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Attitudes, practices and knowledge regarding cervical cancer screening among Greek women in the area of Perth

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**Attitudes, Practices and Knowledge Regarding Cervical
Cancer Screening Among Greek Women in the Area of Perth**

By

**Panagiota Karnaki
B.A. (Psychology)**

**A thesis submitted in partial fulfillment of the requirements
for the award of**

Master of Health Science at the Faculty of Communications

Health and Science

Edith Cowan University

Western Australia

2000

Abstract

The purpose of this thesis is to study the attitudes, practices and knowledge of Greek women in Perth, Western Australia, regarding cervical cancer screening. This is important because no study has yet examined the cervical screening pattern of this group, despite their low participation rate in screening programs.

Qualitative semi-structured interviews among 15 Greek women in Perth were used for data collection. Interviews were conducted both in English and Greek. Eight out of the 15 women interviewed did not participate in frequent screening and many had had only one Pap test in their life.

Culture and religion influenced negative attitudes towards cervical screening; these combined with strong emotions of fear towards the disease and lack of knowledge about the purpose of Pap tests, to create powerful barriers to screening. Preoccupation with morality and misconceptions about heredity and the symptomatology of cervical cancer also influenced attitudes towards Pap tests. Further, women's decisions to screen were influenced by the negative behaviour of General Practitioners. A preference was expressed for specialists/gynaecologists and an unwillingness to attend women's health centres.

Declaration

I certify that this thesis does not, to the best of my knowledge and belief:

- i. Incorporate without acknowledgment any material previously submitted for a degree or diploma in any institution of higher education;
- ii. Contain any material previously published or written by another person except where due reference is made in the text; or
- iii. Contain any defamatory material;

Acknowledgments

I should like to express my appreciation to the people who helped me to conduct and complete this study.

My sincere thanks to my supervisors Dr Lynne Hunt and Mrs. Glenda Jackson for their support, patience and expert guidance.

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CHAPTER ONE: INTRODUCTION

The purpose of this study was to examine the practices, attitudes, and knowledge, regarding cervical cancer screening in a group of Greek women in the area of Perth, Western Australia. Greek women were interviewed to identify attitudes and knowledge towards cervical cancer screening, as well as how often screening occurred and what barriers, if any, were perceived to regular, preventive, cervical cancer screening. The women who participated were of Greek cultural background, born mainly in Greece and Cyprus, as well as women of Greek background born in Australia.

When promoting health protective behaviours, and designing health promotion programs, accessible and suitable for all members of the population, it is important to have a clear understanding of the needs of each sub-population. In Australia, there is an organised approach to the prevention of cervical cancer, with the implementation of the cervical screening program in 1991 (Report of the Evaluation Steering Committee, 1995). Yet, in Australia, many women still die from the disease each year and, despite the establishment of the 1991 program, there is still insufficient coverage of screening (Report of the Evaluation Steering Committee, 1995), particularly for women of Greek background.

The theoretical background guiding the study is the Health Belief Model (HBM), which was developed by Rosenstock and Becker in the 1950's and 1960's (Murray & McMillan, 1993). The HBM provides a framework in studies examining people's intentions to follow health protective behaviours (Straton, 1994; Murray & McMillan, 1993; Dignan & Carr, 1992). Adapted to cervical cancer screening, the HBM predicts that a woman's likelihood to seek screening will be affected by her beliefs about susceptibility to cervical cancer, her beliefs about the severity of cervical cancer, and the perceived benefits from having a Pap test. Lastly the decision to seek screening is negatively influenced by social and psychological barriers (Straton, 1994, Harokopos & McDermott, 1996; Peters, Bear & Thomas, 1989).

Background

Invasive cancer of the uterine cervix is one of the major killer cancers that affects women across the world. The tragedy behind the thousands of deaths occurring each year from the disease is the lost opportunity of them being prevented.

Cervical cancer is prevented primarily through the use of a screening test known as the Papanicolaou test (Straton, 1994; Shield, Daunter & Wright, 1987). The Papanicolaou test (Pap test) was developed in the 1940's in the USA by Dr George N.

Papanicolaou and his colleague H. Traut (Shield, Daunter & Wright, 1987). The test was designed to detect the disease in its very early stages when malignancy is not present. It identifies abnormalities in the uterine cervix, which, if left untreated, could develop into cancer. Appropriate management of these abnormalities can eliminate the possibility of cervical cancer and consequently minimise the deaths associated with the disease (Straton, 1994).

Death rates from cervical cancer have been declining since the introduction of Pap tests to the general public (Austin & McLendon, 1997). Nevertheless, it still accounts for a significant number of deaths each year. In 1997, 195,000 women world-wide died from the disease, the same year the incidence of cervical cancer for the developed nations was 90,000 while for the developing world an estimated 340,000 cases were recorded (World Health Organisation, 1998).

Inadequate screening is the primary reason cervical cancer continues to claim women's lives. The incidence of the disease in Australia is about 11 per 100,000 women and the average risk of it being diagnosed before the age of 75 is 1 in 101 (Reid, Simpson & Britt, 1997; Australian Institute of Health and Welfare, 1998). It is the ninth most common cancer among Australian women and each year approximately 340 women in Australia die from the disease

and 1,000 new cases are diagnosed (Reid, Simpson & Britt, 1997). Over half the cases of cervical cancer occur in women who have never been screened (Australian Health Minister's Advisory Council Report, 1991). Women in Australia who avoid, or neglect, screening usually come from low socioeconomic classes, are under-educated, and have a non-English speaking background (Straton, 1994). In this country, fewer overseas born women (79.0%) than Australian born women (87%) reported having had a Pap test (Madden, 1996). Overseas born women were 5 times less likely to have heard of the Pap test, compared to women born in Australia (Madden, 1996). Specifically for the area of Perth, Honing (1996) reported that from a sample of 286 multicultural women living in the northern suburbs, 39% were overdue for a Pap test or had never had a Pap test.

The Greek-born community of Australia, according to the 1991 census, numbered 136,028 of which 66,342 (48.8%) were women and 69,686 (51.2 %) men (*Hellas Media Network*, 1999). The majority of Greek-born migrants in Australia according to the census were between the ages of 45-54 (41,932, 30% of the Greek migrant population) (*Hellas Media Network*, 1999). The second generation of Greek-Australians in 1991 numbered 151,082 (*Hellas Media Network*, 1999). Specifically, in Western Australia, in 1991 the Greek-born population was 3,515. (*Hellas Media Network* 1999).

An unpublished study (Karnaki, 1998) into the mortality patterns of cervical cancer in Greek women in Australia found that these women were dying at a statistically significant younger age than Australian-born women. Greek women on average died from cervical cancer at a younger age (\bar{M} = 56.5) than Australian women [$(\bar{M}$ = 61.2), ($P < 0.05$)]. A link may exist between the young age of cervical cancer mortality in Greek women and inadequate screening in this population. Statistics show that only 62% of Greek women have ever had a Pap test as opposed to 88% of Australian women (Young & Coles, 1992). In the age group of 55-64 this percentage falls to 40% (Young & Coles, 1992). Insufficient screening in these women may mean that the disease is detected at a much later stage, at which point treatment and treatment outcomes are poor (Shield, Daunter & Wright, 1987). This is further reinforced by epidemiological evidence which shows that over half the women who develop cervical cancer have never been screened (Australian Health Minister's Advisory Council Report, 1991; Mera, 1997). There is a need for further study in order to create a clear understanding about what causes Greek women to die from this disease at a younger age than Australian women.

Even though numerous studies, (Honig, 1996; Ishar Multicultural Centre for Women's Health, 1997; Jameson, Sligo & Comrie, 1999; Cheek, Fuller, Gilchrist, Maddock, & Ballantyne, 1999) have

examined screening practices and attitudes of women from a non-English speaking background, there has been no published Australian-based study that examines cervical cancer screening practices and attitudes among women from the Greek community, even though they represent a significant number of the Australian population. The exception was a project in Victoria developed to attract Greek women to participate in cervical cancer screening. In total 1,760 women were targeted from whom 213 (7.7%) women undertook a Pap test as a result of the project (Australian Greek Welfare Society, 1996). Despite low participation the reasons that led many Greek women to avoid screening in this community intervention were not examined highlighting the importance of this study into Greek women's attitudes and practices in regard to cervical cancer screening.

Screening for cervical cancer is a preventive tool that is capable of decreasing mortality and morbidity if used effectively (Straton, 1994). The reasons that the disease is still so prevalent today despite a successful screening test may be traced to people's overall attitude towards disease prevention and health promotion. Health promotion is not well known to many people who continue to seek medical attention only when sick (Lupton & Najman, 1995). This indicates that prevention is under-utilised among many populations. To work well health promotion, relies on the fact that people are

educated enough about health and modern technology, and that they know where to go and who to consult about health problems (Lupton & Najman, 1995). However, many social, psychological and economic reasons hinder the development of such health behaviour (Lupton & Najman, 1995). Furthermore, people of different cultures will have different ideas about what an illness is and what is considered as being ill. As a consequence, they have different attitudes towards prevention and screening. Greek people in Australia appear to have a low level of knowledge regarding health promotion as smoking, obesity and diabetes are prevalent among Greek born migrants (Young & Coles, 1992). Lifestyle is considered very poor particularly in regard to exercise. There is also high use of sleeping tablets, tranquilizers and painkillers (Young & Cole, 1992). Some insights into Greek migrant health behaviour in Australia may also be gained by observing health behaviours in the country of origin. In Greece, as opposed to all other members of the European Union, there is no national organisation for the promotion of health. Health in Greece has not been influenced by the international rise of health promotion. According to the Institute of Social and Preventive Medicine (private organisation) in Greece, in the 1990's, health services are primarily focused on disease, medicine, and hospitalisation. As a result, despite high life expectancy, Greece is the only country in the European Union where mortality levels from cardiovascular diseases, cancers, and car crashes are increasing

(Ινστιτούτο Κοινωνικής και Προληπτικής Ιατρικής [Institute of Social and Preventive Medicine], 1995; Maliori *et al*, 1995). These facts may imply that in Greece it is not culturally acceptable to consult a doctor when not sick or that it is unnecessary and time-consuming to practice preventive medicine, health promotion and screening. Such attitudes towards prevention may be reflected in the Greek migrant population in Australia, in particular Greek women. It is, therefore, important to examine attitudes and knowledge of cervical cancer and screening in-depth in order to create a profile of health needs and expectations, and to facilitate the success of future health interventions.

Significance of the study

This study is significant because it provides previously unavailable information about Greek women's practices, attitudes and knowledge about cervical cancer screening. It is important also because it reveals barriers to Greek women's participation in screening. The results can be used in screening programs for Greek women in Perth and in the wider Australian community. Furthermore, the results of studies of this nature can facilitate the evaluation of current cervical cancer programs particularly those that target ethnic groups.

Purpose of the study

The purpose of the study was to investigate the practices, attitudes, and knowledge of Greek women in the area of Perth regarding cervical cancer screening. The aim was to see if these women screen for cervical cancer, and, if so, how frequently. An important goal of this research was to identify any barriers stopping women from screening. The study was based on the social model of health. It sought to explore and explain the cultural and social circumstances that influence the health attitudes and behaviour of ethnic-minority Greek women in Perth, Western Australia.

Research question

The research question of the study is:

What are the attitudes, practices, and knowledge of Greek women in the area of Perth, Western Australia regarding cervical cancer screening?

The sub-questions are:

- a. What are the current cervical cancer screening practices of Greek women in Perth?
- b. What are the levels of knowledge regarding cervical cancer screening of Greek women in Perth?
- c. What are the attitudes towards cervical cancer screening of Greek women in Perth?

- d. What (if any) are the barriers to cervical cancer screening among Greek women in Perth?

Definitions of terms

The conceptual and operational definitions of the study are the following:

Invasive cancer of the uterine cervix (Cervical cancer) - malignant tumors that have spread below the surface cells into the deeper tissues of the cervix.

Intraepithelial abnormalities - non-cancerous abnormal growth of the cells of the cervix which are considered as precursors of cervical cancer.

Screening - "the use of presumptive methods to identify unrecognised health risk factors or asymptomatic disease in individuals" (Braverman & Tarino, 1996, p.15).

Papanicolaou test - taking of surface cells from the cervix. These are then examined under a microscope to identify any abnormal cells.

Knowledge - level of information regarding the purpose of the Papanicolaou test, usefulness of the test, frequency of the test, how

the test is performed, and the services, which provide Papanicolaou tests.

Practices - Frequency of Papanicolaou tests. Preferred location of taking the tests.

Attitudes - an attitude is defined as a reaction to a specific object. An attitude is a combination of three types of a reaction to a specific object: (a) affective (concerning emotions towards cervical cancer and cervical screening), (b) cognitive (beliefs, opinions and ideas about cervical cancer and screening), (c) conative/behavioral (concerning behavioral intentions towards cervical cancer screening) (Stahlberg & Frey, 1996).

CHAPTER TWO: LITERATURE REVIEW

Introduction

Despite the apparent success in preventing mortality, it cannot be assumed that cervical cancer screening is unequivocally good. Indeed the literature indicates, as for other forms of screening such as mammography, the existence of considerable debate about its efficacy and cost. In order to contextualise the present study, problematise cervical cancer screening and explain such debates it is necessary first of all to explain what cervical cancer is and what screening includes. This chapter, therefore, reviews:

- The physiology of cervical cancer
- The epidemiology of cervical cancer
- The Papanicolaou test
- Screening programs
- Screening problems
- Cervical screening interventions

The physiology of cervical cancer

The cervix is a round mushroom-like structure that joins the uterus to the vagina. In terms of location, it comprises the lower third of the uterus. Cancer usually develops between the ectocervix and the endocervix, a part that is known as the transformation zone (Chomet & Chomet, 1991; Mera, 1997). The cells and the location

of this zone are constantly changing throughout a woman's life, affected by different hormonal levels at different ages (Chomet & Chomet, 1991; Mera, 1997). Pre-cancerous abnormalities begin in the highly metaplastic cells of the area which eventually develop into cervical cancer (Chomet & Chomet, 1991; Mera, 1997). In its advanced stages cervical cancer may spread to the urinary tract and the bowel through the lymphatic circulation (Mera, 1997).

Two types of cervical cancer develop in two different parts of the female genital tract (Chomet & Chomet, 1991; Shields, Daunter & Wright, 1987). The first is known as squamous cell carcinoma, which develops in the part of the cervix, which is lined with skin, called squamous epithelium (Chomet & Chomet, 1991). The second is adenocarcinoma that arises from the endocervical columnar cells located in the passage from the cervix to the uterus (Chomet & Chomet, 1991). The greater majority (80%) of invasive cervical cancer detected are squamous cell carcinomas while adenocarcinomas are diagnosed more rarely (20%) (Health Department of Western Australia, 1996; Mera, 1997).

Cervical cancer is preceded by abnormalities in the cells of the cervical epithelium, the lining of the cervix (Chomet & Chomet, 1991). These abnormalities are not malignant and they extend over a period of many years (Shield, Daunter & Wright, 1987). Pre-

malignant changes have been assigned many names. Reagan introduced the first definition in 1953. He categorised changes in the epithelium of the cervix into mild, moderate, and severe dysplasia (Shield, Daunter & Wright, 1987). The second classification system termed abnormal cervical changes as carcinoma in situ (CIS). CIS refers to a "neoplastic change affecting the entire thickness of the epithelium" (Shield, Daunter & Wright 1987, p.270). This classification system does not grade abnormal changes into different levels.

Dysplasia and CIS, as definitions, have been characterised as lacking diagnostic value, and for being misleading and complicated, a fact that has led many gynaecologists and health professionals to adopt the classification system that was developed in 1973 by Richards (Shield, Dauter & Wright, 1987). Richards developed a system that included both the three stages of the dysplasia classification system and carcinoma in situ. The new system was labeled cervical intraepithelial neoplasia (CIN) (Shields, Dauter & Wright, 1987). CIN is graded into CIN I that corresponds to mild dysplasia involving abnormal cells that cover less than one third of the epithelium, CIN II that equals moderate dysplasia and covers one to two thirds of abnormal epithelium cells. Finally CIN III refers to severe dysplasia where most cells are already cancerous but are still observed in the epithelial layer and have not invaded the

underlying stroma (Morrow & Townsend, 1987; Mera, 1997). In this stage carcinoma in situ but not cancer is present (Mera, 1997). Cervical cancer is believed to develop when there is full thickness involvement, in other words when the cells have invaded the underlying stroma of the epithelium (Coleman & Evans, 1988; Mera, 1997). The causes of CIN are believed to be the same as those for invasive cervical cancer (Morrow & Townsend, 1987; Kjaer, 1998).

More recently, the Bethesda Group in the USA has developed a new two-grade system for the classification of cervical epithelial abnormalities. "Low grade squamous intraepithelial lesions" (SIL) or high grade SIL". Low SIL corresponds to moderate and severe dysplasia while higher SIL includes mild dysplasia and Koilocytosis. Koilocytosis indicates cellular changes associated with the human papillomavirus (HPV) infection (Herbst, 1990; Shepherd & Fried, 1995). The Bethesda system has been criticised for leading to overdiagnosis and unnecessary treatment (Herbst, 1990).

CIN and invasive cancer

The relationship between CIN and invasive cancer of the cervix has caused a considerable amount of debate over the years among gynaecologists, epidemiologists, and other health professionals. The debate primarily concerns the question of whether or not CIN I, II, III, consistently develop into cervical cancer and, if that is so, how

long this transformation takes. Debate also focuses on how dysplasia and CIS are involved in invasion.

Evidence for the progression of CIN into cervical cancer has been obtained from the study of biopsy specimens, epidemiological studies, and from prospective studies of patients who were not treated for CIN, mainly in the 60's and the 70's (Shields, Daunter & Wright, 1987). In brief, there is considerable evidence indicating that dysplasia (mild, moderate and severe) may predate CIS, on average, of about seven years. The duration of CIS before invasion varies from 1-30 years (Shields, Daunter & Wright, 1987).

Many cases of CIN are observed to spontaneously regress or not to progress into higher levels of epithelial abnormalities. However, a significant number of lesions will progress into cervical cancer if left untreated. For example, a study by Kottmier in 1969 cited in Shields, Daunter and Wright (1987) reported that over a period of 20 years 73% of all 34 patients who initially had CIS developed cervical cancer. A research program carried out at the National Women's Hospital in Auckland, New Zealand did not treat women with pre-malignant abnormalities in the cells of the cervix. This "unfortunate experiment" resulted in more than 100 women developing cervical cancer and consequently many of them dying (Coney, 1988).

Some take the view that progression and regression rates for CIN cannot be reliably predicted and that it is mandatory to treat all cases of CIN regardless of the level of severity (Shields, Daunter & Wright, 1987; Morrow & Townsend, 1987; Mera, 1997). This is particularly necessary because, in some cases, there is no orderly progression through all stages of CIN and cervical cancer may develop from milder forms of abnormalities (Shields, Daunter & Wright, 1987; Morrow, & Townsend, 1987).

It has been noted that CIN III develops into cervical cancer in 20 years or longer and the rate of progression ranges from 20% to 75% or higher (Morrow & Townsend, 1987). However, there is no diagnostic tool that can reliably predict how long it will take for cancer to develop, or which abnormalities will regress or progress. Indeed the Auckland study (Coney, 1988) and the subsequent medical inquiry made it clear that it is unethical to study the behaviour of abnormal epithelial neoplasms among patients who have been left deliberately untreated. Dysplasia and CIS are curable with a survival rate of 100%, something not observed among patients with invasive cancer (Shield, Daunter & Wright, 1987).

The uncertainty about pre-malignant abnormalities and their relationship to cervical cancer has had implications for screening. It remains controversial in some countries, for example the UK, as to

whether or not women with lesser degrees of abnormality should be treated the same way as women with higher degrees or CIN (Davies & Brown, 1994). What is needed is a better and more widely accepted understanding of the natural history of cervical cancer.

