? How satisfied are you with the information you have received?

**Please indicate YES or NO in the box and circle the level of satisfaction for each item (1: quite dissatisfied; 2: mildly dissatisfied; 3: mostly satisfied; 4: very satisfied)*

- | | | | | | |
|--|--------------------------|---|---|---|---|
| 1) What caused my cancer? | <input type="checkbox"/> | 1 | 2 | 3 | 4 |
| 2) How common is cervical cancer? | <input type="checkbox"/> | 1 | 2 | 3 | 4 |
| 3) What is the up-to-date information of my condition? | <input type="checkbox"/> | 1 | 2 | 3 | 4 |
| 4) How is the cancer going to progress? | <input type="checkbox"/> | 1 | 2 | 3 | 4 |
| 5) How long have I got to live? | <input type="checkbox"/> | 1 | 2 | 3 | 4 |
| 6) What are the treatment options? | <input type="checkbox"/> | 1 | 2 | 3 | 4 |
| 7) What is the likelihood of cure after the treatment? | <input type="checkbox"/> | 1 | 2 | 3 | 4 |
| 8) What will happen to my body during and after the treatment? | <input type="checkbox"/> | 1 | 2 | 3 | 4 |
| 9) Will I pass my disease onto my partner or family members? | <input type="checkbox"/> | 1 | 2 | 3 | 4 |
| 10) What are the complementary methods of cancer therapy? | <input type="checkbox"/> | 1 | 2 | 3 | 4 |
| 11) Will cervical cancer or its treatments affect my appearance? | <input type="checkbox"/> | 1 | 2 | 3 | 4 |
| 12) Will cervical cancer or its treatments affect my sexual health? | <input type="checkbox"/> | 1 | 2 | 3 | 4 |
| 13) How is my lifestyle going to change with the cancer and its treatments? | <input type="checkbox"/> | 1 | 2 | 3 | 4 |
| 14) How do other people live and cope with cancer? | <input type="checkbox"/> | 1 | 2 | 3 | 4 |
| 15) Is there any financial or domestic support available for cancer patients? | <input type="checkbox"/> | 1 | 2 | 3 | 4 |
| 16) If I have any queries or health problems, whom can I talk to or get help from? | <input type="checkbox"/> | 1 | 2 | 3 | 4 |

2. What other information have you ever wanted to get after your cancer diagnosis? How satisfied are you with the information you have received?

**Please circle the level of satisfaction for each item (1: quite dissatisfied; 2: mildly dissatisfied; 3: mostly satisfied; 4: very satisfied)*

_____	1	2	3	4
_____	1	2	3	4
_____	1	2	3	4
_____	1	2	3	4
_____	1	2	3	4

3. In general how satisfied are you with the information you have received?

Quite dissatisfied	<input type="checkbox"/>
Mildly dissatisfied	<input type="checkbox"/>
Mostly satisfied	<input type="checkbox"/>
Very satisfied	<input type="checkbox"/>

PART III: *This part is to find out what sources have provided you with the cancer information you needed and how helpful they have been?*

1. Where do you usually get health information from in the area you live?

2. Have you ever received any information related to your cancer from the following sources? How helpful are they?

**Please indicate YES or NO in the box and circle the helpfulness for each source (1: they did not help much; 2: they helped somewhat; 3: they helped a great deal)*

GPs	<input type="checkbox"/>	1	2	3
Oncology specialists	<input type="checkbox"/>	1	2	3
Nurses in the hospital	<input type="checkbox"/>	1	2	3
Nurses in the community (e.g. district nurses, hospice nurses, cancer society nurses, nurses in marae)	<input type="checkbox"/>	1	2	3
Social workers	<input type="checkbox"/>	1	2	3
Counselors or psychologists	<input type="checkbox"/>	1	2	3
Cancer society	<input type="checkbox"/>	1	2	3
Pamphlets or booklets from health agents	<input type="checkbox"/>	1	2	3
Friends or family who have health knowledge	<input type="checkbox"/>	1	2	3
Friends or family members who have cancer	<input type="checkbox"/>	1	2	3
Women's magazines or other magazines	<input type="checkbox"/>	1	2	3
TV or radio programs	<input type="checkbox"/>	1	2	3
Medical books	<input type="checkbox"/>	1	2	3
Internet	<input type="checkbox"/>	1	2	3
Others _____	<input type="checkbox"/>	1	2	3
_____	<input type="checkbox"/>	1	2	3
_____	<input type="checkbox"/>	1	2	3
_____	<input type="checkbox"/>	1	2	3

PART IV: *This part is to find out if you have experienced any problems which were barriers for you to gain access to the health information you need.*

1. Do you know where to get help if you have any queries or problems regarding your cancer diagnosis?
2. Do you feel it is difficult to get the information you need? Why?
3. Have you ever felt uncomfortable to ask doctors, nurses, or other health care workers questions related to your cancer? Why?
4. What are the questions you felt were hard to ask, if there are any?
5. Did you understand the information provided by doctors and other health care sources? If not, why?
6. Was the information from different sources consistent and accurate?
7. In general, are you satisfied with the health services which provide you with the information you need to understand and deal with your disease? For example, is there any information you think you should receive but have not been given?