Epidemiology of cervical cancer

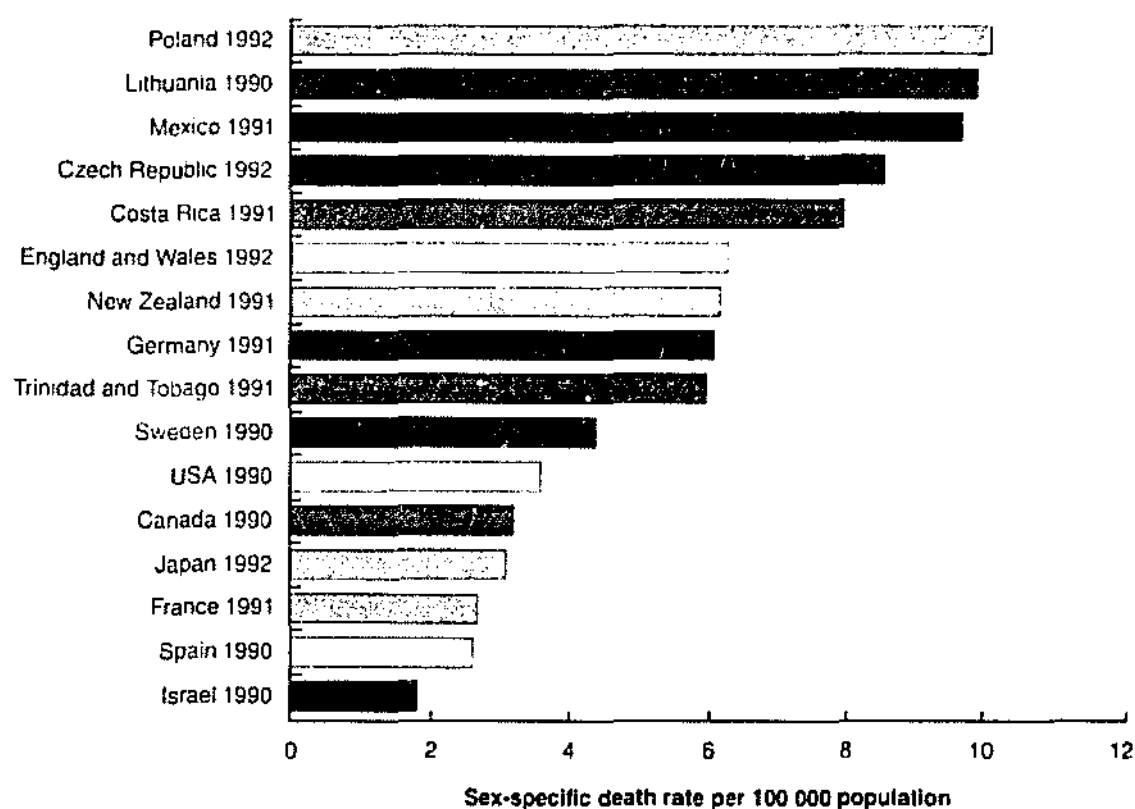
A. Incidence and mortality of cervical cancer

Cervical cancer is the ninth most common cancer diagnosed in Australia. Australian women before the age of 75 have one in 101 chance of developing cervical cancer (Australian Institute of Health and Welfare, 1998). In 1994 there were 1,121 new cases of cervical cancer, 3.4% of all cancers diagnosed and 340 women died from the disease (Australian Institute of Health and Welfare, 1998). In 1999, according to estimates, there should be a decrease in the cases and deaths with 10.4 new cases and 2.8 deaths per 100,000 women (Australian Institute of Health and Welfare, 1998). In Western Australia, in 1994, cervical cancer was the seventh most commonly diagnosed cancer among women with 114 new cases diagnosed and 31 women dying from the disease (Health Department of Western Australia, 1996). The incidence and mortality in this state is the second highest after the Northern Territory (Sutherland, 1992). The incidence of cervical cancer is highest among older women, and women from a non-English speaking background (Sutherland, 1992). Australian women from

Aboriginal backgrounds are more likely to die from the disease than non-Aboriginal Australians (Health Department of Western Australia, 1996).

Figure 1: Mortality pattern of cervical cancer in different countries

(Adapted from Mera, 1997)



Worldwide, cervical cancer is the commonest form of cancer that affects women in all developing countries (World Health Organisation, 1996). A report of the World Health Organisation in 1997 provided official estimates that 195,000 women died of cervical cancer and that in the same year the incidence in developed nations was 90,000, while for the developing world an estimated 340,000 cases were recorded (World Health Organisation, 1998). In developing countries, 80% of the women diagnosed with cervical

cancer will die compared to 80% of the cases in the developed world that will be cured as a result of early detection (World Health Organisation, 1996). Five out of six women with this form of cancer live in the developing nations where screening programs are under-developed or non-existent (World Health Organisation, 1996).

In the developed world, the incidence of the disease is decreasing because of the introduction of cervical cancer screening programs (Mera, 1997). However, screening alone cannot account for the wide variation in the mortality pattern of cervical cancer in different countries (see Figure 1) of the world, which is attributed to differences in sexual behaviour, diet, and the existence of effective screening programs.

The highest rates in the world have been observed in Latin America. The rate there is six times higher than in the USA. The lowest rates in the world have been reported in Israel, among Jewish women (Brinton, 1992). In England and Wales 4,000 new cases are seen each year and about 2,000 women die from the disease (Mera, 1997). According to the same data in England and Wales, cervical cancer affects mostly women over the age of 45 and the five-year survival rate is 52% at age 45 and 40% at age 65 (Mera, 1997). In the European Community 13,212 women died every year between 1980 and 1984 from cervical cancer and it accounts for 4% of all

cancer deaths in women. Higher rates are observed in Denmark, Portugal, and the UK. However, with the exception of Greece and Spain, both the incidence and mortality rates of the disease are decreasing (Moller-Jensen, Esteve, Moller & Renard, 1990). In Greece in 1997, 661 new cases of cervical cancer were diagnosed and 321 women died from the disease (Ευρωπαϊκή Εβδομάδα Κατά του Καρκίνου [European week against cancer] 1997). In the USA in 1941 there were some 26,000 deaths per year from cervical cancer while in 1996 deaths were estimated to be around 4,900 a year (Austin & McLendon, 1997). Recently a study conducted in 24 USA states between 1984-1993 revealed 9,523 cases of women dying from cervical cancer with the highest rate among the ages 40-59 (33.0%) (Sala, Dosemeci & Zahm, 1998). It is estimated that in the absence of an effective screening service by the year 2000, worldwide the number of deaths from cervical cancer will reach 276,000 (Lazcano-Ponce *et al*, 1998).

B. Causes of cervical cancer

The causes of cervical cancer are largely speculative, as for many other forms of cancer. Behavioural causes are probably the most important determining factors in the causation of this disease as is evident from the different patterns of cervical cancer mortality across the world (see Figure 1). It is important, however, to note that a cause and effect relationship cannot, as yet, be determined

due to confounding variables. The suspected causes mentioned in this section have to be considered in unison in order to create an understanding of this disease.

Sexual behaviour. The number of a woman's sexual partners plays a significant role in the aetiology of cervical cancer (Mera, 1997; World Health Organisation, 1986; Brinton, 1992). The risk for cervical cancer is three times higher in women who report 10 or more partners than those who report fewer partners (Brinton, 1992; World Health Organisation, 1986; Slattery *et al*, 1989a; Chomet & Chomet, 1991). Increased susceptibility to cervical cancer has also been observed among those women who begin sexual activity before the age of 15. They have about twice the risk compared to women who become sexually active after 15 (World Health Organisation, 1986; Brinton, 1992). There is suspicion that this relationship reflects a vulnerable period in which a woman's cervix is susceptible to carcinogenic influences (Brinton, 1992). More studies support that cervical cancer is more frequent among women who have had many long-lasting sexual relationships than short-term ones. This may suggest that long-term relationships allow carcinogenic agents to transmit to the woman and thus increase her risk in cervical cancer (Brinton, 1992). However, researchers have failed to provide consistent results concerning these issues. Further research is necessary in order to find more conclusive results.

Studies in countries where religious beliefs and moral values limit sexual experience outside marriage may provide some insight about the role sexual behaviour plays in the causation of cervical cancer.

Preoccupation with sexual aspects of cervical cancer may lead to its stigmatisation of a disease for "promiscuous women". Researchers have expressed concern that this will result in reduced participation in screening (Braun & Gavey, 1998). This concern has been confirmed as some studies have shown that lack of promiscuity is given as a reason for not attending regular Pap tests (Harokopos & McDermott, 1996).

Male sexual behaviour. Wives of men who have had many sexual partners are found to have higher levels of cervical cancer. This indicates that sexual practices of husbands or male partners are as important as those for women (Brinton, 1992; World Health Organisation, 1986). Studies that compared the sexual and behavioural preferences of husbands of women diagnosed with cervical cancer showed that these men had more sexual partners than controls, and had more sexually transmitted diseases such as genital warts, and genital herpes (Brinton, 1992; Brinton *et al*, 1989c; Buckley, Harris, Doll, Vessey & Williams, 1981; Zunzunegui, King, Coria & Charlet, 1986; Kjaer *et al*, 1991). More recently a study in Denmark showed that the most significant risk factors for

cervical cancer were a history of genital warts and non-use of condoms in the male partner of the women (Kjaer, 1998). Lower rates of cervical cancer are reported among women whose husbands used condoms (Brinton, 1992). Studies have not been consistent in supporting a relationship between frequent visits to prostitutes by husbands and an elevated risk of cervical cancer in spouses (Brinton, 1992).

Genital hygiene. According to a report from the World Health Organisation (1986), there has been no evidence of a relationship between poor sexual hygiene and risk of cervical cancer (Brannon & Feist, 1992). However, most studies examining personal hygiene have been conducted in western countries where there is an emphasis on hygiene (Brinton, 1992). One study, conducted in rural China, did find an elevated risk of cervical cancer associated with poor personal hygiene such as lack of genital washing and use of sanitary pads (Zhang, Parkin, Yu, Esteve Yang, 1989). This issue is not one easily investigated by interviews, since personal hygiene is a difficult term to operationalise.

The suggestion that partners of circumcised men have a lower risk of cervical cancer has not been confirmed by most studies (World Health Organisation, 1986; Brinton, 1992). However, this issue recently regained support in a study that found that wives of

circumcised men had lower rates of cervical cancer (Kjaer, *et al*, 1991). The matter clearly needs to be examined in-depth, bearing in mind methodological problems such as defining what circumcision is and the sensitivity of discussing such matters with respondents.

Contraceptive methods. Women who used oral contraceptive methods for more than four years have been found to have an elevated risk of developing cervical cancer as opposed to women who used barrier methods of contraception (World Health Organisation, 1986; Brinton, 1992; Kjaer, 1998). These differences are attributed to different exposures of the cervix to seminal fluids, sperm and viruses such as the genital warts virus, and genital herpes (Mera, 1997; Chomet & Chomet, 1991; Brandon & Feist, 1992; Brinton, 1992).

Cigarette smoking. Cigarette smoking is suspected as an independent cause of cervical cancer (Mera, 1997; Brinton, 1992; Winkelstein, 1990; Kjaer, 1998). Long-term or frequent users of tobacco have been reported to have a two-fold risk of cervical cancer (Brinton, 1992). Researchers have found nicotine and cotinine in cervical mucus which suggests a biological effect of smoking, while it is also possible that smoking suppresses the immune system and as a result the body is weaker in fighting infectious agents like the Human Papilloma Virus (HPV) (Brinton,

1992; Mera, 1997; Kjaer, 1998). There is no agreement on the exact extent to which smoking affects the initiation of the disease and most researchers support the proposed notion that smoking has a synergistic effect on the development of the malignancy (Brannon & Feist, 1992).

Dietary factors. Dietary practices may contribute to cervical cancer development, although studies have failed to show a clear relationship between the two (Brinton, 1992). Risk factors identified are consumption of fat, protein and alcohol. Diets poor in vegetables and fibre seem also connected to an elevated risk of developing cervical cancer (Brannon & Feist, 1992). Recently, studies showed that reduced risk for cervical cancer was associated with high intake of vitamins A, C and E, as well as beta-carotene (Slattery, *et al*, 1990; Verreault, Chu, Mandelson, Shy, 1989; Brinton, 1992). Clearly there is need to investigate the association between diet and cervical cancer more closely since the issue is far from resolved and conclusions have yet to be drawn (Brinton, 1992).

Viral infection. The most probable cause for cervical cancer according to epidemiological studies is some sexually transmitted agent that can be passed on from male to female or vice versa (Morrow & Townsend, 1987; Mera, 1997; Brinton, 1992; Brandon &

Feist, 1992; Chomet & Chomet, 1991). The suspected agents include chlamydia, spermatozoa, herpes simplex virus, bacterial vaginosis, syphilis, and gonorrhoea (Brinton, 1992; Morrow & Townsend, 1987). The role of viral infections in the development of cervical cancer has been suspected since the Papanicolaou test was first developed. In one of the earlier articles on the diagnostic value of cervical tests Dr Papanicolaou points out that:

Chronic cervical infections and parasites, like *Trichomonas* or *Monilia*, sometimes cause structural modifications of the superficial vaginal and cervical cells. A crusade of the medical profession against chronic infections of the female genital tract would go a long way towards reducing unhealthy conditions which might favour the eventual appearance of cancerous lesions (Papanicolaou, 1946, p.323).

The virus that is most suspected to cause cervical cancer is the HPV. Munoz and Bosch (1992) reviewed the literature on the topic and concluded that there is "compelling evidence" suggesting a causal relationship between HPV infection and cervical cancer. Other researchers have pointed out that not all types of the HPV initiate cancer. Some are of lower risk and produce only abnormal changes while others can produce malignancy (Mera, 1997). A recent study in Denmark showed that infection with the HPV in adolescence is associated with increased risk of cervical cancer compared with such an infection later in life (Kjaer, 1998). Epidemiologists agree that the HPV alone cannot account for initiating cervical cancer, other risk factors may operate independently of the suspected virus

(Brinton, 1992; Mera, 1997). There is evidence from recent studies that a possible HPV vaccine could be developed which might reduce the incidence and mortality rates of cervical cancer (Munoz, Crawford & Coursaget, 1995; Lazcano-Ponce, *et al*, 1998). Clearly more research in the area is necessary.

C. Demographic characteristics

Women who develop cervical cancer are usually from socially disadvantaged populations (Brinton, 1992). Studies have also confirmed that race influences the incidence of cervical cancer with rates for African Americans and Hispanics in the USA being twice as high than those for white or oriental Americans (Brinton, 1992). The disease has a higher rate among indigenous populations, for example in New Zealand among Pacific women and women from Maori backgrounds and in Indian populations in Brazil and Columbia (Jameson, Sligo & Comrie, 1999; Guest, Mitchell & Plant, 1990). Aboriginal Australians are nine times more likely to die from cervical cancer. In Western Australia the incidence and mortality from the disease are four and eight times, respectively the rates for non-Aboriginal women (Mak & Straton, 1997; Kirk, 1993).

Cervical cancer has been observed to be high among women who have married early, while it is lower among women from specific religious groups like Catholic nuns, the Amish, and Mormons

(Brinton, 1992; Holly, 1996). Seventy per cent of cases of cervical cancer and 90% of deaths occur in women over 40 years (Cockburn, Hirst, Hill & Marks, 1990). A recent study in 24 USA states for the period 1984-1993 revealed that increased mortality from cervical cancer was observed among maids, cleaners, waitresses, and nursing aides, and among several manufacturing occupations, such as machine operators, printers, and textile machine operators. The study showed that the highest risk for the disease was seen among actors and directors, artists and performers and African American farmers (Sala, Dosemeci & Zahm, 1998).

Evidence consistently has revealed that women who develop cervical cancer have not been adequately screened in the years subsequent to diagnosis (Sutherland, 1992; Peters, Bear & Thomas, 1989; Mera, 1997; Cockburn *et al*, 1990; Price, Easton, Telljohann, & Wallace, 1996). Women who do not screen come from low socioeconomic classes, are less educated, are older, come from non-English speaking backgrounds, are recent migrants and belong to indigenous groups (Brinton, 1992; Peters Bear & Thomas, 1989; Sutherland, 1992; Straton, 1994; Price *et al*, 1996).

The Papanicolaou test

The Papanicolaou test is the primary screening tool for the detection of cervical cancer. The Romanian pathologist Aurel Babes first published a description of the morphology of cancer cells found in vaginal samples (Shield, Daunter, Wright, 1987). Dr George, N. Papanicolaou (Shield, Daunter & Wright, 1987) continued the research. Through this study, he and associates developed a technique for collecting cells and staining them in order to detect abnormalities that could lead to cancer (Papanicolaou & Traut, 1941; Papanicolaou, 1946; Shield, Daunter & Wright, 1987). The Pap test, as it is now known, began to be used in preventive medicine in the early 1950's and it continues to be extensively used in developed countries for the detection of cervical cancer (Shield, Daunter & Wright, 1987). The procedure followed to obtain cells from the cervix and to determine their abnormality differs little from the original one that Dr Papanicolaou described (Shield, Daunter & Wright, 1987).

Austin and McLendon (1997), outlined the 3-phase procedure of a successful Pap test:

Phase 1 - An adequate sample is taken from the woman's vagina. The sample is collected using a wooden spatula and scraped from the endocervix and ectocervix of the cervical area to make certain

that any abnormal cells are collected. (Austin & McLendon, 1997, p.754).

Phase 2 - The sample is taken to the laboratory where it is stained with the Papanicolaou stain (haematoxylin and cytoplasmic stains) (Papanicolaou & Traut, 1941), and examined in order to detect abnormal cells among the thousand typical cells in the vaginal sample (Austin & McLendon, 1997, p.754).

Phase 3 - The final stage includes interpretation of the abnormal cells. Through microscopic examination, abnormal cells are examined in order to determine if they are malignant or benign (Austin & McLendon, 1997, p.754).

Quality of the Pap test

The Pap test is a simple, effective, non-invasive and non-dangerous method for the detection of cervical cancer. The accuracy of the Pap test in recognising pre-malignant and malignant lesions in the cervix is not well documented since many studies have yielded different results (Sheild, Daunter & Wright, 1987). Sensitivity of the Pap test, that is the ability of the test to determine the number of affected individuals in a population ranges around 83% to 90% (Sheild, Daunter & Wright, 1987). False-negative rates, that is a Pap test being erroneously negative, vary in different studies reaching in most 20-40% while many programs report less than 15% of false negative rates (Mera, 1997; Lazcano-Ponce *et al*, 1998). Recently,

in South Wales, UK mistakes occurred in the Pap tests of 14 women two of whom subsequently died (Dobson, 1998). Also two British women, whose cervical abnormalities were not detected, raised a series of questions about the effectiveness of the Pap test (Anderson, 1999). Both these comments were letters to editors of respected medical journals and not results from studies. They do indicate, though, the importance of problematising cervical cancer screening, and explaining its effectiveness in the context of false negative and false positive results.

Many inconsistencies in Pap test diagnosis may be attributable to laboratory errors, which raises the question of quality monitoring of cytology laboratories. According to the European Guidelines for Quality and Assurance in Cervical Cancer Screening a cytologist has to receive at least 80 hours of theoretical training and at least six months of practical training (Coleman, Day & Douglas, 1993). The cytologist should carry out not less than 2,000 Pap tests under strict supervision which is also recommended for the following 7,000 tests before working independently (Coleman, Day & Douglas, 1993). A laboratory should process at least 25,000 specimens per year (Shield, Daunter & Wright, 1987). Finally, Austin and McLendon (1997) stress that physicians should choose carefully the laboratory to which they send Pap tests and to make choices based on the existence of a trained clinician rather than lower prices. In the UK,

concerns about laboratory quality has led authorities to retrain staff and to close down or merge smaller laboratories (Warden, 1998). Another important way to monitor laboratory quality is for the personnel to conduct follow-up of all negative tests that occur in their practice. This method is accomplished easily and it yields valuable information by identifying weaknesses and strengths and setting future goals for better quality (Roberts, Cook, Walsworth-Bell & Barrow, 1995).

A second source of errors in Pap test diagnoses stems from mistakes in sampling. It is important that samples are taken from the squamocolumnar junction in which the majority of the cervical neoplasms arise, thus it is best if the sample is collected both in the endocervix and the ectocervix (Shield, Daunter & Wright, 1987). The instrument of collection is also of great importance for an accurate sample. Technicians have pointed out that a cytobrush is effective in collecting representative samples from all parts of the cervix (Mithcell & Medley, 1991). In addition, false-negative results can be attributed to vaginal washing or trauma before sampling, small samples, and small size of some lesions (Shield, Daunter & Wright, 1987).

Alternative methods of early detection like colposcopy are criticised as not being cost effective and for being time consuming. This is

especially true for developing countries (Mera, 1997). Colposcopy is effective only when it is combined with intensive comprehensive cytology, in which case it reduces not only cervical cancer but also pre malignant abnormalities (Benedet, Anderson & Matisic, 1992).

Recently, two tests have been used in addition to the Pap test. These are referred to as the PAPNET and the ThinPrep. The Papnet is a computer program that is designed to re-screen negative smears for abnormal cells, which are difficult or impossible for the cytotechnologist to find (Western Diagnostic Pathology, nd). The ThinPrep is a technique that utilises the cells remaining on the Pap smear brush after the smear is made, and reduces the screening error by making high quality smears so that abnormal cells are more easily identified (Western Diagnostic Pathology, nd). Studies on the effectiveness of the PAPNET do not show consistent results and suggest that this method may increase significantly the cost of cytology (Brotzman, 1999).

In recent years some articles have been published questioning the effectiveness and usefulness of the Pap test. Comments are based on reviews of the evidence from the Nordic countries and British Columbia and claim that the decrease in cervical cancer mortality is insufficiently substantial to recommend screening at a population level and that a decrease in cervical cancer mortality was evident

before the introduction of Pap tests (McCormick, 1989; Skrabanek, 1987). The authors of these articles also mention that screening is not cost effective compared with lives saved (McCormick, 1989; Skrabanek, 1987).

Despite controversy regarding the effectiveness of the Pap test, most professionals in medicine and health science agree that it remains an effective measure for reducing the incidence of cervical cancer mortality (Lazcano-Ponce *et al*, 1998). According to some authors, the attack on the reliability of the Pap test originates in economic issues and law suits resulting in huge rewards given to women who have had problems with their tests (Austin & McLendon, 1997). Unless there is substantial evidence in the future that the Pap test is not effective in reducing cervical cancer, it is recommended that all sexually active women from 18 to 70 years old that have not had a hysterectomy have a Pap test at least once every two or three years. The age that a woman should stop having Pap tests and the recommended interval between tests vary from country to country.

Screening for cervical cancer

The Pap test is primarily a preventative rather than a diagnostic tool since it is designed not only to detect cancer but more importantly to detect non-malignant abnormalities that could develop into

cancer. Since the test was perfected in the 1950's, it became evident that introducing it into a screening program could have a great effect on the incidence of cervical cancer and related mortality. Screening refers to "the use of presumptive methods to identify unrecognised health risk factors or asymptomatic disease in individuals" (Braverman & Tarimo, 1996, p.15). The Pap test adheres to this definition since it detects abnormalities at a stage when intervention can prevent the development of cancer. The benefits of screening can be assessed only indirectly since experimental randomised clinical trials have never been conducted (Lynge, 1989).

Screening for cervical cancer every three years has proven to prevent up to 90% of cervical cancer in countries that have adopted an organised approach to the prevention of the disease (Byles, Sanson-Fisher, Redman, Dickinson & Halpin, 1994; Health Department of Western Australia, 1996; Sutherland, 1992; Straton, 1994; World Health Organisation, 1986). In the Nordic countries, reductions in incidence and mortality from cervical cancer are directly related to the intensity of organised screening in each country (Sigurdsson, 1993). In Iceland where there is an organised program for screening the reduction in mortality from the disease was 80% (Sigurdsson, 1993; Laara, Day & Hakama, 1987). The mean age of detecting invasive cancer has decreased and cancer

has become "practically non-existent" among correctly screened women over the age of 69 (Sigurdsson, 1993). Similarly, a reduction in cervical cancer has been achieved in Denmark, Sweden, and Finland (World Health Organisation, 1986). A study conducted in the Netherlands concluded that, after a long history of cervical cancer screening in these countries, an organised program is still essential to ensure proper coverage of the population (Bos, Ballegooijen, Gessel-Dabekaussen & Habbema, 1998).

In British Columbia, a cervical cancer-screening program resulted in a reduction in the rate of cervical cancer and a reduction in the incidence of pre-cancerous abnormalities (Benedet, Anderson & Matisic, 1992). In Denmark, cervical cancer incidence and mortality was influenced by the number of Pap tests and the proportion of women participating in screening (Lynge, 1989). In Miyagi Province in Japan, the organised use of the Papanicolaou method resulted in the mortality rate decreasing to one-third from 12.1% to 4.0%. A case control study also provided epidemiological evidence of a reduction in the incidence of the disease (Sato, Makino, Matsunaga & Yajima, 1998). In the USA, the death rate due to cervical cancer has declined by 70% over the past 40 years and this is primarily attributable to cervical cancer screening programs (Mera, 1997).

Principles of an organised approach to cervical cancer screening

According to the International Union against Cancer (Miller, Chamberlain, Day, Hakama & Prorok, 1990) the following conclusions were drawn at an international conference about cervical cancer screening:

1. Screening for cancer of the cervix is an effective method for reducing incidence and mortality and is applicable as public health policy (Miller *et al*, 1990, p.763).
2. Organised screening is more effective than opportunistic screening in reducing risk from cancer, because it achieves higher compliance, it is cost effective, and prevents over-use of services (Miller *et al*, 1990, p.763).
3. An organised approach with high coverage that initiates screening at age 25 and continues until 60 with intervals of 3 to 5 years achieves maximum effectiveness (Miller *et al*, 1990, p.763).

An effective, organised screening program for the detection of cervical cancer aims at reducing the incidence of the abnormalities that precede cervical cancer in order to reduce the incidence of the disease in the population (Smith, Elkind & Eardley, 1989). The essential elements for an effective program as defined by the World Health Organisation are (Weisberg, 1991, p.23):

- (a) an identified population;
- (b) an agreed screening policy;
- (c) a means to identify individual women;
- (d) measures to guarantee high attendance levels;
- (e) adequate and acceptable Pap test services; and
- (f) adequate laboratory facilities for reporting Pap test results.

Problems affecting cervical cancer screening

According to the World Health Organisation the target for the year 2000 is to reduce the incidence of cervical cancer by at least 20%, from 15 per 100,000 to 12 per 100,000 women (Lazcano-Ponce *et al*, 1998). This target is not likely to be achieved primarily because of the inability of many countries to establish an organised approach to the prevention of cervical cancer (Lazcano-Ponce *et al*, 1998). This is more evident in developing countries where poverty, war, lack of food, and basic medication make cervical cancer screening not a priority and population cover an impossible achievement. For countries with limited resources, the World Health Organisation recommends at least one Pap test in a woman's lifetime at the most appropriate age, a policy that is very hard to establish (Lazcano-Ponce *et al*, 1998). It is very important for the international community to provide the necessary resources

in order to provide the women of these countries with some form of screening.

In developed countries there remain significant numbers of women who die every year from cervical cancer, despite the fact that it is a preventable disease. This fact is caused primarily from lack of screening. Many countries have yet to establish an organised program or the programs have failed to yield the desired results. In the UK, for example, despite the introduction of cervical cancer screening in the 1960's, the impact on mortality and incidence has been disappointing (Elkind, Eardley, Haran, Spencer & Smith, 1989; Robertson, 1989 *et al*, 1989; Davis & Brown, 1994). This fact could be attributed to the five year interval between Pap tests that was recommended for many years in the UK and which has been described as ineffective by some researchers (Herbert, Stein, Bryant, Breen & Old, 1996). In New Zealand, cervical cancer screening has prevented about 25% of cases, while it has not been sufficient to prevent cancer in women born since the 1940's (Paul *et al*, 1991).

Much debate surrounds the reasons some programs fail to produce desired results in terms of reduced incidence and mortality from cervical cancer. Some of the reasons suggested include: screening intervals; age of screening; screening uptake; and disagreement

regarding pre-cancerous abnormalities. In addition, management policies and the involvement of communities and general physicians have also been noted as important factors affecting the success of screening programs (Davis & Brown, 1994; Straton, 1994).

Screening intervals. The frequency of a Pap test affects both the effectiveness and the cost of the program (Shields, Daunter & Wright, 1987). If it were possible for all women to be screened once every month, cervical cancer would be non-existent. This is not possible because of trauma to women's cervix and for economic reasons (Shields, Daunter & Wright, 1987). The Scandinavian countries that have experienced the most success in reducing incidence from cervical cancer recommend a 2-5 year interval following a negative test (Shields, Daunter & Wright, 1987). Studies have estimated that there is no significant difference in the number of cervical cancer cases prevented between an annual and a three-year interval. Screening every three years will result in 91% reduction in the risk of cancer as opposed to only a 93% for annual screening (Weisberg, 1991; Straton, 1994). A five-year interval is not effective in reducing incidence and mortality from cervical cancer (Herbert, Stein, Bryant, Breen & Old, 1996) but not all research agrees on this point (Sherlaw-Johnson, Gallivan & Jenkins, 1999). A recent study showed that women over the age of 50, with normal Pap tests and no history of papillomavirus screening could

cease screening, resulting in a 25% reduction in screening costs (Sherlaw-Johnson, Gallivan & Jenkins, 1999). This research does not address the ethical consequences of withdrawing women from screening. There is still considerable debate on the issue and an acceptable screening interval is not fully agreed.

Financially, cervical cancer screening programs are cost-effective when the screening interval is between 2 to 4 years (Gyrd-Hansen, Holund, Andersen, 1995). Screening every two to three years can prove cost-effective because expensive treatment required for the advanced stages of cervical cancer are not used due to earlier treatment of pre-cancerous abnormalities (Shields, Daunter & Wright, 1987).

The issue of high-risk groups being screened more frequently has been raised suggesting that women who have had many sexual partners or who started sexual relations early in life need to have more Pap tests than others (Shields, Daunter & Wright, 1987). In practice, this is hard to establish because of the risk of cervical cancer screening being labeled as a disease for sexually promiscuous women (Shields, Daunter & Wright, 1987). Any attempt to establish frequency of screening based on high-risk categories is unacceptable, especially when there is no evidence showing that the development of cervical cancer is more rapid in

high-risk women (Shields, Daunter & Wright, 1987). Recently, concerns have been raised about whether teenage girls should participate in screening since there is a high level of sexually transmitted diseases in this population (Kahn & Emans, 1999). This strategy, though, is likely to be met with caution by the community (Kahn & Emans, 1999).

Age of screening. The International Union Against Cancer recently recommended that all sexually active women from 25 to 60 years have Pap tests (Straton, 1994). However, evidence that older women have increased rates of cervical cancer (Straton, 1994) and the recent numbers that show younger women being affected more by the disease (Paul *et al*, 1991) has led many professionals to modify ages to include older and younger women. The most recommended ages for screening are between 20 and 70 years of age, even though some researchers suggest that screening under the age of 25 is "poor use of resources" (Paul *et al*, 1991, p.291).

Screening uptake. It is important for the success of a screening program to achieve high rates of attendance and to establish a population cover of all women who need to be screened, regardless of race, socioeconomic status, occupational status, and location of residence. This is a challenging issue for health professionals and the focus of much research (Straton, 1994). Women who are under-

screened are older in age, come from a lower socioeconomic status, and are unemployed and single. Women who do not respond to screening are also less educated and have more children (Peters, Bear & Thomas, 1989). Studies in Australia and across the world have found that under-screened women come from ethnic minorities for example, Maori New Zealanders and Pacific Island women (Jameson, Sligo, Comrie, 1998; Bonita & Paul, 1991). In Australia, Aboriginal Australians and women from non-English speaking backgrounds such as Vietnamese and other Asian born women, Greek, and Arabian women have lower rates of screening (Straton, 1994; Cheek *et al*, 1998; Australian Greek Welfare Society, 1996; Young & Coles, 1992; Lesjak, Ward & Rissel, 1997). In the USA, women who are not screened are usually of Hispanic, African American and Asian background (Hiatt *et al*, 1996). The reasons why women do not participate in screening programs are of social, economic, ethnic, cultural and psychological nature (Straton, 1994).

Management policies. The initial and most important aspect of an organised approach to the prevention of cervical cancer is identifying and approaching the target population. Some of the methods developed for identification of all women who should screen are call and recall letters, electoral polls, and general practitioners' databases (Straton, 1994). For example, the

Netherlands has experienced success in organised programs for a number of years. In this country addresses are obtained from the country's national population registry and initial, comprehensive invitation is issued by mail (Straton, 1994). In Australia, use of electoral registries as a source of identifying women for participation in screening programs have yielded different results. Attempts in Western Australia, New South Wales, and Victoria have shown promising outcomes but have not yet resulted in total success (Straton, 1994). The failure of many programs to create an adequate method of targeting and following the eligible population has caused the failure of many organised programs, for example, in the UK (Straton, 1994). However, the screening program in the UK has had more success since 1990 when the contract for general practice gave general practitioners principle responsibility for cervical cancer screening and a call and recall method was established (Ibbotson, Wyke, McEwen, Macintyre & Kelly, 1996). Population coverage increased from 61% in 1989-90 to 83% in 1992-93 (Ibbotson *et al*, 1996). The increase in screening rates and the decrease in cervical cancer mortality in the UK in the last ten years suggests an improvement in the screening program (Quinn, Babb, Jones & Allen, 1999) that can be achieved in other countries if similar policies are adapted.

Follow-up occurs with the establishment of cytology registries with the participation of laboratories and general physicians' databases. Cytology registries are valuable in reminding women about a forthcoming test but have little value when they do not include those women who are inadequately screened or not screened at all (Ibbotson *et al*, 1996). This suggests that the role of doctors, both in initiating screening and monitoring follow-up, is extremely important.

Problems regarding screening programs arise from organisational issues. Austoker (1994, p.243) outlined the main strategies that have to be followed in order to overcome such obstacles. These are the following:

- run a systematic call and recall system;
- improve the coverage of the target population;
- follow-up women who do not respond to personal invitations;
- improve the quality of the smear taken;
- communicate with the laboratory;
- deal with normal results;
- deal with abnormal results;
- improve the follow-up of smears that are not normal;
- reduce patients' anxiety and dissatisfaction;
- run an effective fail safe system; and

- monitor and evaluate the effectiveness of the screening program in the practice of doctors.

Recently, some authors have suggested alternative methods to cervical cancer screening based on the epidemiological evidence on the causation and natural history of the disease. For example, Braun & Gavey (1998) indicated that health promotion should focus on preventing the incidence of precursor lesions that could lead to cervical cancer. They suggest that by focusing on primary prevention to change sexual behaviour towards more "safe" sexual practices such as use of condoms, sexually transmitted diseases and the HPV infection, suspected to contribute to the formation of the disease, would be reduced (Braun & Gavey, 1998). Davies and Brown (1994), on the same issue, suggest that, although the role of the suspected risk factors for cervical cancer is not yet clear, health education aimed at modifying risky health behaviours could prove useful for the prevention of cervical cancer. Strategies, they point out though, should not only include women but also men and young teenagers (Davies & Brown, 1994). Concerns have been raised regarding primary prevention because of the risk of portraying cervical cancer as a promiscuous disease (Braun & Gavey, 1998).

Cervical cancer screening programs in Australia

The 'Organised Approach to Preventing Cancer of the Cervix' was introduced to Australia in 1991 after the failure of the previous opportunistic method to show any substantial decrease in incidence and mortality from the disease (Report of the Evaluation Steering Committee, 1995). In Australia, according to the new policy, all sexually active women who have not had a hysterectomy between the ages of 18 and 69 should have a Pap test every two years while Pap tests are recommended for women over 70, who have not previously been screened (Report of the Evaluation Steering Committee, 1995). The first evaluation of the ongoing program in 1996 found problems with cancer registries, which pose important difficulties for efficient follow up. Furthermore, the reports found that there is need for more women over 35 years to be screened, with special emphases on women over 50. Indigenous women were also found to be under-screened. Finally, the report drew attention to general practitioners and stressed the importance of their involvement (Report of the Evaluation Steering Committee, 1995). The second phase of the program finishes in 1999, after which a final report on the 'Organised Approach' will be presented.

Western Australia entered the National Screening Program in 1992 and, since then, it has established a Cervical Cytology Registry that reminds women with previous normal tests about their coming

appointments. The registry also serves as a follow-up to women with abnormal test results, and assures laboratory quality (Health Department of Western Australia, 1996). The plan for the years to 1999 included improvements in the areas of: coordination; communication and recruitment; special services; quality management; cervical cytology registry; data management and monitoring; and evaluation (Health Department of Western Australia, 1996).

Increasing participation in cervical screening

Cervical cancer is one of the few diseases that can be successfully prevented through screening yet it still affects women worldwide. The primary reason for this is inadequate screening of certain groups of women. Many attempts have been made to increase participation of women in screening programs. In Australia for example, several organised programs for cervical screening have targeted women from non-English speaking backgrounds and Aboriginal Australian women. The Bilingual Community Educator Project for Pap tests and breast self-examination organised by the Brisbane Women's Health Centre employed multicultural workers to help in recruiting women for screening and to address issues of concern to the women such as embarrassment, lack of knowledge, and language barriers (Ganguly, 1995). The program was characterised as successful and its continuation was highly

recommended (Ganguly, 1995). In Victoria a cervical cancer screening, community-based, program targeted at Greek women utilised bilingual doctors and health workers for community talks, and interviews with the local media and newspapers. They managed to enhance the number of Greek women participating in screening (Australian Greek Welfare Society, 1996).

In New South Wales use of three community-based strategies resulted in a significant increase in the number of women participating in screening (Byles, *et al*, 1994). The strategies were: (1) television media; (2) television media combined with letter of invitation; (3) television media and general practitioners. In Perth, Western Australia, one study demonstrated the effectiveness of providing Pap tests to women while in the hospital for a non-gynaecological reason (Straton, Sutherland & Hyndman, 1995). The authors concluded that hospital-based interventions have the potential to recruit women for screening who otherwise would be hard to reach (Straton, Sutherland & Hyndman, 1995).

A cervical screening program in remote Aboriginal communities in Australia provided a call-recall system and facilities for Pap tests (Mak & Straton, 1997). Although educational campaigns were characterised as necessary for this population, no such activities were undertaken because of lack of resources (Mak & Straton,

1997). The success of the program was dependent on the enthusiasm and dedication of a single person and its continued success was deemed unlikely unless support was provided by local health services (Mak & Straton, 1997). Clearly more programs are needed for Aboriginal and non-English speaking groups to increase cervical cancer participation.

Health professionals stress that not all strategies to increase cervical screening will work for all women and that the success of programs depends on culture and financial factors (Vellozzi, Romans & Rothenberg, 1996a). Furthermore, it is important to have an adequate knowledge of the barriers to screening each population faces (Hiatt *et al*, 1996), hence the significance of the present study about Greek women's attitudes and behaviour in regard to cervical cancer screening.

In the USA, a community program called "Su Vida, Su Salud/ Your life, Your Health", based on an innovative outreach strategy with the participation of local health departments had success in increasing participation of Mexican American and African American women (Suarez, Nichols, Pulley, Brady & McAlister, 1993). Positive role models were featured in the media, and community volunteers gave positive social reinforcement through the support and organisation of the local health departments, which were the key

factor for the success of the intervention (Suarez *et al*, 1993). Using their personal influence, community leaders assisted with the implementation of a program targeted at African American women (Williams, Abbott, Kay & Taylor, 1997). The authors concluded that community leaders play a significant role in the success of community programs because they can influence directly both the target population and the media (Williams *et al*, 1997).

Still in the USA, health promotion professionals utilised the services of a local urban church as a source of social influence to increase participation in cervical cancer control activities (Davis *et al*, 1994). Ninety percent of the targeted women, as a result of the intervention, presented for screening. Fifty-two percent of the local churches initiated cancer control activities within two years (Davis *et al*, 1994). The procedures and methods of intervention used in this program are valuable for the design of similar activities (Davis *et al*, 1994). Many studies in the USA have concluded that the combination of media-based strategies combined with the help from local community leaders, lay educators and volunteers and with local health departments are necessary for the success of cervical screening and breast screening programs targeted at minority or disadvantaged populations (Kornfield *et al*, 1998; Maibach, Davis, Maat, & Rivera, 1998; Vellozzi, Romans & Rothenberg, 1996a). Other attempts to increase participation in cervical screening as well

as breast cancer screening have used mobile screening units to reach women on their workplace (Thorton & Chamberlain, 1989), or to reach women in rural or isolated locations (Velozzi Romans & Rothenberg, 1996b).

In order to increase cervical screening, in 1993, the Health Department of Greece issued a law decreeing that hospitals should provide free Pap tests to all women without any charges to their insurance (Υπουργείο Υγείας, Πρόνοιας και Κοινωνικών Ασφαλίσεων, 1993 [Ministry of Health, Welfare and Social Security]). In 1987 the European Community (EC) began the "Europe Against Cancer" program in a major effort to control cancer in the European Community and its member states. With the support of this program, the Hellenic Ministry of Health began a pilot study to establish a population-based screening program in the northern regions of Greece, Messinia and Ilia. Mammograms and Pap tests were offered to all eligible female permanent residents of these areas. The program is designed to run for ten years and gradually will include other rural areas of Greece. At present the results have been evaluated as successful by the Ministry of Health and the European network of reference centres for breast cancer screening, and the European guidelines for quality assurance in cervical cancer screening (Ελληνική Ογκολογική Εταιρεία, 1997 [Greek Oncological Society]).

Conclusion

This chapter provided an analysis of cervical cancer and cervical cancer screening. This was necessary in order to fully understand the extent of the problem both in Australia and worldwide and to understand why cervical cancer, a preventable disease, still claims lives today. The topics discussed in the chapter referred to the pathology of cervical cancer, the epidemiology of the disease, screening programs and associated problems, and screening interventions. The following chapter establishes the theoretical framework for the study. The information sets the scene for the present study of cervical cancer screening and ethnic-minority, Greek women in Australia.

CHAPTER THREE: THEORETICAL FRAMEWORK

Introduction

The Health Belief Model (HBM) provides a framework for studies investigating health behaviour. It predicts changes in health behaviour from pre-determined scales namely *perceived susceptibility, perceived severity, perceived benefits, and perceived barriers*. In this chapter, the rationale for using the HBM in a study of cervical cancer screening and the historical development of the model and its components are analysed. Examples of studies using the HBM as a theoretical framework provide concrete examples of the relevance and significance of the model.

The Health Belief Model (HBM)

The HBM was initially developed in the 1950's in the USA by a group of social psychologists trying to explain the failure of people to respond to, and participate in, disease prevention programs (Strecher & Rosenstock, 1997). Rosenstock and Becker amended the model in the 1970's and changes and improvements to its structure and application continue today (Ingham & Bennett, 1990). The HBM predicts individuals' preventive health behaviour and is used in studies to determine the factors that reinforce and influence peoples' intentions of practicing preventive health and predicting adherence to recommended protective health behaviours (Strecher,

Champion & Rosenstock, 1997; Strecher & Rosenstock, 1997; 1984; Murray & McMillan, 1993).

According to the model, a person's intention of practicing recommended health behaviour is a function of the following components.

- *Perceived susceptibility.* This dimension measures a person's individual perception of being susceptible to a disease. The more prone a person feels to developing a particular illness, the higher the chances of following the recommended health behaviour (Strecher, Champion & Rosenstock, 1997; Strecher & Rosenstock, 1997). Applied to cervical cancer, perceived susceptibility refers to a woman's perceptions and thoughts about being prone to developing the illness. The degree to which a woman feels prone to cervical cancer, according to the HBM, will predict adherence to cervical cancer screening.
- *Perceived severity.* This component of the model addresses feelings regarding the severity of the illness. It refers to a person's subjective evaluation of the seriousness of the disease and the seriousness of leaving the condition untreated. Subjective evaluation also includes assessment of medical (death, pain, disability, future medical costs) and social consequences (effects on family, social relations and work) arising from an illness (Strecher, Champion & Rosenstock, 1997;

Strecher & Rosenstock, 1997). In the case of cervical cancer, perceived severity refers to a woman's feelings about the seriousness of the illness and the assessment of the medical and social consequences if the disease developed.

- *Perceived benefits.* This component predicts that a person's intention of following a recommended behaviour is a function of the degree to which he or she believes the behaviour will be beneficial in reducing risk from a particular illness (Strecher, Champion & Rosenstock, 1997; Strecher & Rosenstock, 1997). For this study, the degree to which screening is regarded as a protective act against cervical cancer would predict the frequency of Pap tests among women.
- *Perceived barriers.* This component refers to the negative aspects of the recommended health behaviour. According to the HBM, people go through subjective mental evaluations about the expected effectiveness of the behaviour against perceptions of it being costly, dangerous, difficult, and time consuming (Strecher, Champion & Rosenstock, 1997; Strecher & Rosenstock, 1997). The effectiveness of the Pap test would thus be weighed against potential difficulties in screening such as time, money, and risk. The outcome of this evaluation will influence a woman's intention of seeking screening.