Appendix II: Interview Schedule for Health Professionals

The Informational Needs of Women with Cervical Cancer
Health Professional Interview Schedule

Date: _____

Position: Oncology Specialist
 Nurse who works in a hospital
 Nurse who works in the community
 Cancer Patient Counselor

Gender: Male Female

PART I: *This part is to find out what information you have been asked by or provided to patients with cervical cancer, and how often it was asked or provided.*

1. Have you ever been asked the following questions by patients with cervical cancer? How often were they asked?

**Please indicate YES or NO in the box and circle the frequency of questions being asked for each item*

(1: seldom; 2: sometimes; 3: often; 4: very often)

- | | | | | | |
|--|--------------------------|---|---|---|---|
| 1) What caused my cancer? | <input type="checkbox"/> | 1 | 2 | 3 | 4 |
| 2) How common is cervical cancer? | <input type="checkbox"/> | 1 | 2 | 3 | 4 |
| 3) What is the up-to date information of my condition? | <input type="checkbox"/> | 1 | 2 | 3 | 4 |
| 4) How is the cancer going to progress? | <input type="checkbox"/> | 1 | 2 | 3 | 4 |
| 5) How long have I got to live? | <input type="checkbox"/> | 1 | 2 | 3 | 4 |
| 6) What are the treatment options? | <input type="checkbox"/> | 1 | 2 | 3 | 4 |
| 7) What is the likelihood of cure after the treatment? | <input type="checkbox"/> | 1 | 2 | 3 | 4 |
| 8) What will happen to my body during and after the treatment? | <input type="checkbox"/> | 1 | 2 | 3 | 4 |
| 9) Will I pass my disease onto my partner or family members? | <input type="checkbox"/> | 1 | 2 | 3 | 4 |
| 10) What are the complementary methods of cancer therapy? | <input type="checkbox"/> | 1 | 2 | 3 | 4 |
| 11) Will cervical cancer or its treatments affect my appearance? | <input type="checkbox"/> | 1 | 2 | 3 | 4 |
| 12) Will cervical cancer or its treatments affect my sexual health? | <input type="checkbox"/> | 1 | 2 | 3 | 4 |
| 13) How is my lifestyle going to change with the cancer and its treatments? | <input type="checkbox"/> | 1 | 2 | 3 | 4 |
| 14) How do other people live and cope with cancer? | <input type="checkbox"/> | 1 | 2 | 3 | 4 |
| 15) Is there any financial or domestic support available for cancer patients? | <input type="checkbox"/> | 1 | 2 | 3 | 4 |
| 16) If I have any queries or health problems, whom can I talk to or get help from? | <input type="checkbox"/> | 1 | 2 | 3 | 4 |

2. What other questions have you been asked by patients with cervical cancer? How often were they asked?

**Please circle the frequency of questions being asked for each item (1: seldom; 2: sometimes; 3: often; 4: very often)*

_____	1	2	3	4
_____	1	2	3	4
_____	1	2	3	4
_____	1	2	3	4
_____	1	2	3	4

3. What other information (apart from those mentioned above) have you provided to cervical cancer patients without being asked because you think it is important for them to know? How often did you provide these information?

**Please circle the frequency of questions being asked for each item (1: seldom; 2: sometimes; 3: often; 4: very often)*

_____	1	2	3	4
_____	1	2	3	4
_____	1	2	3	4
_____	1	2	3	4
_____	1	2	3	4

PART II: *This part is to find out what informational sources are helpful and accessible to cervical cancer patients and whether you have noticed any problems which may be barriers for the delivery of health information to cervical cancer patients*

1. Where do you think are the most helpful and accessible sources for patients with cervical cancer to get information regarding their cancer diagnosis?

2. In general, do you consider most cervical cancer patients know where to get help from the local health services if they have any queries or problems regarding their cancer diagnosis?

3. In your experience of working with cervical cancer patients, have you noticed any barriers for those patients to get access to the information they need?

4. In your experience of working with cervical cancer patients, have you noticed any information that is important to those patients but often they feel uncomfortable to ask?