Recent formulations of the HBM resulted in the inclusion of components such as *cues to action* referring to factors that trigger and give cause for action such as bodily changes or environmental indicators like the media (Strecher, Champion & Rosenstock, 1997; Strecher & Rosenstock, 1997). According to the HBM, other variables, that affect health behaviour, are diverse demographic, socio-psychological, and cultural factors. In recent years the HBM has incorporated in its explanatory components of health behaviour, the concept of *self-efficacy*, originally developed by social psychologist Albert Bandura (Strecher, Champion & Rosenstock, 1997; Strecher & Rosenstock, 1997). Self-efficacy refers to a person's "conviction that one can successfully execute the behaviour required to produce the outcomes" (Strecher & Rosenstock, 1997, p.47).

There are many examples of the application of the HBM, these include studies investigating folate knowledge (Kloeble, 1999), coronary heart diseases (Mirotznic, Feldman & Stein, 1995), hypertension (Brown & Segal, 1996), chronic diseases (Mirotznic, Ginzler, Zagon & Baptiste, 1998) and health promotion in older populations (Caserta, 1995). There has also been extensive use of the HBM in studies of mammography and cervical cancer screening. Most results confirm that some, but not all, components of the HBM predict participation in screening (Fulton *et al*, 1991; Murray &

McMillan, 1993; Bernstein-Hyman & Baker, 1992; Hill, Gardner & Rassaby, 1985; Cockburn, Murphy, Schofield, Hill & Borland, 1991; Price *et al*, 1996). The relationship between health beliefs and breast –self examination (BSE) was examined in a study conducted by researchers who identified, using questionnaires structured according to the HBM, that the perceived benefits of BSE and perceived susceptibility to breast cancer significantly increased the likelihood of women practicing this protective behaviour. On the other hand the study identified that an increase in perceived costs, a barrier to BSE, significantly reduced the likelihood of the practice (Ronis, Kaiser, 1989)

The extensive use of the HBM has also led to criticisms which indicate that the model explains only 20-40% of differences in screening behaviours and that it limits research to the examination of specific pre-determined variables (Savage & Clarke, 1998). Pre-determined variables restrict the ability to examine alternative influences, which are not included in the model, but which may equally influence and predict health behaviour. Critics of the HBM have also emphasised the difficulty of operationalising the model's components, questioning the validity of studies using measuring instruments (questionnaires) derived from the model's structure (Strecher & Rosenstock, 1997; Strecher, Champion & Rosenstock, 1997). Regardless of the criticisms, the HBM is used extensively

today in health research and is considered a valid theoretical framework for explaining and predicting health protective behaviours (Strecher & Rosenstock, 1997; Strecher, Champion & Rosenstock, 1997).

In the present study, the HBM was used as a theoretical framework to guide the examination of cervical screening among Greek women. Because of the complexity of the behaviour under investigation, the HBM was important as a theoretical background to guide the design, analysis and interpretation of the research.

During the design of the study the HBM was used as a reference point for generating interview questions. Many of the questions were structured in accordance with the components of the model but were open-ended to allow for the exploration of other possible factors influencing cervical screening among Greek women. This line of questioning was chosen to give women the opportunity to talk about their own perceptions of screening, rather than structuring their response with predetermined questions. For example, in order to reveal whether or not women felt susceptible to cervical cancer, questions about who should have a Pap test and how often, as well as general questions aimed at women's knowledge of screening and cancer were asked. In order to explore the level of seriousness

participants attributed to cervical cancer, women were asked questions about their past experience with this disease.

Conclusion

The HBM is the most used theoretical framework in studies investigating health behaviour. It was initially developed in the 1950's in the USA and has been repeatedly revised and changed until today. The present study aimed at understanding screening behaviour and the

CHAPTER FOUR: METHODOLOGY

Introduction

Qualitative methods were used in this study to examine the screening behaviour of a particularly under-examined group: Greek women in Perth, Western Australia. Qualitative methods of investigating health phenomena have the power to uncover feelings and ideas that are important to the participants. The open nature of a qualitative approach can reveal new variables of interest and new hypotheses for future research. This chapter:

- outlines the rationale for choosing a qualitative approach;
- describes the design of the study and the technique for data analysis;
- describes the people who participated;
- outlines the difficulties in conducting the research; and
- discusses ethical considerations and limitations.

Rationale for qualitative methodology

A qualitative methodology was chosen for this study to facilitate the in-depth exploration of the cervical screening behaviour of Greek women in Perth. The aim was to encourage women to talk for themselves about their screening practices and their perceptions about screening. Their expressed ideas and opinions formed the basis for this study. These issues are hard to examine with large

population surveys, primarily because the attitudes of Greek women in Australia regarding cervical screening are not known and thus appropriate measurable variables have not been established. Questionnaires, designed to measure the attitudes and practices of women regarding cervical cancer have been designed, but these have been used mostly for Australian women from English speaking backgrounds (Sutherland, 1992). Because there is no adequate information on screening attitudes of Greek women (apart from statistical data showing this population to be under-represented in screening programs) a qualitative methodology was chosen. It is important to note here that the purpose of this study was not to generalise findings to the wider Greek migrant population of Australia. The study aimed to uncover issues seen as important by a group of women. Their experiences may provide insights into screening practices, attitudes and knowledge and create ground for further study into the wider Greek population in the diaspora and in their country of origin. The researcher's interest in this study was to discover the essence of the issues discussed to generate themes to enhance health promotion in a diverse, multicultural society rather than to generalise the findings to the whole Greek population of Australia.

Health and disease are influenced by complex economic, political, social and cultural factors that differ for each group in society

(Baum, 1998). Through qualitative methods these complex relationships can be revealed and investigated in depth (Daly, Kellehear & Gliksman, 1997). Qualitative methods can reveal feelings, perceptions and attitudes, which reflect, predict and explain individual health behaviour (Minichiello, Aroni, Timwell & Alexander, 1990). Qualitative approaches give insight into the cause and nature of health actions (Minichiello *et al*, 1990) and issues that are important for health promotion and public health in a constantly changing and diverse society. In contrast, surveys can only reveal numbers about how many people participate in health programs and how frequently they practice health behaviours (Baum, 1998). This information is not adequate for health professionals who need to know the circumstances that lead to specific actions. If health promotion aims at changing harmful behaviours, the reasons that make people change need to be understood from their own perspective. Pre-determined categories explain little of the diversity of health beliefs and behaviours and may not be valid for all groups. For example, different ethnic groups may have entirely different reasons for their actions than those anticipated in structured questionnaire surveys (Waxler-Morrison, Doll & Hislop, 1995). Quantitative research methods, especially those conducted with poorly-researched groups, do not allow the discovery of new or unexpected variables, thereby limiting the value of the results (Waxler-Morrison, Doll & Hislop, 1995). Qualitative studies can offer

insight into reasons and provide a guide to the correct path for understanding people and behaviour. Qualitative research allows participants to express their own perceptions of reality and the researcher to understand the world directly from the perspective of the target population (Patton, 1990). The end result of qualitative studies is to make sense and give meaning to situations and phenomena according to the meaning people ascribe to them (Patton, 1990).

Participants

This study sought to identify and examine cervical screening among ethnic Greek women, in Australia. Ethnicity refers to "commonly linked shared factors which bind a group of people together and give them a sense of belonging. Language, system of beliefs, religion, history, customs, values and traditions are important here" (Tsolidis, 1995, p.124). For this study, Greek women were identified mainly by language spoken at home, religion (Greek Christian Orthodox) and by answering the simple question "do you identify yourself as Greek. Country of birth does not establish Greek ethnicity, because Greeks have a traditional presence outside of Greece referred to as the Greek diaspora (Tsolidis, 1995). For example, the Greek diaspora is found in Asia Minor (parts of Turkey), Egypt and, in particular, Alexandria, which has had a strong Greek community since the time of Alexander the Great

(Tsolidis, 1995). Greeks also live in Russia and Hungary where they took refuge after the Greek civil war, America, Australia, Canada, and England and also Zimbabwe, Finland, Thailand, and Latin America (Tsolidis, 1995). Greek Cypriots are also considered to have Greek ethnicity because they share the same religion, language, customs, history, values and traditions (Tsolidis, 1995). This account was necessary to explain why ethnic Greek women, actually born in Hungary, Alexandria (Egypt), Russia and Cyprus were included in this study.

The existence of so many Greek communities outside of Greece, whose members have migrated to Australia, poses an important obstacle for studies utilising results from population-based statistical databases such as the Australian National Health Survey. The fact that country-of-birth does not establish ethnicity is a disadvantage for such studies that might exclude many people who could influence statistical outcomes.

Fifteen women participated in this study. Except for one, all women were married. Eight were over 50 years of age while the rest ranged in age from 30 to 50 years old. All women spoke Greek and Greek was the first language spoken in their homes. Nine interviews were conducted in Greek and the remaining seven in English.

The sampling method followed was snowball or chain sampling which "identifies cases of interest from people who know people who know what cases are information rich, that is good examples for study" (Patton, 1990, p.182). To find respondents, the researcher approached a community centre, in which a Greek group functioned, and asked women from there to participate. The name and location cannot be revealed because the particular centre is small and the women would be too easily identified. The second source was personal contacts within the Greek community of Perth, Western Australia. However, in order to minimise bias, no interviews were conducted with women who were personally known to the researcher.

The research was delayed for many weeks because of difficulties in finding women to participate. The women were suspicious of the study, even though the researcher contacted them all personally, talked to them in Greek, explained the purpose and significance of the proposed study and assured anonymity. In one case, after a woman had agreed to participate, the husband blatantly stated that his wife is not interested in such things and that an interview was out of the question. In yet another case a woman and her husband refused to listen to the details of the proposed study, refused to read the informed consent and offered, instead, money to make-up for their refusal. More than 10 women refused, not only to

participate, but also to listen to the details of the study even though anonymity was repeatedly emphasised. This refusal rate is important. Not only does it indicate the sensitivity of the subject, it also suggests that cervical cancer screening is not an issue that is openly discussed in Greek communities. While the values and norms of the Greek community of Perth are accepted and respected, they do have implications for health and thus need to be examined.

Data collection instrument and procedure

The qualitative method chosen for data collection was semi-structured interviews. These are used when the researcher is familiar with the elements of the topic under investigation, but is unable to consider or have knowledge of all possible responses in order to structure a set interview questionnaire (Morse & Harrison, 1992). This method of data collection enables the researcher, in the course of the interview, to ask additional questions, if new information is revealed, and to explore answers in-depth in order to come to a more substantial understanding. Studies using semi-structured interviews have been used for the investigation of breastfeeding duration (Morse & Harrison, 1992), the examination of attitudes towards the "female condom" (Gil, 1995), and knowledge of sexual risks (Singer, 1995). A list of questions was generated for the interview schedule with reference to the HBM. The items included general questions about country and year of birth,

first language and language spoken at home to establish Greek background.

This research sought to reveal attitudes. As a consequence, the measuring instrument for data collection included questions on the three components that make up an attitude. These are affective (emotions), cognition (beliefs, opinions, ideas), and conative/behavioural (behavioural intentions) (Stahlberg & Frey, 1996). There were, therefore, questions about women's emotions towards screening and cervical cancer, questions on what they believed screening was and whether or not it was useful, and finally questions regarding their screening behaviour. Open-ended questions were chosen to allow interviewees to respond freely and to address issues of concern to them (Savage & Clark, 1998).

The interview schedule was printed both in English and Greek (Appendix A). In the course of the interviews participants discussed many issues, not included in the questions. This indicates the strength of the measurement instrument in maintaining a structure while exploring detailed responses and revealing original information that is of value in creating an in-depth understanding of the factors influencing cervical screening among Greek women.

Once permission was obtained to begin the study, participants were contacted and given informed consent forms explaining who the researcher was, the purpose, significance and details of the study. Informed consent forms were written both in English and in Greek (Appendix B). Interested women contacted the researcher and an interview was scheduled at a location and time that suited the respondent. Before initiation of the interview, all participants signed consent forms. All interviews were conducted in participants' houses, mostly during morning hours. The interviews lasted between 20 and 40 minutes and were conducted by the researcher in English and Greek according to the preference of the interviewee.

Data analysis

Apart from three women who chose not to be audiotaped, all other interviews were recorded on audio-tape. Analysis of the data began only after all interviews were completed to avoid the possibility of the researcher being influenced by the responses of previous interviewees. The researcher and a bilingual person, independent to the study, developed the final version of the transcribed interviews. The process involved two independent translations, which were then compared. Any differences were discussed and reconciled. The inclusion of a second independent person in the translation process minimised bias and ensured conceptual equivalence. This approach is termed *translation by committee* (Pasick et al, 1996). The

approach usually followed in studies conducted with different cultures is the one-way approach where one translated version is created from a single bilingual person (Temple-Smith, Banwell Gifford, & Presswell, 1995; Culpin, Gleeson, Thomas & Bekiaris, 1996). This method has been criticised as inadequate in the USA where most health surveys are conducted in languages other than English (Pasick *et al*, 1996). Other approaches to translation is the double- or back-translation in which one individual translates the interview from English into another language and then an individual person translates the version back into English or the opposite (Pasick *et al*, 1996). This process ensures equivalence, but is mainly used when the purpose of interviews is to lead to the development of a questionnaire (Pasick *et al*, 1996; Lesjak, Ward & Rissel, 1997). For this research, it was too difficult to find two independent bilingual people to conduct back-translation. Further, this method was not chosen because it could jeopardise confidentiality among the small Greek community in Perth. Translators from the Greek community could have identified individual participants from information on country of birth, date of birth and marital status.

The researcher transcribed all interviews. All women who participated were given pseudonyms; none of the names given corresponded to an actual interviewee. Each woman was categorised as screened (S), and under-screened (U-S) to facilitate

the presentations of results. Once all interviews were transcribed the researcher analysed each respondent's case, which is the first step in analysing qualitative data and is termed case analysis (Patton, 1990). The main issues were highlighted in each transcript and important responses were given thematic labels. Because of the wealth in information, content analysis "the process of identifying, coding, and categorising the primary patterns of data" (Patton, 1990, p.381) was lengthy. The process of giving first labels to responses was long and required reading the transcribed interviews many times. These first steps of the data analysis were fruitful and revealed much information about the issues discussed.

After the interviews were analysed to extract the main ideas, responses were grouped according to their labels and key patterns from the responses started to emerge. The interpretations of responses were based on these patterns which emerged as key findings of the study. All responses indicating perceptions, attitudes, knowledge, and practices about cervical cancer and screening were considered, even if the idea represented in the quote was mentioned only once. In the presentation of the findings in the results chapters of this thesis, emphasis was placed on presenting to the reader direct quotes from as many women as possible in order to show how the issues emerged and to give voice to the authentic experiences of participants. Interpretation, comparisons,

and analysis then followed. Even though qualitative, inductive analysis outlined in Patton (Patton, 1990) guided this research the analysis had to adjust to the uniqueness of the study. As Patton (1990) indicates, all research following this paradigm is unique and consequently the methods used for analysis have to adapt to the characteristics and demands of each study.

Ethical considerations

Ethics approval was sought and obtained from the Higher Degrees and Ethics Committees at Edith Cowan University. Participants were informed about the significance and purpose of the study and the estimated length of the interview. They were assured confidentiality, anonymity, and their right to withdraw at any time during the process of the interview. All participants read and signed consent forms both in Greek and English (Appendix C).

Tapes, transcription data, and translated data are kept in a locked filing cabinet accessible only to the researcher and will be destroyed in five years; these details were made known to the women. The respondents were also given the contact numbers of the Ethics committee of Edith Cowan University and the researcher in the event they had any comments to make about the study and the interview process.

A translator was used to translate Greek interviews into English. Following the guidelines of the Ethics Committee of the University, all possible precautions were taken not to disclose any information that could lead to the identification of participants. All names were hidden and code numbers were used to identify interviews. The translator had to sign a confidentiality agreement (Appendix D) stating that any information revealed through translation would not be disclosed.

Limitations of the study

In the process of conducting and writing this thesis the following limitations were observed:

- Issues of cost and time did not permit a larger sample of participants. Although the words and opinions of a single woman are important when studying determinants of health behaviour, a larger sample could have contributed further valuable information. However, a core principle of qualitative research is that saturation is reached. In these interviews, a point where no new themes emerged was reached indicating that the most important information had been secured.
- The second limitation involves the sample used for the collection of data. Because many women refused to participate in the study important information about Greek women's screening behaviour could have been excluded. Thus, although the sample

interviewed did contribute a wealth of information, other information-rich cases, as Patton (1990, p.169) calls them, could have been missed. Furthermore, although two sources were used as samples for data collection in order to increase external validity, it is likely that these were not representative of all Greek migrant women in Perth, Western Australia especially because no women from rural parts of the state were included. However, the cervical cancer screening needs of rural, ethnic women is a study in its own right.

- Although all precautions were taken so as not to use leading questions and probes during interviews, the posture, and non-verbal gestures of the researcher could have influenced interviewee's answers thereby affecting the reliability of the study. Equally, though, the conversational style adapted may have added to the quality and depth of information.
- Some of the main findings revealed that Greek women in Perth were very protective of their personal lives, and did not communicate between themselves about sexual and screening issues. It is possible therefore, that many opinions, beliefs, and ideas concerning sex, morality and screening were not disclosed because of the women's unwillingness to talk about these matters. Furthermore, the young age of the researcher could have also been the reason for the possible non-disclosure of some information, because, as the research revealed,

communication between younger and older generations regarding sensitive sexual issues was difficult.

Conclusion

Qualitative methods of analysis, specifically interviews, were used in this study since the main aim was to identify and explore in depth the attitudes of Greek women regarding cervical cancer screening. Many problems were encountered during interviewing as many women did not trust the purpose of the research and feared for privacy issues. The chapter provided the rationale for using qualitative methods, and described the methodology for collecting data, and the limitations and problems encountered during the research. The following chapter focuses on the findings arising from the study. Specifically, the focus is on the attitudes and practices of Greek women in Perth in regard to cervical cancer screening.

CHAPTER FIVE: PRACTICES AND ATTITUDES OF GREEK WOMEN TOWARDS CERVICAL SCREENING

Introduction

Fear of cancer, fatalism, and preoccupation with morality and sexuality, misinterpretation of the role of heredity and lack of knowledge about the symptoms of cervical cancer were the main findings from the analysis of Greek women's attitudes towards cervical cancer. From the analysis, it was found these attitudes had components of an emotional, cognitive and social nature which, in combination, influenced women's decisions about cervical screening. This chapter provides an analysis of the main findings contextualised in relevant literature on cervical cancer screening behaviour.

The screening practices of Greek women

Fifteen women participated in the study of whom seven reported having had a Pap test in the past two to three years referred to as screened (S). Eight had not received a test in the last three to ten years referred to as under-screened (U-S) with many not remembering the last time they had a Pap test. Of the women who were under-screened, three indicated they had only had one Pap test in their lives. Four of the under-screened women were over 50 years old, a fact which places them in a higher risk group for

developing cervical cancer than younger women (Blesch & Prohaska, 1991).

All women participating in this study had received at least one Pap test in their life. Except for one, all had their first Pap test, often also the last one, after they had their children. For example, Haroula (U-S) said:

"I have had one or a couple [Pap tests]. I did not start that long ago. I guess after my daughter was born. No not even then, I do not think I started until I was in my late 30's".

Fotini (U-S) indicated:

"No, no I never did things like that before I was married, [Pap tests] never in Cyprus. I think you understand about things like that. No, no I gave birth to my first baby and then I had some problems and my doctor said I should have one. I do not like talking about these things anyway I did it for 6 years and I had them 3 times. After that I stopped I did not think I needed them after that".

Elina (S) a 55-year-old Greek woman indicated:

"I started having Pap tests six years ago. This year it was the fourth I had. I never had them before because I worked, I never had time, and no one had ever told me that I had to do such things. My doctor never told me anything either".

The fact that Greek women started screening late could be connected to lack of knowledge about cervical cancer and screening, and could also be a consequence of the women's migrant status, especially during the earlier period of them settling in Australia. Although women did not refer to their experiences of their first

years in this country, it is possible that, during this time, health care and health education were hard to access. Contributing factors could also have been the barrier of language and the social difficulties of life in a strange country.

Eugenia Tsoulis (1998) an Australian of Greek heritage in her novel *"Between the Ceiling and the Sky"* writes about the experiences of Greek migrants, in particular Greek women, in Australia. She tells the story of a woman and her experiences going to the doctor for a gynaecological problem. In the process she refers to problems women faced in accessing health and in the number of roles women had to adopt as mother, wife, and employee.

"...Everyone in the house needed mothering, to be taken care of, to have some relief from the monotony between work and sleep..." (Tsoulis, 1998, p.121).

"It had taken forever to get the doctor's as the bus had been late-it was always late when it rained. She was drenched by the time she arrived..." (Tsoulis, 1998, p.122).

"She had put up with the embarrassment of all that, but she had protested at an internal examination, even when he assured her he needed to take all the necessary precautions. This was the final humiliation, thank God she was facing it alone. And after baring her bony frame for his scrutiny, and having to open up her legs, and have the coldness of his fingers in the rubber glove poking round her private parts, she than had to face him across the desk" (Tsoulis, 1998, p.123-124).

These quotes illustrate the pattern of life early migrant women encountered in Australia and the demands put on them by the family. Although none of the women in this study described similar

experiences, possible connections can be made about how a particular style of life during early immigration led Greek women to ignore their health needs and focus more on family and work, which are traditionally of great importance to the Greek way of life.

The impact of fear, fatalism and lack knowledge on screening behaviour

"The Papanicolaou test is to find if you have a bad disease, isn't that so? I do not want to say the name" Elpida (U-S).

"They have told us that it is for cancer. For the doctors to discover, to find...where it is. If you do it, you will be in time for the bad thing". Fotini (U-S).

"I do not know what the Pap test is. Where is it done? Is it the one they do for the womb"? Antigoni (U-S).

These women's words illustrate two important findings arising from this study. The first is that these Greek women fear cancer. This is why Fotini (U-S) referred to cancer as the "bad disease" and refused to call it by name. The second finding refers to the lack of knowledge, which is highlighted here by the women's notion that the Pap test is designed for the detection and not the prevention of cervical cancer or simply by not knowing what the test was. Thus, emotions and cognition, that is fear of cancer and lack of knowledge, shaped Greek women's attitudes towards cervical cancer screening.

In Greek society, especially among the older generation, even mentioning the name cancer is regarded as a bad omen. Cancer is a "bad disease", which is best not to be talked about, and anything that is connected to cancer, like the Pap test, is avoided because of fear. Cancer is something that cannot be cured or treated according to the women in this study. It is better if one does not know of its existence than have to deal with the consequences of a positive test. Olimpia (U-S) recounted the story of a Greek relative and in doing so illustrated how many Greek women feel about cancer and cancer screening.

"I think women who do not do the Pap test maybe are embarrassed first and second they say well if I have it I have it, why should I know of this badness [cancer] and be sad. It is worse for me [when I know] because when the badness grows it is hard to make it disappear. I had a sister-in-law she died from breast cancer. She knew she had it and never went to the doctor. When she got to the final stage and went he told her [the doctor] why did you come now there is nothing to be done and gave her only six months to live and in six months she died".

For Olimpia (U-S), the experience of a close relative dying of cancer did not motivate her to seek screening. For her and other women it is preferable not to know about "the badness" (referring to cervical cancer) because, once someone has it, there is nothing to be done. The consequences of these attitudes are that women refuse to acknowledge cancer as a threat, and, because of fear, deny screening, even when the symptoms are evident, at which point treatment is much less effective than if diagnosed at earlier stages.

Fear of cervical cancer was also found to be connected to fatalism an attitude evident among many Greek women in this study. Fatalism refers to "general outlook on life founded on the belief that life events are inevitable and that one's destiny is not in one's own hands. Fatalism puts the locus of control outside of the individual, often in the hands of metaphysical force such as God" (Chavez, Hubbell, Mishra & Valdez, 1997, p.418). For example, Haroula (U-S) commented:

"You can only look after your body so much and eat the right things to avoid cancers but I think it is not in our hands, it is in God's hands if that happens to you. I do not think we can do much about it. Apart from exercising, eating healthy and properly".

Fotini (U-S) also mentioned:

" I do not think that I need to have a Pap test, now if I have it and do not know only God can help".

According to Fotini (U-S) and Haroula (U-S) their health was in the hands of fate and God and they could not do much to prevent cervical cancer. Their words indicate a sense of helplessness regarding this disease and, and at the same time, their lack of knowledge about prevention. Straton (1996) comments that fatalism is more prevalent among women living in poverty, a fact not applying to the women in this study, who did show fatalistic attitudes yet, lived in comfort. It is evident therefore that culture and religion, shown from the way women referred to God in their quotes, are as important as socioeconomic status in influencing and

shaping fatalistic attitudes. The implication of fatalism is low participation in screening because of the notion that one does not have control over cancer and more generally health.

Support for the findings on fatalism may be found in the Greek Women's Papanicolaou Project (Australian Greek Welfare Society, 1996) in Victoria, Australia, which indicated that fatalistic attitudes among Greek women accounted for non-participation in the program designed for this community. According to this report, many women responded to the invitation to have a Pap test with comments such as "when it is my time to die, no-one will be able to save me except God. No test can save me if I have this disease..." (Australian Greek Welfare Society, 1996, p.21). Fatalism towards cancer also predicted non-participation in screening programs among Latino (Hispanic) women in the USA and researchers proposed that it is important for health care professionals to address such beliefs when designing health programs (Chavez *et al*, 1997).

The involvement of local communities in health promotion is brought into focus with the following quote made by Fotini (U-S) who also talked about her own and other Greek women's fears regarding Pap tests.

"They informed us once through the ... community, they gave us a piece of paper to go and do it somewhere for free, I think in ... but we did not mention it to any of them. None of them go. [Because] Women are afraid of the cancer that might be there and they do not want to know it, like me. You see this thing you can not buy. Nobody gives it to you, if you have it you have it, so you are scared and you do not want to know. You try to avoid it".

Fear of cancer resulted in the dismissal of attempts made by health promotion organisations like the one mentioned here by Fotini, who invited women from a particular community to attend free screening sessions. Distorted knowledge about the purpose of the test led the leaders of this community to reject the offer out of fear of alarming the women. This information brings to focus the involvement of authority figures in communities, the accountability of their decisions and the effect these have on community members. It also highlights the importance health promotion institutions place on culture and the extent to which programs are designed to be culturally sensitive. Had the health organisation known of the attitudes of fear towards cancer, and the lack of knowledge this particular group had about cervical cancer, it might have chosen to conduct community talks addressing such issues before offering free Pap tests. Thus assessing the needs and characteristics of a community before designing a program is essential to ensure successful implementation and better outcomes.

Evidence of the impact of fear of cancer on screening behaviours is supported by findings of a study showing that under-screened

women were more anxious and concerned about cancer than women who did screen (Savage & Clarke, 1998). A study in Melbourne conducted among women from the former Yugoslavia, showed that women were reluctant to talk about cancer and indicated that attending a screening program may well bring on the disease (Gifford, 1990).

Fear observed among the women in this study is, to an extent, an understandable reaction because cancer is a much-feared disease, despite recent medical development (Dignan, 1993). Most of the women interviewed were over 50 years of age (N=10), a fact indicating that they had probably experienced cancer among relatives or friends. It is hard for younger people to understand the emotions of fear these women experience, who have probably seen many people they loved, die from the disease. Consequently, it takes a lot of effort from health professionals to alleviate fears and persuade women to screen for cancer.

Fear of cancer also had positive influences on the screening behaviour of some Greek women interviewed. However, this compliance was accompanied by an apparent lack of knowledge because none knew about the preventive nature of the Pap test. For example, when asked if she knew what the purpose of a Pap test was Ifigenia (S) responded:

"The Pap test is to find if you have cancer, I thought I had to do it after I was 50, I heard the stories and thought I had to do it. When you are young you don't think about things like that".

Ifigenia (S) was scared of cancer thus turned to screening as a way of alleviating her fears about the disease. She continued saying: *"you are at the age now that you have to look out for these things"*, indicating that for her having a Pap test was regarded more as a reassurance against cancer in general rather than an act of preventing specifically cervical cancer. Elina (S) said:

"I do it but to tell you the truth I don't know what it is. The Pap test it seems to me is for the diseases, some diseases, for carcinomas that is what I think, my doctor says I have to do it for my health so I do it".

Elina's attitudes about doing as she was told by her doctor was also mentioned by four other participants, implying that respect for physicians was, for these women, more important than knowing what the test is or why they were having it.

Through the women's words, the relationship of fear of cancer and lack of knowledge about the preventive nature of the Pap test to screening adherence becomes complicated. Fear of cancer among some women predicted compliance to screening and in others led to its avoidance. This finding limits the value of the HBM as an explanatory tool for health behaviour, since the model predicts that fear of disease leads to the uptake of health protective behaviours (Strecher, Champion & Rosenstock, 1997). Furthermore, it is not

clear how lack of knowledge relates to the uptake of screening because in this study both screeners and non-screeners did not know of the preventive nature of the Pap test. Most women, regardless of their screening status, did not see the Pap test as a health-promoting act but rather as a diagnostic tool that detected cancer. Antigoni said (U-S):

"What is that, what test, is it the one they do for the womb? No I have not done anything like that".

"I guess it is [Pap test] to find cancer, cervical cancer" Athina (S)

"What is this test Papanicolaou, tell me first. Is it the one for cancer in the womb..." Eleutheria (S).

The vagueness of how fear and knowledge predict screening only highlight the complexity of human behaviour and emphasises the importance of understanding individuality instead of categorising and labeling people's actions.

Lack of knowledge about cervical cancer and screening in this group could be a result of lack of communication about women's issues among Greek women. According to research, personal experiences and word-of-mouth communication motivates other women to become involved in screening programs (Gregory & McKie, 1990). In their own words, the authors noted that: "one good experience, reported to other women, seems to do more than we might think" (Gregory & McKie, 1990, p.40). However, the findings of the

present study indicate that informal communication among Greek women regarding cervical cancer and screening was not common. The majority of women did not speak between themselves about Pap tests. For example, when asked whether the issue of Pap tests was often discussed among women Elpida (U-S) commented:

"No, I am opposed to that [discussing]. You know if you are not ill I could not say to a woman go and do that [Pap test], or go to the doctor. If someone tells me yes, I am suffering down there, and I have problems then maybe I will tell her something that I heard or read or advise her to go to the doctor".

Fotini (U-S) responded to the same question:

No, we do not speak about these things [Pap tests, cancer], I do not know it is just that the conversation does not turn to that subject. I do not speak about such matters, I do not know the other ladies. Because of embarrassment maybe. When we are all together you will say other things you will laugh and say jokes. This cancer is bad, killing so many people".

Ariadni (U-S) also commented on the same issue:

"To tell you the truth in my circle of friends nobody had such problems so we never talked specifically for this matter [Pap test]. If someone does not have a problem we never talk because these are serious issues".

During the period of data collection for this study, many women who were interviewed contacted the researcher to ask questions about Pap tests, and cervical cancer. A frequent question asked was whether a woman should continue to have Pap tests if she has had a partial hysterectomy. Friends of the interviewees made this inquiry, as no women interviewed had had a hysterectomy. During interviews, more than five women asked questions on behalf of

their husbands about prostate cancer. These observations serve as an indication of the lack of knowledge this population has about health issues and emphasises the continuing need for health education.

The 1989-1990 National Health Survey indicates that awareness of women's health issues, including knowledge of Pap tests, among Greek born migrant women were considered poor, but improving in the younger ages (Young & Coles, 1992). Poor awareness of women's health issues affect screening behaviour as only 62% of Greek born women reported ever having a Pap test as opposed to 88% of all Australian born women. Sixty-two percent also reflects the level of knowledge about cervical screening among Greek-born women (Young & Coles, 1992). Between the ages of 55-64, the percentage of Greek women who had ever had a Pap test or knew of the Pap test was 40% compared to 86% of Australian women (Young & Coles, 1992).

Low levels of knowledge of Pap tests, and the low numbers of Greek women participating in screening, could be a consequence of the lack of knowledge about health promoting information generally in Greek society and culture (Institute of Social and Preventive Medicine, 1995; Maliori *et al*, 1995; Young & Coles, 1992). Obesity and diabetes are prevalent among Greek born migrants, while

lifestyle is considered very poor in regards to exercise (Young & Paul, 1992). There is a high use of sleeping tablets, tranquillisers and painkillers, while the prevalence of smoking among Greek men in Australia is considered very high (Young & Coles, 1992; Culpin, Gleeson, Thomas & Bekiaris, 1996). General Practitioners who participated in the Greek women's Papanicolaou project commented that "the concept of prevention is unfamiliar to Greek women, and they have a reluctance to think about cancer and disease" (Australian Greek Welfare Society, 1996, p.26), issues substantiated in this study. These observations suggest that prevention may simply not be embedded in Greek culture - a fact requiring further investigation if health promotion programs are to be designed for this ethnic group.

Many studies have shown that low levels of knowledge about the purpose of the Papanicolaou test among women of all ages predicted low participation rates in cervical cancer screening programs (Baillie & Petrie, 1990; Swartz *et al*, 1989; Peters, Bear & Thomas, 1989). Lack of knowledge among different ethnic groups regarding Pap tests has also been identified as the principle reason for non-attendance (Ganguly, 1995). A survey of knowledge of and attitudes towards cervical screening in London showed that out of 600 women only 11% knew the preventive purpose of the Pap test while 71% thought it was a test that detected cancer (Swartz *et al*,

1989). Similarly, another study found that only 47% of the 1,416 women who participated in the research knew about the real purpose of the Pap test (Nicoll, Narayan & Peterson, 1991). In an Australian study, 16% of the sample of overseas-born Arabian-speaking women studied did not know about the Pap test and cervical cancer screening (Lesjak, Ward & Rissel, 1997).

A combination of fear of cancer, anxiety and fear of results, lack of knowledge, and a sense of powerlessness women felt towards cancer created a powerful barrier to cervical cancer screening. It is hard to disentangle these factors and to examine them separately because they have an inextricably intertwined influence on screening behaviour of Greek women.

Attitudes towards morality

Greek women in this study consistently referred to issues of sexuality and morality especially when the discussion turned to the causes of cervical cancer. This suggests that, for Greek women, issues of propriety prevailed over health matters. For example, Elpida (U-S) commented:

"You see I don't like the idea girls that start having sexual relationships with men from a young age. Especially the single girls, I do not like the idea at all. I would like to start with one man and stay so you can control him. I think everything starts from there, all the cancers I mean. Here the Australian women from a young age they start having problems with the doctor. It is my opinion that the very young girls begin they sexual life from a very young age. That

is harmful because these organs are delicate they are not for... Now that I was coming in the car there was a program exactly for these kinds of things. Some girls are opposed they want their first experience to be after the age of 21 and to get married. That I like".

Fotini (U-S) answered the question on what needs to be done to avoid cervical cancer with the following words:

"I think the microbe is always there and it depends on how your body will react. In addition, I think it is from the life they lead [women], from sex. They do not take care.... I am sorry I can't tell you more".

Some women volunteered the information that screening was not an issue for them because of their sexual activities at present,

Haroula (U-S) for instance said:

"From what I know multiple partners is how to avoid cervical cancer but I don't really know. I have not given it much thought, it has never been an issue for me to give it much thought. I do not feel that am prone to it [because] I think of the quiet life".

Alkmini (U-S), a young Greek women also cited monogamy as her reason for not having a Pap test in the past five years:

"I do not think it is important for me because I have only had one partner, my husband. Now with the children we are so busy that we have no time for anything anyhow".

Evidently for these women morality and sexuality play a more important role in shaping their attitudes and behaviour than health.

Preoccupation with the causes of cervical cancer diverts attention from prevention and screening.

Greek women's words indicated that, for them, screening for a disease connected to sex could imply a woman's immorality. Pre-occupation with morality is a characteristic observed in the Greek migrant population of Australia. Although the emphasis on women's premarital virginity is waning, it is still influential and Greek women have much more conservative views on the issue than Australian women (Tsolidis, 1995). Greek men are still observed "to adhere to the double standard, being more inclined to expect virginity and faithfulness of their partners but not of themselves" (Tsolidis, 1995, p.137).

Through the discussions it was evident that women knew that sex and cervical cancer were connected, but this relationship was not clear to many women, especially those of an older age, who assumed that only young, promiscuous women were at risk for the disease. Only one woman who referred to sexual matters seemed to have a clear picture about the relationship between cervical cancer and sex. Drosoula (S) a young Greek woman said:

"Cervical cancer can be a preventable disease by not sleeping with anyone without a condom, if you are not married you know what I mean. And by having your Pap tests and nothing could go wrong".

Most women, led by distorted information on how sex and cervical cancer interact, were confident that monogamy and abstinence provided adequate protection from cervical cancer. However,

epidemiological evidence on the causes of cervical cancer indicate that women who are no longer involved in sexual intercourse and those who have had one sexual partner need to be screened since the risk for developing the disease is still high (Brinton, 1992; Holly, 1996). Important, causative factors for cervical cancer are sexual practices of a woman's sexual partner, young age of marriage, number of children, and smoking (Brinton, 1992; Holly, 1996). Facts not known to the Greek women participating in this study,

Preoccupation with morality has two important implications for this study. The first refers to insufficient screening and the stigmatisation that may apply to single, Greek women with positive attitudes towards screening, who might find themselves being characterised as promiscuous for having Pap tests. This suggests a second implication of how single Greek women would feel about a screening program designed for their community when there could be a chance of being labeled by older members. This assumption was reinforced through the women's pattern of referral for other participants for this study. They made a point of suggesting only married women take part in the study because only they would know of such matters. Single women would not be suitable because they knew nothing of Pap tests and they were "good girls" as they mentioned. These observations have been made in other cultures, for example Pacific women in New Zealand. Younger and unmarried

women in this community expressed their concerns about having Pap tests especially in an organised program because of the sexual connotations attached to screening by older women (Jameson, Sligo, & Comrie, 1999).

The women in this study did not discuss sex in detail. When the discussions turned to sexual issues many women chose to end the interview with comments like those made by Fotini (U-S): "...oh I can not tell you anything more about these things" and Olimpia (U-S): "...I do not know anything else I am sorry" indicating the sensitivity of the topic. The age of the researcher could have also influenced the women during discussions related to sexuality. Women were probably uncomfortable talking to a single, young, Greek woman about sexual matters.

The presentation of cervical cancer as a disease for the promiscuous reinforces the interconnection between emotional and cognitive components of health attitudes. According to Quilliam (1990), associating cervical cancer with promiscuity leads to consequences for women with positive Pap results. "Especially when women receive a positive test result, they often experience feelings of guilt about past sexual experiences with many women feeling they are being judged by family, friends, and health professionals" (Quilliam, 1990, p.31). In general, the role of sexual attitudes in connection to

cervical screening has not been widely analysed in the literature and only a few studies have addressed the issue (Harokopos & McDermott, 1996; Braun & Gavey, 1998; Quilliam, 1990; Dignan, 1993; Hurley, 1993; Hubbell *et al*, 1996). Some of these studies place responsibility for portraying cervical cancer as a disease of the promiscuous at the door of the media, which are accused of confusing women by not clarifying the exact causes of the illness (Harokopos & McDermott, 1996; Hurley, 1993).

Lack of communication about screening issues may also be the reason that cervical cancer is connected in such a way to sex. This issue was prominent especially among younger Greek women, who indicated that their mothers did not speak to them about screening or anything implying a sexual nature. For example, Asimina (U-S), a young Greek woman commented on the cultural conventions associated with sexual matters:

"You cannot talk about things like that especially with older women. It is a private issue, which is not discussed. Obviously, women do not have Pap tests because they do not have the knowledge. It is like... talking about sex. They do not like talking about sex for the same reason because it is not something you talk about you just accept it and you deal with it yourself. Pap tests are the same, they should have more information they should have programs explaining these things to Greek women."

Athina (S) reinforced this finding:

"We never had the time [with the mother] to talk about these thing. It was also a communication barrier. We did not sit and talk about things like that, embarrassing things. She thought [mother] we

would find out for our selves. It took me though a couple of years after I had my children to make the time to have a Pap test".

Haroula (U-S) indicated about her own daughter:

"I have grown up in such a way that these things were never spoken of and I have never spoken about them even with my daughter at this age when she is married and I do not think I would either when she is older. I do not know at what age to start doing this test. Honestly I do not know at what age to start off checking these things".

The implication of not discussing screening is that such topics remain hidden, providing unspoken support for the association of screening with "bad" women. When information is not exchanged, screening remains an unknown topic for women and becomes a taboo subject like sex. Consequently, the likelihood of compliance with recommendations to screen regularly for cervical cancer is diminished.

Preoccupation with morality, sexuality, and lack of communication regarding screening issues among Greek women highlight the necessity for health promotion programs that address these aspects of Greek culture, since they have such an impact on health beliefs and behaviour. An intervention program, for example, could focus not only on educating Greek women about cervical cancer screening, but also on sexuality and women's issues in general. Furthermore, the findings of this study highlight the importance of private, non-threatening environments in which all health promotion

activities should be conducted. The importance of privacy for Greek women has been observed during the Greek Women's Papanicolaou Project (Greek Women's Papanicolaou Project, 1996). The program coordinators organised separate seminars for men and women about cervical cancer, incontinence, and sexuality in the middle years. Surprisingly, as the authors commented, the seminars were attended mostly by men interested in incontinence, while women's seminars were cancelled because of low participation. They concluded that the sensitivity of the issues presented was probably the most important reason why few women attended. They agreed that it is important to educate Greek women in Australia about screening in "safe environments in which to discuss issues that are considered taboo in the Greek community. Strategies targeted to smaller groups in their local area could be considered to provide such an environment" (Australian Greek Welfare Society, 1996, p.16). Their conclusions reinforce the findings of this study regarding privacy indicating their generalisability to the larger Greek population of Australia.

Attitudes towards heredity

Although genetic inheritance is not an established risk factor for cervical cancer, Greek women considered heredity to be an important cause of the disease. In general, disease and susceptibility to disease, in particular cervical cancer was perceived

to be related to who a woman's parents were and in the condition of their health rather than the influence of any external factors. If cervical cancer (and not cancer in general) was not in the family, peace of mind prevailed and concerns about susceptibility were not aroused. Consequently, the women in this study did not see themselves as being eligible for screening. For example, Haroula (U-S) expressed the following thoughts about the issue:

"I think the fact that it is not in the family [cervical cancer] gives me a little peace of mind. If it was in the family I would be a little bit more worried and screen more often".

When asked if she felt prone to the disease and about how much she knew of Pap tests Olimpia (U-S) responded:

"No, no the doctor never told me anything and on the other hand I never had anyone in the family who suffered from that kind of disease and so I say how can it be that I will get it. I know it is not right but..."