5. Do you think most cervical cancer patients understand the information provided?

6. Have you noticed any information from health sources which is inconsistent or inaccurate? If so, please explain.

7. In general, are you satisfied with the existing health services and their ways of delivery health information to cervical cancer patients?

Appendix III: Patient Participant Information Sheet

The Informational Needs of Women with Cervical Cancer

Information Sheet for Patient Participants

Principal Investigator: Cecilia Zhang (09) 630-9943 ext. 4150 or (09) 525-6773

Invitation:

If you have had your cervical cancer diagnosis for at least one month, you are cordially invited to take part in this research project. Your experiences and opinions are very important to the development of health information services to cervical cancer patients in New Zealand. You are under absolutely no pressure to take part and you are free to ask any questions about the research project at anytime. Should you decide to participate in the study, you will be asked to sign a consent form under the conditions stated in this information sheet.

Investigator:

The investigator of this research project is Cecilia Zhang, a Gynaecologic Oncology nurse and a Masterate student in Nursing at Massey University. Dr. Gillian White, senior lecturer at Massey University, is the research supervisor.

Purpose:

Women who have been diagnosed with cervical cancer need information to understand the disease they suffer and to cope with the stresses they face. The purpose of this study is to assess the informational needs of women with cervical cancer and evaluate the effectiveness of health services in meeting the informational needs of these women. The findings of this study may help health professionals to recognize the unmet needs of women with cervical cancer, identify problems which hinder the delivering of useful information to these people, and provide research-based patient-centered health services to cervical cancer patients.

The study:

This study is in two parts. Both cervical cancer patients who live in Auckland or nearby regions and health professionals who care for cervical cancer patients in the region are invited to an interview to explore issues of the informational needs of women with cervical cancer. Research findings from both parts of the study will be compared and analyzed using suitable methods. This study has been approved by North Health Ethics Committee and Massey University Human Ethics Committee.

Your involvement:

The research process involves a face-to-face interview with the project investigator. The interview will take place at a private and convenient place of your choice, possibly while you are in the hospital or when you attend a clinic appointment. The interview will take approximately 45 minutes and you will be asked questions related to the issues of the informational needs of women with cervical cancer. You may ask to see the questions before you decide to participate. You may decline answering any of those questions in the interview or withdraw from the study at anytime.

If you are worried about not being able to understand or speak well in English, you are welcome to bring in a friend or relative who is competent to interpret for you during the interview.

Risks and Benefits:

Participating in this research project has no potential risk to your health and other aspects of your life. Although you will not receive any direct rewards from taking part in the study, any future improvements of the health services for cervical cancer patients resulting from this study may bring benefits to your own health care. If you want to find out the outcomes of this study, a summary of the research findings will be available to you upon request.

Confidentiality and Anonymity:

The information you provide to the investigator in the interview will be treated with utmost respect. They will be safely stored and used exclusively for this research and publications arising from this research project. Your identity will be protected and your name will not be used in any reports of the study without your permission.

Queries:

Should you wish to ask questions about this research project, please contact the project investigator. If you have any queries or concerns regarding your right as a participant in this research, you may contact the Health Advocates Trust, 97 Manukau Rd., Epsom (Tel. 09-623 5799).

Contact details:

Project investigator: Cecilia Zhang

Tel/Fax: 09-525 6773 or Ward 36, National Women's Hospital at 09-630 9943 Ext. 4150

Research supervisor: Dr. Gillian White

Tel: 09-443 9373 or School of Health Science, Massey University (Albany)

Appendix IV:**Health Professional Participant Information Sheet**

The Informational Needs of Women with Cervical Cancer

Information Sheet for Health Professional Participants

Principal Investigator: Cecilia Zhang (09) 630-9943 ext 4150 or (09) 525-6773

Invitation:

If you are Oncology specialists, Oncology nurses, nurses who work with Oncology patients in the community, or cancer patient counsellors, you are cordially invited to take part in this research project. Your experiences and opinions are very important to the continuous development of health information services to cervical cancer patients in the region. You are under absolutely no pressure to take part and you are free to ask any questions about the research project at anytime. Should you decide to participate in the study, you will be asked to sign a consent form under the conditions stated in this information sheet.

Investigator:

The investigator of this research project is Cecilia Zhang, a Gynaecologic Oncology nurse and a Masterate student in Nursing at Massey University. Dr. Gillian White, senior lecturer at Massey University, is the research supervisor.

Purpose:

Women who have been diagnosed with cervical cancer need information to understand the disease they suffer and to cope with the stresses they face. The purpose of this study is to assess the informational needs of women with cervical cancer and evaluate the effectiveness of health services in meeting the informational needs of these women. The findings of this study may help health professionals to recognize the unmet needs of women with cervical cancer, identify problems which hinder the delivering of useful information to these people, and provide research-based patient-centered health services to cervical cancer patients.