Elpida (U-S) commented:

"I have not had a Pap for many years [because] I do not like having them. We do not have diseases like that in our family, never anything like that. In my mind, it seems that I do not need anything since I do not have complications".

She continued:

"... Unless it is hereditary. If it is from the family, disease from the family and you have taken the same blood then I guess it is more important [to have Pap tests]. But my mother never had anything like that, she never went to the doctor".

These findings indicate, once more, the lack of knowledge Greek women have about screening and the disease, since heredity is not considered a direct cause or risk factor for cervical cancer. No

evidence was found in the literature to support the hypothesis that the illness is more prevalent among the daughters of those women who died or developed cervical cancer. The most probable causative factors for cervical cancer are primarily behavioural and possibly environmental (Mera, 1997; Brinton, 1992; Holly, 1996). Nevertheless, offspring of people who have died of any form of cancer are considered to have more chances of developing malignancies, but epidemiologists stress the fact that heredity and genetics alone cannot account for all cancers and it is rather the interplay of behavioural, environmental and genetic factors that trigger cancer (Mera, 1997).

The finding of this study that hereditary factors are used as rationalisations for avoiding screening are significant because little has been reported about this feature of health behaviour in the literature. A study about older women's representations of cancer (Savage & Clarke, 1998) showed that participants considered heredity and family history as causes for cancer and the authors suggest that these assumptions may lead to lack of screening (Savage & Clarke, 1998). The emphasis on family history and its involvement as a cause for disease is a trend followed in academic literature (Savage & Clarke, 1998) but also in popular literature and the media, where the relationship is not adequately explained. The result of this emphasis on heredity "may give some women a false

sense of security, if there is no cancer in the family" (Savage & Clarke, 1998, p. 541). This false sense of security can lead people to think they are not prone to a disease because the family has had no instances of the illness. Greek women in the present study confirmed this false sense of security. They misinterpreted notions about heredity and rationalised that lack of cervical cancer in particular in the family is protection enough and that screening is unnecessary. It is difficult to avoid the conclusion that lack of knowledge about cancer, the purpose of screening, and lack of health promotion in general, are responsible for Greek women refusing to have frequent Pap tests.

Lack of visible symptoms

Another prevailing attitude among most of the Greek women who did not screen was their notion that lack of visible symptoms indicated no need for a Pap tests. For example, Elpida (U-S) said:

"I don't have complications, there is nothing that says that I have to go to the doctor, I don't like it. I always felt very healthy in that part of the body, so I never thought of going to have anything like a Pap test. I started out healthy. Not like some other people that are always sick and then the situation just gets worse. I would never go unless I had some sort of warning".

Asimina (U-S), a young woman who had not screened for many years commented:

"It is out of mind out of sight, I have not really thought of it, I suppose it is ignorant of me, I have not had any problems that way so I sort of put it out of my mind I should go every year but I

don't... I do not really think about it. I am not sick that often so I do not think about going to the doctor just for that. It tends to slip my mind, unless I have a problem and then I say I should go and have a Pap test".

Fotini (U-S), who has been living in Australia for thirty years explained:

"... You know I am not afraid because I think there is nothing wrong with me, I cannot see anything wrong. Some women you know took pills so they do not have children. I never took anything like that. I never did any of those things".

Clearly, these women do not have adequate knowledge about cervical cancer. The prevalent belief is that medical attention is needed only when there are visible symptoms indicating something wrong. This assumption is false according to the pathology of cervical cancer. Visible symptoms during the pre-invasive and early phases of the development of the disease seldom appear (Mera, 1997). Once invasive cervical cancer has affected the cervix, warning signs are vaginal bleeding between periods, post-menopausal and post-coital bloodstained fluid, and vaginal discharge (Mera, 1997). Symptoms of advanced disease include pelvic pain, abdominal and back pain, lack of appetite and weight loss (Mera, 1997). Cervical cancer need not develop if pre-malignant abnormalities are treated in time, but the only way of detecting abnormal cells is by having regular Pap tests. However, the attitude of Greek women towards screening limits the chances of pre-malignancies being effectively detected and treated therefore increasing the possibility of invasive cervical cancer.

The fact that lack of obvious symptoms and signs of cervical cancer affected Greek women's intentions of seeking screening could be a result of conceptions about the nature of the illness in general. In particular, it reveals attitudes about seeking medical help and assumptions about what constitutes sickness. This accords with previous studies indicating that people have assumptions about illness that affect their health behaviour (Leventhal & Nerez in Savage & Clarke). In psychology, these mental processes are known as illness representations (Croyle & Barger, 1993). People assess information from a number of different sources (bodily experiences, past illness experiences, social and cultural influences) and create an individual mental representation or illness representation about what disease and health is (Leventhal, Nerez & Steele, 1984). Such representations play an important role in how people seek medical attention, and consequently how people screen (Skelton & Croyle in Savage & Clarke, 1998). According to Savage and Clarke (1998), who conducted a study based on the theoretical framework of illness representations, how a person identifies an illness and what is thought to cause the illness, directly influences screening behaviour. The way a woman identifies a disease for example will predict whether she will seek screening for cervical cancer. Greek women in this study identified cervical cancer as being manifested with symptoms and absence of such symptoms

indicated no reason to screen. For example, Elpida's (U-S) point of view was common among under-screened women:

"Even a little sign will make me run to the doctor but now there is nothing..."

Evidence about how lack of visible symptoms affect screening behaviour are found both in studies investigating Pap test uptake and use of mammography for breast cancer (Lane, Polednak & Burg, 1992; Elkind, Haran, Earderly & Spencer, 1989; Savage & Clarke, 1998). Women in all these studies indicated that they saw no reason for screening since there were no alarming signs to suggest something was wrong.

These findings have implications for health promotion. It is important when designing health promotion programs for Greek women to understand attitudes of illness representations, to build strategies to change misconceptions about cervical cancer and to explain the preventive nature of the Pap test. Greek women's screening behaviour will not change if their attitudes towards cervical cancer are not changed.

Conclusion

Many factors influencing decisions to participate in screening among the women of this study were raised in this chapter. Fear of cancer

that had positive and negative influences on screening behaviour, and attitudes of fatalism, brought to focus the influence of emotions in shaping screening behaviour. Other issues raised were: pre-occupation with morality and misconceptions about the relationship between cervical cancer and sexual behaviour; heredity; and incorrect assumptions about the symptomatology of the disease. These findings reveal Greek women's illness representations showing a lack of knowledge about the purpose of screening. Lack of communication about screening, and issues of privacy were also raised during interviews indicating that these issues have an important role in shaping women's attitudes towards screening.

All findings were supported by evidence in the form of direct quotes from the Greek women and contextualised in relevant background literature. The main findings of this chapter are presented in Figure 2.

Figure 2: Summary of Greek women's conceptualisation of cervical cancer screening

- **Fear of cancer**
 - ⇒ Positive influences on screening behaviour. Women were scared of cancer and screened as a result.
 - ⇒ Negative influences on screening behaviour. Women feared cancer and feared what a Pap test might show thus choosing to avoid cervical screening.
- **Fatalism**
 - ⇒ Negative influence on screening. Screening for these women was not regarded as protective because according to their beliefs health is a matter over which only God has control.
- **Lack of knowledge**
 - ⇒ Lack of knowledge about the purpose of the Pap test was found among both women who did screen and those who did not. For Greek women this test was a diagnostic and not a preventive tool.
- **Morality/Sexuality**
 - ⇒ Misconceptions about the relationship between sex and cervical cancer caused women to feel less susceptible to the disease and consequently led them to inadequate screening. These findings indicate that Greek women were preoccupied with issues of sexuality and morality rather than health matters.
- **Heredity**
 - ⇒ Misconceptions about the relationship between heredity and cervical cancer caused women to feel less susceptible to the disease and led them to inadequate screening.
- **Lack of visible symptoms**
 - ⇒ Misconceptions about the symptomatology of the disease led women to think they did not need screening because of the lack of evidence that suggested something was wrong.
- **Lack of communication about screening**
 - ⇒ Screening and cancer were not issues of discussion among women and among mothers and daughters making these taboo subjects.

This chapter has focused on Greek women's attitudes to cervical cancer and the extent to which attitudes and knowledge influence willingness to screen. However, a significant part of the jigsaw of women's feelings and reactions concerned the process of screening itself. This brings into sharp profile the role of health professionals, which provides the subject matter of the next chapter.

CHAPTER SIX: THE ROLE OF HEALTH PROFESSIONALS IN CERVICAL CANCER SCREENING

Introduction

"My problem with Pap tests is the doctors, they have to be more sensitive because we are sensitive". These are the words of Ariadni, a young Greek born woman living in Perth. In her own words, she drew attention to the involvement of doctors and their contribution to the creation of negative attitudes towards cervical screening. Her attitudes towards the role of doctors in screening were representative of the majority of women interviewed. They identified that an important barrier to screening was the negative behavior of doctors. A significant theme in the interviews was that a single stressful event could make women avoid having Pap tests in the future.

In this chapter, women's negative experiences with doctors are discussed and the influence of these experiences on future screening behaviour analysed. Other themes, which emerged from the interviews, were distrust towards general practitioners (GPs) and confidence in specialists, and distrust and lack of knowledge regarding women's health centres. Each of the themes is presented in detail supported by direct quotes from the women and background literature.

Doctors' negative attitudes

Five of the women who were not adequately screened revealed that the main reason for not having Pap tests was dissatisfaction with the doctor who was taking the test. A crucial finding was that women were deterred from regular Pap tests by a single negative event that caused them to experience embarrassment, fright and anxiety. Asimina (U-S) recalled her experience when visiting her doctor for a Pap test.

"The last couple of times I had them [Pap tests] it was not a very pleasant experience for me because well...it was a very big room and though it was a woman doctor she put me in this big chair where you put your legs up and I felt a little bit intimidated. After that I did not like going any more and because I have not been to anyone else I guess it remained in my mind that, that is what they do always which I don't know if it is true, I have not had one since."

It is obvious that Asimina felt threatened by the situation, which was, on its own, enough to make her refuse other tests in the future. She continued:

"Because you are just sitting there for the world to see. I was imagining there was a camera opposite the wall and I thought oh what if they are filming me, it was just a little bit funny for me and I did not go back since".

Elpida (U-S) said:

"I went to the doctor because I was burnt down there and when you go of course the doctor asks you how it happened. I told him and together with the treatment, he did that too without telling me [Pap test]. Since then I have never had another one. I tell him you fooled me once, not again. The answer came to my house and I did not know what it was. I told myself I never did anything like that, I must have done it without knowing it".

In addition, she concluded:

"The procedure is delicate, something that I don't like. I did not like things like that ever since I was young, I will not go again".

Other women mentioned that after the stressful event with the doctor they experienced emotions like pain and fear and avoided any further contact with the doctor for a Pap test. Olimpia (U-S) pointed out:

"I use to go to the doctor when I was in London. I use to go every two years. When I came here 11 years ago, I did it once. As I told you I went and then caught an infection from the procedure. I had to go to another doctor to give me the right medication. Since then I became scared and I never went back".

According to the women, responsibility for the negative experience is placed on the doctor who conducted the examination. The doctor is perceived more as a threat, as someone who fooled her into having a test, as Elpida (U-S) said or made her feel uncomfortable and caused her pain as Antigoni (U-S) and Olimpia (U-S) pointed out:

"Ever since he fooled me into having a Pap test I have never gone back".

"No, no I don't want to go, I am not comfortable with what happened and I don't want to go".

"I see it frequently on television but because of what happened that time I am scared and I never go, I don't want to go".

It is obvious from the words of the women, and also ironical that the health care provider is, in fact, the barrier to screening. Some women, for example Antigoni (U-S), Elpida (U-S), and Olimpia (U-

S), revealed that after the stressful incident with their doctor 10 years had passed in which they had not had a Pap test. As a consequence, these women now belong to the high-risk category of the under-screened. Epidemiologists accept that most women who develop this disease are those who avoid having regular Pap tests and studies have found that the majority of women diagnosed with cervical cancer have not been screened in the last five years. (Chomet & Chomet, 1991; Peters, Bear & Thomas, 1989).

Failure to receive regular Pap tests caused by barriers raised by other people, in this case the doctor, are referred to as social barriers (Peters, Bear & Thomas, 1989). Apart from doctors, a study in the USA identified also, the husband, family, and friends as social barriers, which influence a woman's decision to have a Pap test (Peters, Bear & Thomas, 1989).

Whilst it has been well established that a range of barriers inhibit screening, the significance of this study is that it has revealed the importance of a single event and the importance of the doctor's behaviour during this event that influence women's screening intentions. This could be a function of two reasons. The first reason stems from the loss of trust in the doctor, who is, for Greek women, an important authority figure. According to research, Greek women in Australia show great reliance and faith in doctors (Australian

Greek Welfare Society, 1996). This characteristic is consistent with findings from the Australian Bureau of Statistics indicating that Greek women are second highest among women in Australia to consult a doctor in a given two week period (Young & Coles, 1992). The second factor refers to cultural barriers that exist towards gynaecological procedures observed among Greek women in Australia (Australian Greek Welfare Society, 1996). These two reasons in conjunction (loss of trust of an important figure in the process of a pelvic examination) can account for the stress caused to Greek women in the study which resulted in refusal to have further Pap tests.

The words of the women regarding negative experience with doctors are confirmed by the following studies that identified the physician as a major barrier towards cervical screening. Schwartz, Savage, George, and Emohare (1989), examined women's experiences of cervical cancer screening and revealed that 54% of their sample found the procedure painful or uncomfortable. They concluded that this might be attributable either to the technique of the doctor or the women's anxiety that prevents them from relaxing, resulting in distress and pain. Lack of support from the doctor does not lessen the stress and in most cases, women do not return for other tests. Further evidence may be found in Honig (1996) who developed a cervical cancer-screening project for women of non-English

speaking backgrounds and reported that women expressed negative attitudes towards screening because of fear from a previous bad/painful experience. A study conducted in New Zealand showed that for the participants the nature of the relationship they had with the doctor, predicted their screening behaviour (Broadmore, Carr-Gregg & Hutton, 1986). Many participants in the same study recalled their last vaginal examination as being unpleasant and uncomfortable (Broadmore, Carr-Gregg & Hutton, 1986).

Lack of support and counseling

Women in this study did not receive any sort of counseling or reassurance from their doctor after the stressful event they experienced, although this was very important for their future screening behaviour. The women interviewed did not have a chance to discuss with their doctor the event that created their negative attitudes. There was no opportunity to alleviate the women's fears and possible misunderstandings that could have changed their behaviour towards cervical cancer screening.

Antigoni (U-S) described how her last visit to the doctor went. She was very embarrassed to talk about her experience and the reasons she had not gone to the doctor for a Pap test for the last ten years.

" I was very annoyed by the procedure. I hurt a lot that is the truth. It was so annoying that I never went back. Last time the doctor had

to leave it because I could not take it when he put that in.... That was the mistake. It was okay in the beginning but when he put that thing, in to take out the sample I could not take it. I could not let him put in that metal object. I left it and never went back”.

Despite the obvious trauma, the doctor did not discuss the matter with her: “ *No, he did not say anything to me. He told me that I am too old for such a thing and can do without it*”. The woman at the time of the incident was 50 years old and married. The incidence of carcinoma in situ is higher among older women and epidemiological evidence shows that married women have higher chances of developing the disease (Mera, 1997). The consequence of the doctors’ behaviour was to relay inaccurate health promotion messages. The health of a migrant woman, who had limited knowledge regarding screening and cancer, could not speak English, and was obviously scared and upset, did not give the doctor sufficient reason to provide reassurance and comfort to her. Antigoni (U-S) has not screened for cervical cancer since. In her exact words she said:

“No, I know that this has to be done [Pap test], but because I was hurt and I am not comfortable now with things like that, I do not do it. Otherwise I know it should be done”.

Ariadni (U-S) talked about her experience with her doctor that resulted in fear and discomfort and consequently avoidance of Pap tests. In her own words she recalled:

“One reason that I don’t want to have Pap tests is because of the doctor. I went to take the IUD out and the doctor told me that I

have cancer. I told him how can I have cancer I feel fine. Therefore, I do not want to go. It is not that I am afraid of the doctor or embarrassed or anything like that it is the fear of what I will hear. Once I went to have the test and from the moment, the doctor took it something did not go well. I do not know the doctor did something wrong, there was blood or something and the test was not clear. They called me at home after 8 at night and told me that something was not well with your test, that your doctor is not here, he will come in three or four days and come then to have other tests. I went crazy and did not sleep all night. Ever since I did not go again".

Ariadni commented on the exact reasons that led her to avoid screening:

..."My problem is not if it is a woman or a man. My problem is the abrupt way doctors tell you. They should tell you in a more sensitive way instead of telling you straight out that you have cancer. After I went to the specialist, who was Greek, he was much more sensitive. He told me my test results straight away and explained everything. The others tell me straight out. I do not know if it is I but I can not hear such things straight out like that, so I do not go any more. Other people have mentioned this to me as well. They get a shock every time they speak to the doctor".

Obviously, the implication for this woman is that she might have untreated carcinoma in situ, but she did not continue her personal story. Ariadni said she visited a "more sensitive" doctor but continues to postpone having Pap tests, more than three years after the incident. This fact also brings into focus the importance of emotional support to women who receive a positive result. It is vital as Karen Dignan (1993), midwifery tutor in a hospital in Manchester, stated that positive results be discussed with the appropriate support and management. Women should be offered

counseling and support when dealing with this disease because it involves delicate and sensitive parts of the female body.

These stories illustrate some serious implications for screening. It is evident that if doctors had intervened in these situations, fear and distress could have been alleviated and consequently the women could have continued having regular Pap tests. The reasons that physicians avoid counseling have to do with their belief in their abilities to conduct counseling and their belief in how much they can do to motivate their patients to change their behaviour (Martin & Coates, cited in Walsh & McPhee, 1992). Doctors' attitudes towards preventive medicine have also been found to influence the amount of information a doctor gives to her/his patients on preventive care activities (Walsh & McPhee, 1992). Some doctors find prevention boring while they find managing disease much more interesting and challenging (Orlandi, 1987). Others practice preventive medicine only when they find it necessary and vitally important for the patient's health (Dietrich & Goldberg, 1984). Furthermore, it is important to bear in mind that GPs are members of the medical profession and thus work under the biomedical model of health, which pays scant attention to the effectiveness and usefulness of health promotion (O'Connor & Parker, 1995).

Physicians, according to research, become uncomfortable by women who are embarrassed to have tests (Bowman, Redman, Reid & Sanson-Fisher, 1990). If women do not initiate discussion of screening, doctors avoid mentioning it, thinking that there is not much to be done (Bowman, Redman, Reid & Sanson-Fisher, 1990). This phenomenon is observed more with women from ethnic minority groups, and older women. In these groups, communication can become very difficult, explanations about the necessity and importance of Pap tests lengthy and thus not cost-effective (Bowman *et al*, 1990; Heywood, Firman & Ring, 1996). Women from these groups are termed "difficult" patients who require a lot of time and effort on the part of the doctor who chooses, instead, not to address the issue (Heywood, Firman & Ring, 1996).

This problem observed among practitioners can be overcome by educating medical students to practice preventive medicine instead of focusing on states of abnormality (Gifford, 1990; Bowman *et al*, 1990). Furthermore, it is necessary to educate future doctors not only on technical aspects of Pap tests but also about how to understand and communicate with female patients. In brief, there is a need for sensitivity training and the inclusion of women's health issues in medical curricula. If GP's are not able to attend to the psychological needs of women, who are screening for cervical cancer, it is important to explore the need for additional services

provided by health educators, nurses or counselors, who can work with women to overcome problems.

According to the women in this study, the reasons that doctors were not supportive in alleviating their fears about any negative situation were economic in nature. Eleutheria (U-S), Nausika (S) and Ifigenia (S) mentioned that doctors are too busy to explain. Women said that doctors have no time and are always in a hurry to finish the visit, Ifigenia (S) indicated:

"Now doctors. They do not explain anything; they bring you in and out tell you what you have without explaining anything. Before it was not like this. Now because their wages are very small they do not give you much attention. Of course all they want is to finish quickly".

Nausika (S) pointed out:

"How can they discuss things when they have so many people waiting. With me something went wrong and I started crying in front of him, only then did he explain to me what was going on".

Antigoni (U-S) commented after she finished the interview:

"In the past years they [doctors] would help us more. Now they only are concerned how to make more money. The more patients they see the more money they make so they do not sit down to explain anything".

Studies have shown that the reasons behind doctor's negligence in promoting health protective behaviours are indeed economic, but also have to do with lack of time, forgetfulness on the part of the doctor, and, most importantly, organisational issues like inability to

follow women who are late for a Pap test. (Walsh & McPhee, 1992; Austoker, 1994).

Insufficient promotion of health protective behaviours in general practice brings into focus the importance of professional collaboration in health promotion. Indeed, in the context of restricted and diminishing health funding it is not cost-effective for GPs to spend a lot of time practicing preventive medicine. However, preventive medicine itself has been shown cost-effective (O'Connor & Parker, 1995). For example, much of the decline in diseases such as cardiovascular conditions, diabetes, accidents, and cancers can be attributed to prevention (O'Connor & Parker, 1995). To improve the health of populations it is vital for organisations that deal with health to work together. In the case of cervical cancer screening, GPs could cooperate with women's health centres, nurses, social workers and health promotion professionals to develop programs that would target under-screened women in order to increase participation in cervical cancer screening and to make the experience sufficiently non-threatening to ensure repeated visits.

For some women in this study the issue of a female doctor was important but the majority did not regard it as the main problem. Fotini (U-S) commented:

"I have no problem but I have a friend that does not go unless the doctor is a woman. I think she is ashamed".

Some women did not like their personal GP to take Pap tests because the doctor was a family friend; they knew him or her for many years and did not feel comfortable going through the procedure with them. In answering the question whether or not they would go to their GP for a test women responded with comments like the following:

"No I don't feel comfortable so I don't go to him"

"I am ashamed of my GP, he is so much younger than me".

"The doctor is our family friend, I am not comfortable going".

The fact that some women did not feel comfortable being with a younger doctor has implications for screening because research has shown that younger male doctors are more likely to offer screening as opposed to older general physicians (Austoker, 1994).

Cervical cancer screening in general practice

The role of the doctor, as it was raised in the interviews, shows the importance of their involvement in cervical cancer screening. Large numbers of Australian women are in frequent contact with their doctors allowing the opportunity for GPs to educate and promote cervical cancer screening. Within a 12-month period 84% of Australian women, visit their GP for some medical reason (Bowman *et al*, 1990). Australian women aged 20 years visit their GP on

average four times a year while women in their 60's attend a doctor's practice around six times annually (Bowman *et al*, 1990). Greek women have a very high number of consultations with their doctors as was evident from the National Health Survey (Young & Coles, 1992).

Despite this unique position, cervical cancer screening is largely under-utilised in general practice, and many opportunities given to doctors to promote screening are not taken up (Ward & Sanson-Fisher, 1992; Byles, Sanson-Fisher & Redman, 1996; Bowman, Sanson-Fisher, Boyle, Pope & Redman, 1995). A study showed that, out of 374 videotaped general-practice consultations with female patients, doctors mentioned cervical cancer screening only 30 times and only 5% of these were initiated by the GP (Dickinson *et al* cited in Cockburn, Hirst, Hill & Marks, 1990). Even more important is the fact that when doctors do provide Pap tests they are not able to deliver the service in a way that would be comfortable to the women, as is indicated in this study.

There have been some successful cervical cancer screening interventions within general practice (Straton, 1994). However, these are limited to single practices and are attributed to the interest and enthusiasm of a single practitioner, who has demonstrated the ability for better organisation and coordination,

factors that are not easily dealt with when many practices and practitioners are involved (Straton, 1994). A single general practitioner in Scotland achieved an 84% coverage of all eligible for screening women in her Glasgow general practice in five years (Ross, 1989). In New South Wales, a male general practitioner within five years managed an overall screening coverage of 86% among women who were attending his office (Beattie, 1992). A doctor in Western Australia achieved 73% coverage in his practice by reviewing women's histories of screening and targeting those who were under-screened (Brett, 1992). Shroff *et al* (1988) reported 30% coverage after two years in women aged 20-64 in a single practice in Paddington, England.

Programs have also been designed in which general practitioners invited women specifically for cervical screening. These programs provide doctors with the opportunity to give women personal information about screening, and about the process and results of their Pap tests (Reid *et al*, 1991; Pierce, Lundy, Palanisamy, Winning & King, 1989; Havelock, Webb, Queenborough, 1988). The results from such programs revealed an increase in the numbers of participating women, indicating the importance of doctors in sustaining the increase in population coverage for cervical cancer screening (Reid *et al*, 1991; Pierce, Lundy, Palanisamy, Winning & King, 1989; Havelock, Webb, Queenborough, 1988). A study in the

Netherlands showed that a personal invitation for cervical cancer screening by general practitioners achieved an 18% increase in overall attendance (Kant, Palm, Wentink & Van Weel, 1997). Similarly, studies targeting women who were not adequately screened, showed that an invitation letter from a GP was relatively effective in increasing participation (Byles, Sanson-Fisher & Redman, 1996; Bowman *et al*, 1995). According to Austoker (1994), strong predictors of a doctor offering screening to her/his patients were: (a) the younger age of the general practitioner; (b) the more rural practice; (c) larger practice size; (d) employment of a nurse; (e) belief in the efficacy of screening; and (f) a positive attitude to the time spent on cervical screening; (Austoker, 1994, p.243).

The lost opportunities for general practitioners to increase, cervical screening participation was evident in this study. Many women indicated that their GP had never mentioned a Pap test before and thus never thought they needed one. This finding, accords with the HBM and its component of cue to action (Price Easton, Telljohann & Wallace, 1996). The cue for action for many of these women would be a suggestion from their GP and, since this never came, the result was for women to think they did not need to screen. Many women interviewed indicated that they did visit their GP for other health issues, such as blood pressure and stomach problems. There was

thus an opportunity for the GP to intervene and to suggest a Pap test or to explain and alleviate fears caused by a negative event.

For example, Fotini (U-S) indicated:

"I had them three times, I thought I did not need them after that. I was 44 years old and ever since I have been going backwards and forwards to the doctor for my stomach but he never said anything to me".

There is the opportunity for GPs to contribute to the community in terms of population cover of cervical cancer screening. They are exposed to the population more times a year than any other professional, they are distributed in all geographical areas, are familiar with community members and are well respected (O'Connor & Parker, 1995). These advantages can be utilised to developing effective strategies in the community to increase the number of women participating in cervical screening.

The chance for doctors to introduce women to cervical cancer screening in the process of a non-gynaecological visit is revealed through Elina's (S) experience:

"I started doing it six years ago. Until then I was working I had no time, no one had ever told me anything about doing that sort of thing, not even my doctor. After that when I had a heart operation the doctor told me that I had to do all those tests. Only then I was told about this [Pap test]".

Elina followed doctor's orders thinking that somehow the Pap test was connected to her heart condition. She did not really know the

reason she was doing the test or the purpose and use of the results.

In her own words she indicated:

"When the doctor told me that I had to do this thing [Pap test] I hesitated a little but I know that it is mandatory for me to do it, I have to. After I went and did the heart operation, they put the pump in and the doctor said now you have to do this test every two years so as to know if you have an infection".

General practitioners versus specialists

To understand the opinions and beliefs of Greek women, it is important to explain the cultural context of their responses. Screening for cervical cancer in Greece is opportunistic and is performed mainly by gynaecologists both in hospitals and in private practice. Specialists are regarded as the doctors who have the knowledge, experience, and responsibility to perform Papanicolaou tests. These assumptions are reinforced by the fact that in Greece the concept of the general practitioner or the family doctor does not exist (Iatridis, 1990). Patients consult the appropriate specialist according to the nature of their health problem. Primary health care in Greece is "mainly provided by unspecialised, untrained physicians and medical graduates who have to spend a compulsory year in a rural dispensary to have the right to begin specialty training" (Iatridis, 1990, p.182). This background may account for some respondents' strong "faith" in gynaecologists as opposed to general practitioners. Five women (of whom three preferred not to be audiotaped) expressed their preference for specialists saying that

they did not trust general practitioners for screening. For example,

Haroula (U-S) said:

"I have never been to a GP, I prefer a specialist, and I would not like a nurse to take the test because I prefer someone who is highly qualified".

Drosoula (S) commented on general practitioners:

"I would not like to go to a GP for a Pap test because I don't think they know what they are doing. No, because for Pap tests you need a gynaecologist, for your throat you need a throat specialist. Everyone specialises in their field. I go to a specialist when it is time to have a Pap test because I feel that he knows what he is doing".

The prevailing attitude among these women was that only someone who was specialised in an area could be qualified enough to treat their problem. Athina (S) said:

"Of course a specialist is more equipped to do things like that".

This preference could be interpreted in many ways. Women might be positively influenced by the flexibility of specialists to discuss health issues at length and in more detail. For example, Nausika (S) and Agape (S) indicated that they started going to specialists when it became impossible for them to communicate with their GP. They commented that although they had to pay more for a visit they were more satisfied. Nausika (S) in particular indicated:

"Of course a specialist is better and I have more faith in them. The private doctor is very good, I pay and he talks to me for half an hour. The public doctor finishes the visit very quickly".

What can be derived from discussions with women who preferred a gynaecologist for Pap tests is that, communication was no longer a

problem. This contrasts with women who visited GPs for screening and reported anxiety, stress and lack of communication. According to research by Blesch and Prohaska (1991), obstetricians and gynaecologists were significantly more likely to recommend Pap tests than family or general practitioners. Thus Greek women, who choose to consult a specialist for a Pap test, might be expected to be properly screened. The problem is, asymptomatic women are unlikely to visit a gynaecologist.

The preference for a specialist may also stem from the fact that Greek immigrants, like people living in Greece, are not accustomed to the term general doctor. The term "general" could imply to the women that GPs are not really qualified to deal with gynaecological problems. Furthermore, this preference could also be related to the need of these women for privacy and confidentiality. As many younger respondents indicated, Greek women do not want anyone to "know their business". It could be possible that in a private specialist's practice there is less likelihood of identification than in the busy office of a general practitioner. Privacy has been found to affect decisions for screening among other ethnic groups (Gifford, 1990). In a study examining screening practices of women from the former Yugoslavia, participants explained that they would not have a Pap test in the practice of a doctor from their country because their community was so small and as they commented "there is

always the possibility of meeting the doctor at a wedding or other community functions" (Gifford, 1990, p.78). Pacific women in New Zealand expressed concerns about a Pacific Islander smear-taker not being appropriate because of confidentiality issues (Jameson, Sligo & Comrie, 1999).

The implications of choosing a gynaecologist to perform a Pap test are primarily increased visit costs, and the amount of forward planning involved. Gynaecologists usually have long waiting lists requiring long waiting periods for women who choose to attend their clinics for a Pap test. Forward planning, as Haroula (U-S) indicated, meant for her that schedules and priorities changed and consequently the long-scheduled appointment was cancelled. In her own words she indicated:

"With mine I have to make an appointment months ahead and I have to travel a long way to go and see her so I guess...when you make an appointment ahead of time two to three months something comes up and sometimes you have to cancel and that's why I had to put it off anyway".

Clearly, there is a need for Greek women to understand that having a Pap test is a simple, uncomplicated procedure that GP's are highly qualified to deliver. It is also the responsibility of the GP to inform women about the simplicity of performing the test and assure them that any abnormalities can be quickly and effectively treated. On the other hand, health professionals can benefit from the fact that

some women are happier visiting a gynaecologist although they had to pay more money. This preference could indicate specific strategies that specialists follow in order to make women more accepting towards Pap tests. These strategies should be reviewed by health promotion professionals to be replicated by general practitioners for the benefit of women. The indication is that privacy and length of appointment are significant factors.

Women's health centres

"To me I don't like going to places like that [Women's health centres]. I prefer a private situation the doctor I know and I feel comfortable that way. I would not go to a place like that, to a clinic like that, no".

In these words Haroula, drew attention to women's health centres that have been operating for many years in Western Australia. Haroula, expressed her distrust towards centres, although she did not know exactly what they were. The lack of understanding about the real services that women's health centres provide can account for the fact that none of the 15 women interviewed had ever visited a centre and did not know where one was. After the discussion on women's health, centres two of the women indicated that if they knew where one was and if they had company, they would make a visit.

Women's health centres are public organisations that provide holistic services for women. The philosophy behind them lies in the feminist movement and specifically in the assumption that a patient's health should be treated holistically and that process – how people are treated, is as important as health outcomes (Hunt, 1997). Better outcomes can be created if patients are encouraged to plan their own strategies based on self-determination and self-responsibility (Van Den Brink-Muinen, 1998). This can be achieved if one takes into consideration both body and lifestyle (Van Den Brink-Muinen, 1998). Women's health workers are not simply doctors who are concerned with women's health. They are driven by an ideology that people's health is influenced by social and psychological factors and that in dealing with them it is necessary to address all problems rather than concentrate strictly on the medical aspect of the disease. In dealing with health problems all aspects of a woman's life are considered and treatment includes dealing with social, psychological, and economic factors that influence women's lives and contribute to health problems (Hunt, 1997).

Privacy is an important issue for Greek women, which may account for their dislike of health centres, and the fact that none of the women knew of the existence of any centre nor had they ever visited one. As Afroditi, a young woman who did screen said, Greek women would not attend such places because of fear that everyone

would know that something was wrong. She commented that even a program specifically for Greek women would not be successful because of lack of privacy. Specifically she commented:

"I do not think that women's health centres would be able to attract Greek women to have Pap tests. I think they are pretty funny about people knowing their business, they are not very approachable. They would not like to be seen in public. I think they would be more comfortable going to an Australian program if there were any instead of going to a Greek one. I am thinking of women from my generation and a little older. I do not think a Greek program will help".

The dislike Greek women showed towards health centres and in some cases even nurses come as a contradiction to the findings of researchers, who indicate that women prefer nurses in women's health centres to take Pap tests (Kingston, 1987; Standing & Mercer, 1984; Bowman *et al*, 1990). According to some authors (Denny, Koren & Wisby 1989; Blesch & Prohaska, 1991) nurses have the ability to provide effective cervical screening by emphasising the personal need of elderly women to maintain their dignity. Research has also shown that nurses' abilities in taking correct Pap tests are more than satisfactory. For example, Kottke & Trapp (1998) conducted an analysis of all Pap tests submitted to a pathology laboratory. They found that 70.8% (95% CI = 75.9-83.7) of specimens provided by nurses were wholly satisfactory. The researchers concluded that nurses, after one week of training, can collect Pap tests specimens that are of the same quality as those collected by physicians (Kottke & Trapp, 1998).

Studies conducted among ethnic non-English speaking women confirm the findings of this present study. Among older Italian and former Yugoslavian women living in the western suburbs of Melbourne, a dislike was indicated about nurses and other health care providers taking Pap tests (Gifford, 1990). Another study found that, although women knew of the existence of health centres in their area, they did not consider them to be an appropriate place for screening because these were seen as places which provided social and general medical services (Temple-Smith, Banwell, Gifford & Presswell, 1995).

In practice, women's health centres are able to provide answers to Greek women's concerns and problems but this is not possible when there is a lack of understanding among them about the functions of such centres. It is important to educate women about the services and work such centers provide. From the accounts of women about negative experiences with doctors, it is evident that there is a need for them to talk, express concerns, be understood, and reassured. Even more important these women need to understand the necessity of screening, and the usefulness and purpose of the Pap test. If general practitioners are unable to perform these functions, women's health centres can and will because they are designed to meet such needs.

Conclusion

Five out of the seven Greek women who did not screen for cervical cancer described a negative event that occurred with their doctor in the process of taking a Pap test, as the primary reason for not screening for cervical cancer. The chapter has analysed the process that led from this negative event to the women rejecting further screening. Further themes that emerged from the discussions were the preference of Greek women for gynaecologists, as opposed to general practitioners, and the lack of trust, in and knowledge about women's health centres. The examination of these themes was illustrated with direct quotes from the women interviewed, and appropriate literature was reviewed in support of the findings. The main findings of this chapter and their consequences for screening are summarised in Figure 3.

Figure 3: The role of health professionals in shaping cervical screening behaviour among Greek women

- **Negative event with doctor**
⇒ Avoidance of screening because of fear of repetition of the negative experience.
- **Lack of support and counseling after the negative event**
⇒ Negative feelings were not dealt with by the doctor leading to repetitive avoidance of screening.
- **Doctors failing to emphasise cervical screening**
⇒ Women were not aware of the importance of having Pap tests because doctors failed to emphasise the necessity of frequent cervical screening.
- **Preference for a specialist as opposed to a GP**
⇒ Specialists require long waiting lists and are more expensive resulting in women missing and postponing screening appointments.
- **Dislike towards women's health centres and nurses**
⇒ Lost opportunities for education about cervical screening and dealing with negative screening experiences.

Having explained the key issues for cervical cancer screening among Greek women in Perth, the next question is: So what? What are the implications for health promotion? What do the findings of this study suggest about future health promotion programs for this population in particular and for ethnic minority women in general? What implications do the stories of the Greek women in this study have for traditional models of explaining health behaviour such as the HBM? These issues are taken-up in the next chapter.

CHAPTER SEVEN: IMPLICATIONS AND CONCLUSIONS

Introduction

The views of the respondents have implications for future strategies to increase screening participation in this group. Further the findings suggest a number of inconsistencies in the explanatory power of the HBM. These primarily concern the components of the model regarding fear and susceptibility to disease. Indeed, the identification of the practices, attitudes and knowledge of Greek women in Perth regarding cervical screening and the exposure of the barriers hindering this protective health behaviour suggest modifications to the application of the HBM. This chapter draws out the implications of the findings for the HBM and suggests future directions for research.

Implications for the HBM

The HBM provided this study with a framework for understanding screening behaviour, however, the analysis revealed many limitations in its explanatory power. The HBM leads health professionals to think in terms of personal motivations to explain and predict health behaviour. For example, the model states that people's *perceived susceptibility* and personal assessments of the *seriousness* of disease as well as *perceived barriers* and *benefits* of health action predict adherence to recommended protective health

behaviours (Strecher & Rosenstock, 1997). From the women's words, though, it became evident that different factors to those suggested by the model explained their screening behaviour. Greek women's screening behaviour was shaped by personal perceptions of Pap tests which, in turn, were influenced by culture, religion and doctors. Cultural beliefs about sexuality, religion, and experiences with significant others, such as doctors, provided the filter through which women assessed health issues and determined how they chose to react to them.

It was not possible, thus, to assign most findings to the pre-determined categories of the HBM because they did not correspond clearly to any of its sub-scales. Experiences such as the importance of a single negative event during a gynaecological examination, or the negative behaviour of doctors, and distrust towards GPs and women's health centres, were hard to theorise in terms of the HBM.

Lack of communication among women, illness representations, placing low value on preventive medicine, and negative feelings about promiscuity and sex were prominent attitudes revealed through interviews. These observations, although not fitting any of the HBM components, had significant implications for screening and did affect women's decisions about the frequency of Pap tests. These findings illustrate how compliance with models such as the

HBM can limit the power of research to reveal new information. While a theoretical framework is helpful in guiding research information, which gives new directions for knowledge, can be brought to bear in a re-evaluation of the theoretical model.

An example of the limitations of the HBM as an explanatory theory may be provided by the findings concerning fear of cancer. Fear of cancer was found to have negative and positive effects, leading some women to adopt and others to avoid screening. For women who did screen, fear could have been a product of subjective evaluations concerning the seriousness of the disease and the seriousness of leaving the condition untreated. In the HBM, this is referred to as *perceived severity* (Strecher, Champion, & Rosenstock, 1997; Strecher & Rosenstock, 1997). However, it could also have been a simple case of seeking reassurance from screening, especially when these women were over 50 years of age. The concept of reassurance extends the explanatory value of the HBM.

For women who did not screen, fear was a major influence on their decision not to have Pap tests. They feared "the bad thing", "the cancer", "what might be there" and chose not to know of its existence rather than to have to deal with a positive result. These women saw cervical cancer as a serious disease but this affected

their screening behaviour in a manner contrary to that predicted by the HBM. This calls into question the value of modeling health decision-making and behaviour, particularly in diverse cultural contexts.

The assumptions underlying HBM categories do not correspond to the feelings and experiences of the women described in this study. However, the most recent version incorporating diverse demographic, sociopsychological, and structural variables could provide a framework in which to analyse emotions and experiences of fear. Although, according to Strecher and Rosentock (1997), sociopsychological, demographic and structural variables are believed to have only an indirect effect on behaviour, this study suggests a much stronger relationship.

One component of the HBM, which clearly predicted non-adherence to screening, was *susceptibility* to disease. According to the theory, the level to which a person feels susceptible to a disease predicts compliance to health protective behaviours (Strecher, Champion, & Rosenstock, 1997; Murray & McMillan, 1993; Harokopos & McDermott, 1996; Strecher & Rosenstock, 1997). However, while the model predicts that lack of susceptibility to disease affects the uptake of health protective behaviours, it does not provide a framework for analysing the specific reasons, which lead people not

to feel prone to disease. In this sense, the knowledge base of the HBM is incomplete. The significance of this study is that it explains lack of susceptibility in detail revealing that views on susceptibility are influenced by morality, heredity, and the lack of visible symptoms. This indicates a need to disseminate clear information about cervical cancer and screening.

A recently introduced category of the HBM '*cues to action*' was confirmed as a predictive tool for health behaviour. According to the model, factors that trigger and give cause for action such as bodily changes or environmental indicators, like the media, can influence women's decision to participate in screening (Strecher, Champion & Rosenstock, 1997; Strecher & Rosenstock, 1997). General practitioners could have served as important cues for action influencing and reminding women of their need for screening. Most women in this study, though, revealed that their doctors rarely or never mentioned cervical screening. Their doctors failed to provide the '*cues to action*'. When they did, women conformed, even without understanding the nature of the test. The question is: Is compliance enough? The knowledge dimension of the HBM and this study suggest not. Sound information is what leads to informed health decision-making.

In-depth examination of the reasons Greek women avoided cervical screening was possible through qualitative analysis, which provided the means to explore responses and to understand the origins of women's attitudes. These attitudes were complex, difficult to disentangle, label and categorise, reinforcing the critiques of models, such as the HBM, which question their ability to understand human diversity in health decision-making.