The study:

This study is in two parts. Both cervical cancer patients who live in Auckland or nearby regions and health professionals who care for cervical cancer patients in the region are invited to an semi-structured interview to explore issues of the informational needs of women with cervical cancer. Research findings from both parts of the study will be compared and analyzed using suitable methods. This study has been approved by Auckland Health Care, North Health Ethics Committee and Massey University Human Ethics Committee.

Your involvement:

The research process involves a face-to-face interview with the project investigator. The interview will take place at a private and convenient place of your choice. The interview will take approximately 45 minutes and you will be invited to discuss the issues of the informational needs of women with cervical cancer. You may ask to see the interview schedule before you decide to participate. You may decline answering any of the questions in the interview or withdraw from the study at anytime

Risks and Benefits:

Participating in this research project has no potential risk to you. Although you will not receive any direct rewards from taking part in the study, any future improvements to the health services for cervical cancer patients resulting from this study may bring benefits to your patients. If you want to find out the outcomes of this study, a summary of the research findings will be available to you.

Confidentiality and Anonymity:

The information you provide to the investigator in the interview will be treated with utmost respect. They will be safely stored and used exclusively for this research and publications arising from this research project. Your identity will be protected and your name will not be used in any reports of the study without your permission.

Queries:

Should you wish to ask questions about this research project, please contact the project investigator. If you have any queries or concerns regarding your right as a participant in this research, you may contact the Research Development Office of Auckland Health Care (Tel. 09-6389909 Ext. 4077) or Health Advocates Trust (Tel. 09-623 5799).

Contact details:

Project investigator: Cecilia Zhang

Tel/Fax: 09-525 6773 or Ward 36, National Women's Hospital at 09-630 9943 Ext. 4150

Research supervisor: Dr. Gillian White

Tel: 09-443 9373 or through the School of Health Science, Massey University (Albany)

Appendix V: Participant Consent Form

The Informational Needs of Women with Cervical Cancer Consent Form

I have heard and understood an explanation of the research project I have been invited to take part in. I have read and I understand the information sheet dated 22 April 1998 for volunteers taking part in this study. I have had the opportunity to ask questions and I am satisfied with the answers I have been given. I understand that taking part in this study is voluntary (my choice) and I may withdraw from the project at any time and this will in no way affect my future health care.

I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports on this study. I understand that the interview will be stopped if it should appear harmful to me. I understand that I may decline to answer any particular questions and I have had time to consider whether to take part.

I agree to provide information to the researchers on the understanding that my name will not be used without my permission.

I, _____ (full name) hereby consent to take part in this study.

Participant's Signature: _____ Date: _____

Project explained by: _____ Project role: _____

Signature: _____ Date: _____

Witness Name (print): _____

Witness Signature: _____ Date: _____

If you have any concerns about the study, you may contact the Health Advocates Trust, telephone (09) 623 5799.

Principal Investigator: Cecilia Zhang (09) 630-9943 ext. 4150 or (09) 5256773

English	I wish to have an interpreter	Yes	No
Maori	E hiahia ana ahau ki tetahi tangata hei korero Maori ki ahau	Ae	Kao
Samoan	Oute mana'o e iai se fa'amatala upu	Ioe	Leai
Tongan	'Oku fiema'u ha fakatonulea	Io	Ikai
Cook Island	Ka inangaro au I tetai tangata uri reo	Ae	Kare
Niuean	Fia manako au ke fakaaoga e tagata fakahokohoko vagahau	E	Nakai

Appendix VI: Binomial Test of Proportions

The following is the test statistic used to determine whether the percentages in Table 4.1 have statistical significance.

Ho: $p = 50\%$,

H1: $p = 50\%$.

When Ho is true, the formula for the standard error (se) as follows:

$$\begin{aligned} \text{se} &= \text{square root } [p (1-p) / n] \\ &= \text{square root } [0.5 \times 0.5 / 19] \\ &= \text{square root } [0.0131579] \\ &= 0.115 \end{aligned}$$

Test Stat = (measured $p - 50\%$) / se

Reject Ho at the 5% significance level if Test Stat exceeds 2

This will be the case whenever measured $p > 0.5 + 2 \times 0.115 = 0.73$.

e.g. When measured p is 74%: Test stat = $(74\% - 50\%) / 0.115 = 2.09$ (to accept Ho)

When measured p is 68%: Test stat = $(68\% - 50\%) / 0.115 = 1.57$ (to reject Ho)

The Test Stat suggests that anything below 73% is ambivalent and statistically insignificant.

(Reference: Dr. Denny Myer, personal correspondence on 23 March, 1999)

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