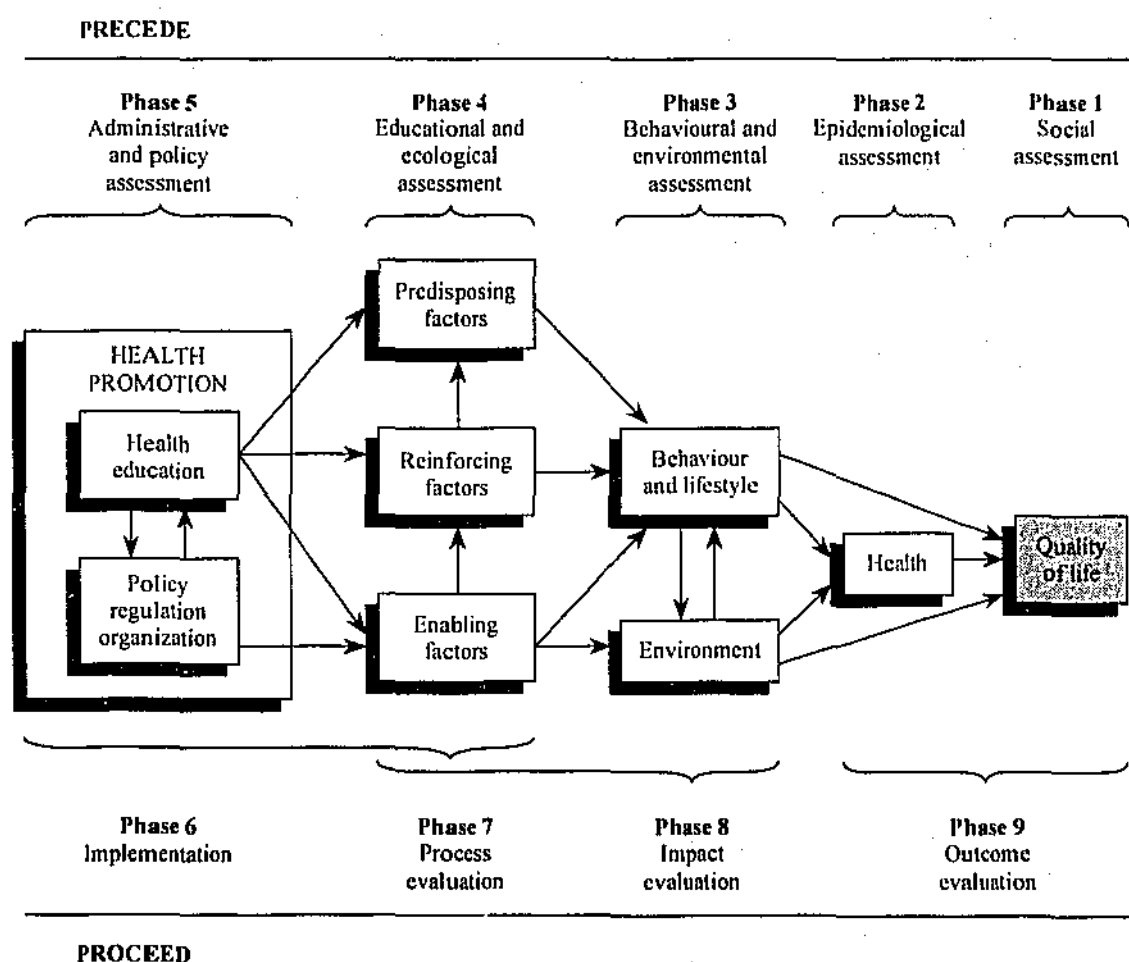
Implications for health professionals

The identification of the characteristics, needs and problems of Greek women regarding cervical cancer screening while not applicable to the whole Greek migrant population of Australia can lead to intervention suggestions to improve screening. Because the HBM, the theoretical model used in this study, is a tool for diagnosing and predicting health protective behaviours, a health promotion model is needed at this stage to guide intervention suggestions. This is the PRECEDE-PROCEED, model.

The model originated in the 1970s. It was developed in order to improve health education interventions by offering a systematic planning process (Carlson-Gielen & McDonald, 1997). PRECEDE is the assessment phase of the model and stands for *predisposing, reinforcing, and enabling* constructs in *educational/ecological diagnosis and evaluation* (Green & Kreuter, 1999). PROCEED is the

developmental phase of planning which follows assessment and refers to *policy, regulatory, and organisational constructs* in *educational and environmental development* (Green & Kreuter, 1999). The model is divided into nine stages (see Figure 5). The ultimate goal is quality of life, which is used as a starting point for planning based on the assessment and diagnosis of the characteristics of the target population (Green & Kreuter, 1999).

Figure 4. PRECEDE-PROCEED PLANNING MODEL.



Source: Green & Kreuter, 1999, p.50

Health promotion strategies according to PRECEDE-PROCEED are designed after health problems are assessed, behavioural, environmental diagnosis is conducted, and predisposing, reinforcing, and enabling factors are examined, a process already conducted during this study. It is important to explain the process and present the factors on which the suggested strategies are based on in order to clarify the structure of the health promotion recommendations arising from this study. Further, the model provides a framework to summarise the key findings of this research. For example, phase 2 of PRECEDE, epidemiological diagnosis, requires a descriptive analysis on the extent and nature of the health problem identified with the presentation of epidemiological evidence (Green & Kreuter, 1999). This was done in the introduction to this thesis, which indicated that:

- Cervical cancer is the sixth most common cancer in Australia.
- 340 women die from the disease each year.
- 1,000 new cases are diagnosed each year.
- Over half the cases of cervical cancer occur in women who do not screen.
- In Australia women who do not screen come from a non-English speaking background, including Greek women.

Phase 3 of PRECEDE is an analysis of the behaviours associated with the health problem. Chapter 4 described Greek women's views on

the causes of cervical cancer. In part, these reflected emerging, but inadequately substantiated, epidemiological evidence including age of marriage, number of sexual partners, age of first intercourse, smoking of tobacco and the existence of sexual transmitted diseases (Brinton, 1992).

Inadequate screening has been identified as the most serious contributor to cervical cancer (Mera, 1997) and is thus a priority behaviour for intervention particularly when applied to underscreened groups like Greek women in Perth because:

- Greek women are unrepresented in screening programs. Sixty two percent of Greek born women have had a Pap test as opposed to 88% of Australian born women (Young & Coles, 1992). In the ages between 55-65 the percentage of Greek women who have never had a Pap test is 40% (Young & Coles, 1992).
- In this study over half the women interviewed were not screened
- Greek born women die from cervical cancer at a younger age than Australian born women (Karnaki, 1998).

Phase 4 of PRECEDE refers to educational and ecological assessment. It examines factors influencing health-related behaviour and conditions affecting the behaviour (Green & Kreuter, 1999). Based on these, appropriate strategies are designed. Three

categories of factors are examined. These are predisposing, enabling and reinforcing factors (Green & Kreuter, 1999). Predisposing factors are "antecedents to behaviour that provide the rationale or motivation for the behaviour" (Green & Kreuter, 1999, p.153). Predisposing factors include factors relating to attitudes, knowledge and behaviour. In this study the predisposing attitudes influencing screening were identified as:

- Belief in the relationship between sexuality and cervical cancer.
- Belief in the relationship between heredity and cervical cancer.
- Belief that without symptomatology the disease does not exist.
- Fear towards cancer.
- Fear of test results.
- Fear of the examination.
- Fatalism towards cancer.
- Increased feelings of privacy towards medical issues especially where women's health was involved.
- Preference of going to a specialist instead of a GP for a Pap test.
- Rejection of women's health centres.

Greek women demonstrated lack of knowledge about cervical cancer and cervical cancer prevention that influenced the uptake of screening. Women did not have adequate knowledge about the causation and symptomatology of cervical cancer, the purpose of

screening, and the nature and purpose of the Pap test, purpose and location of women's health centers.

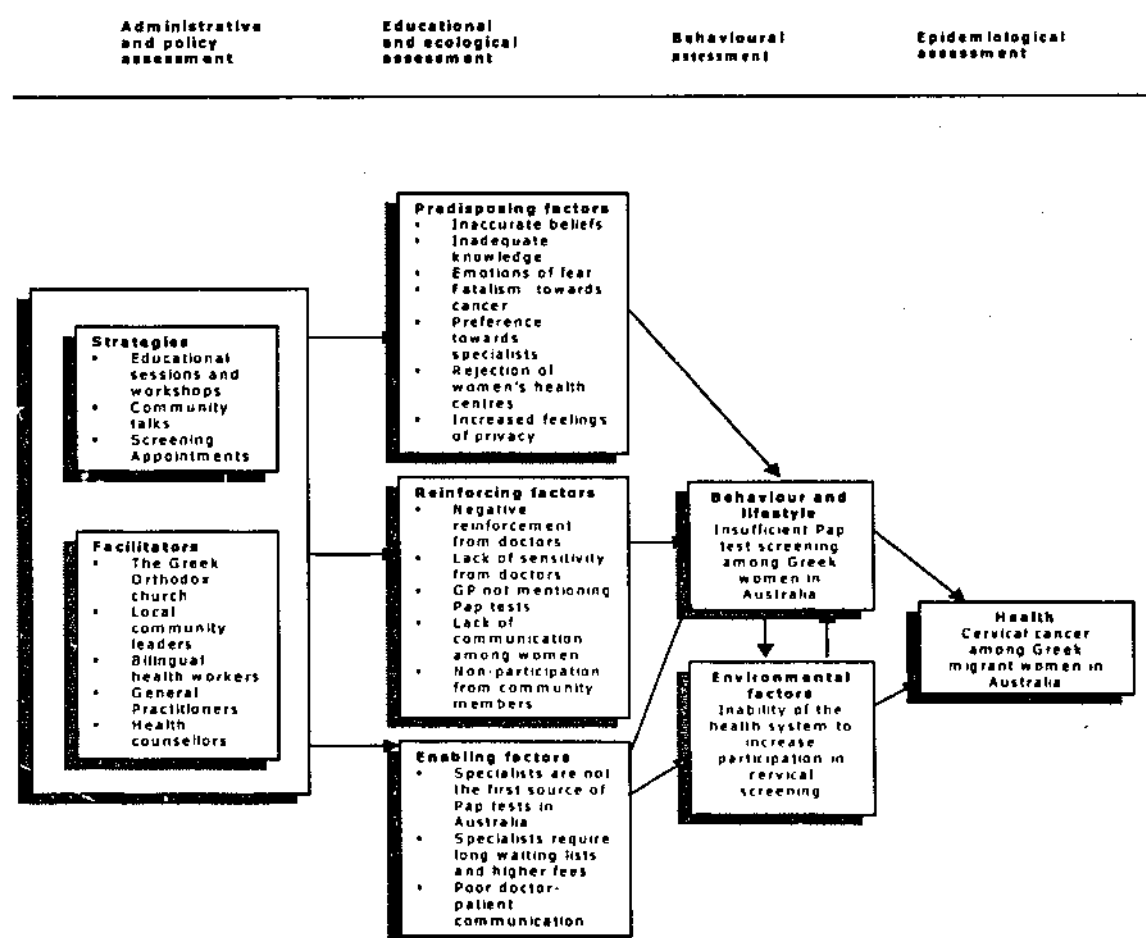
Reinforcing factors are "factors following a behaviour that provide the continuing reward or incentive for the persistence or repetition of the behaviour" (Green & Kreuter, 1999, p.153). Greek women received negative reinforcement from doctors who did not, during a gynaecological examination, deal effectively with a stressful situation (poor doctor-patient relationship, patient dissatisfaction). Doctors showed a lack of sensitivity, as they did not offer counseling or time to discuss screening issues that caused concern (poor doctor-patient relationship, patient dissatisfaction). General practitioners contributed to negative reinforcement also because they failed to suggest to their patients to have Pap tests during regular, non-gynaecological visits.

Negative reinforcement was also evident from the lack of communication about women's health issues between women and between women and their daughters. Lastly, negative reinforcement was evident from the way community leaders rejected attempts from health promotion organisations to provide free Pap tests.

Enabling factors are "antecedents to behaviour that allow a motivation to be realised" (Green & Kreuter, 1999, p.153). Among

Greek women enabling factors refer mainly to specialists who are not the first source of Pap tests in Australia, as is the case in Greece. Specialists, who are preferred by some Greek women in this study, have long waiting lists, are more costly than GPs and require referral notes from a general practitioner posing important barriers for the women who prefer them for cervical screening. The following diagram (Figure 6) summarises, based on the PRECEDE model, the key findings and recommendations of this study of the attitudes, knowledge, and practices of Greek women in Perth, Western Australia.

Figure 6: The PRECEDE model of cervical screening in Greek women



The specification of the health problem, the behavioural and environmental diagnosis and the identification of the factors that influence the specific behaviour in the target population, lead to the next step which is program intervention. This component marks the turning point from PRECEDE into PROCEED (Green & Kreuter, 1999) and is the subject matter of the next section, which makes recommendations to enhance Greek women's participation in screening.

Recommendations for intervention strategies

The importance of religion in shaping women's attitudes to health suggests the importance of involving the Greek Orthodox Church in health interventions. This is necessary for two reasons. Firstly, the fatalistic attitudes towards cancer that were observed in Greek women in this study could be alleviated if the church was to intervene as an education facilitator. Secondly, the participation of such a respected and trusted institution of the Greek community should increase participation, which is unlikely, if an outside body was implementing the program. The church has been used effectively in other cervical cancer screening programs with African American and Hispanic women in the USA (Williams, Abbott & Taylor, 1997; Davis *et al*, 1994). This suggestion, however, needs to be problematised in the context of health promotion for women, because world-wide the church is a patriarchal institution, that has

intervened to the detriment of women's reproductive health, for example by inhibiting the dissemination of information about contraception. The Greek Orthodox Church is less strict about contraception and sexual matters but also less involved in health and particularly women's health which is as much a problem as being detriment.

The involvement of the church in intervention programs means also the involvement of community leaders. However, this study revealed instances where community leaders actually excluded women's health workers from entering the community. There are no models to resolve these dilemmas. Rather, what is suggested here, is that it is important to start from women's own perceptions and to acknowledge, in planning, their importance in shaping women's health attitudes and behaviour.

A cervical cancer screening intervention for women in the Greek community of Perth should use bilingual health workers. Although none of the women mentioned language as a barrier to screening, many women did not understand English, health related words such as 'screening'. Bilingual health workers could deliver community talks and assist in the translation of materials provided by doctors. Bilingual health workers could also help to increase women's trust

towards women's health centres, which in this study was found to be low.

A clear finding in this study is the importance of GPs in health promotion. For many women the behaviour of GPs was the reason they avoided Pap tests. The inclusion of doctors in an intervention could give women the opportunity to discuss screening problems which would alleviate fear of Pap tests and restore trust and faith in GPs. For some women in this study, previous screening experiences were very stressful and painful resulting in total avoidance of screening. In these cases health counselors could address these issues and help women to deal with the past situation and restore faith in screening. This reinforces the point that health professionals need to work in collaboration in order to achieve best results for the community.

Strategies for increasing participation in screening in this community should be designed for small groups and conducted in familiar locations. These issues are important because Greek women value privacy and issues believed to involve sex, as is the instance with cervical cancer, are considered taboo and sensitive. Strategies designed could also include educational sessions, workshops, community talks and screening appointments.

Conclusion

The originality of this work may be found in the identification of the components of culture relevant to health promotion, with specific reference to cervical cancer screening. It is now commonplace to note the importance of cultural issues in health promotion issues (Gifford, 1990; Gunguly, 1995; Hiatt *et al*, 1996; Lesjak, Ward, & Rissel, 1997) but health practitioners are often less well-educated about which features of culture are pertinent. Issues of key significance in Greek women's lives are morality, privacy, and religion. These cultural beliefs influenced their attitudes towards screening, notably fear of cancer and fatalism giving rise to beliefs that health is a matter over which people do not have control. The women's words also revealed a lack of communication regarding women's issues and a strong sense of privacy about topics involving sexuality and screening. Lack of knowledge about cervical cancer and screening, which resulted in misconceptions about the symptomatology of the disease and the misinformation about the role of sex and heredity were also prominent reasons for avoiding Pap tests.

Of interest here is the clash between paradigms. Well-intentioned health workers seek to promote health. Their value system gives health a high priority. However, Greek women give priority to morality, privacy, sexuality and religion. The juxtaposition of the

professional culture of health workers and the Greek culture of women illustrate in bold relief that health promotion is about cultural change. Indeed the PRECEDE-PROCEED model provides an action plan for it. Acknowledging this is helpful because it raises the debate about cultural imperialism. This has, perhaps, best been argued in the context of female genital mutilation (Nahid, 1993). The question is: Is culture sacred? Is health intervention a form of cultural imperialism imposing good health as a primary value? In the recent International Interdisciplinary Conference on Women and Health, held in Edinburgh, Scotland Professor Ilona Kickbusch in her closing speech noted that culture is made and can be unmade. Culture, in any case, is not static. The issue then becomes: which parts of culture should be changed in the interests of enhancing health and quality of life. The health promotion question is: How can health be protected in an empowering manner that acknowledges culture?

This thesis has focused on just one aspect of the large debate: cervical cancer screening among Greek women. There is clearly a case for improving screening in this group. But how? The strength and originality of this thesis is that it has recommended specific, culturally appropriate health intervention strategies that reflect the needs of Greek women in Perth.

As always, a study of this nature raises as many questions as it answers. For example, Greek communities in Australia under-utilise preventive, public health services. Why this is so requires further research. As this study has indicated, there may be no solutions applicable to the whole Greek community. Women and men have different needs, as so older and younger Greek women. The possible involvement of the church is a particular intriguing outcome of this study. What is required is an action research health intervention with the Greek Orthodox Church to ascertain the efficacy of religious involvement. This is particularly important for women's health promotion where the involvement of a patriarchal institution risks being as unhelpful as it is helpful. Overall, the value of this thesis is that it has given voice to Greek women's own concerns. It is fitting, therefore, to conclude with their comments, which have been the focus of this thesis:

"All women [Greek women] are afraid. But you see nobody sat down all these years to talk to us about these things, to give us details, to explain".

Maybe it is time for someone to sit down, to talk, give details, and explain.

REFERENCES

- Anderson, G. M. (April 10, 1999). Smear tests were not on trial but should have been. British Medical Journal, 318(7189), 1007.
- Austin, M. R., & McLendon, W. W. (1997). The Papanicolaou smear: medicine's most successful screening procedure is threatened. Journal of the American Medical Association, 277(9), 754-755.
- Austoker, J. (1994). Screening for cervical cancer. British Medical Journal, 309, 241-248.
- Australian Greek Welfare Society (1996). Greek Women's Papanicolaou Project. Victoria: Health and Community Services.
- Australian Health Minister's Advisory Council. Cervical Cancer Screening Evaluation Committee (1991). Cervical cancer screening in Australia: options for change. Australian Institute of Health: Prevention Program Evaluation Series No2. Canberra: Australian Government publishing Service.
- Australian Institute of Health & Welfare. (1998). Australia's health: The sixth biennial health report of the Australian Institute of Health and Welfare. Canberra: Australian Governmental Publishing Service.
- Bailie, O., & Petrie, K. (1990). Women's attitudes to cervical smear testing. New Zealand Medical Journal, 103, 293-295.
- Baum, F. (1998). The new public health: an Australian perspective. Melbourne: Oxford University Press.
- Beattie, A. A. (1992). Pap smear taking in a general practice. Outcomes of a quality assurance audit. Australian Family Physician, 21, 307-311.
- Benedet, J.L., Anderson, G.H., & Matistic, J.P. (1992). A comprehensive program for cervical cancer detection and

management. American Journal of Obstetrics & Gynaecology, 166(4), 1254-1259.

Bernstein-Hyman, R., & Baker, S. (1992). Constructing of the Hyman-Baker mammography questionnaire, a measure of health belief model variables. Psychological Reports, 71(3), 1203-1213.

Binstock, M. A., Geiger, A. M., Hackett, J.R., Yao, J.F. (1997). Pap smear outreach: a randomised controlled trial in an HMO. American Journal of Preventive Medicine, 13(6), 425-426.

Blesch, K.S., & Prohaska, T. R. (1991). Cervical cancer screening in older women. Issues and intervention. Cancer Nursing, 14(3), 141-147.

Bonita, R., & Paul, C. (1991). The extent of cervical screening in New Zealand women. New Zealand Medical Journal, 104(918), 349-352.

Bos, A. B., Van Ballegooijen, M., Van Gessel-Dabekaussen, A., & Habbema, J. (1998). Organised cervical cancer screening still leads to higher coverage than spontaneous screening in The Netherlands. European Journal of Cancer, 34(10), 1598-1601.

Bowman, J., Redman, S., Reid, A., & Sanson-Fisher, R. (1990). General practitioners and the provision of Papanicolaou smear-tests: current practice, knowledge and attitudes. The Medical Journal of Australia, 152, 179-183.

Bowman, J., Sanson-Fisher, R., Boyle, C., Pope, S., & Redman, S. (1995). A randomised controlled trial of strategies to prompt attendance for Pap smear. Journal of Medical Screening, 2, 211-218.

Brannon, L., & Feist, J. (1992). Health psychology: an introduction to behaviour and health. Pacific Grove California: Brooks/Cole Publishing Company.

- Braun, V., & Gavey, N. (1998). Exploring the possibilities of sexual-behavioural primary prevention interventions for cervical cancer. Australian and New Zealand Journal of Public Health, 22(3), 353-359.
- Braveman, P., & Tarimo, E. (1996). Health screening, development, and equity. Journal of Public Health Policy, 17(1), 14-27.
- Brett, T. (1992). Opportunistic cervical screening among 50-70 years olds. A prospective study in general practice. Australian Family Physician, 21, 1781-1784.
- Brinton, L. A. (1992). Epidemiology of cervical cancer-overview. In Munoz, N., Bosch, F. X., Shah, K. V., & Meheus, A. (Eds.). The epidemiology of cervical cancer and human papillomavirus. International Agency for Research on Cancer: IARC Scientific Publications No. 119.
- Brinton, L. A., Reeves, W. C., Brenes, M. M., Herrero, R., Gaitan, E., Tenorio, F., Britton, R. C., Garcia, M., & Rawls, W. E. (1989c). The male factor in the etiology of cervical cancer among sexually monogamous women. International Journal of Cancer, 44, 199-203.
- Broadmore, J., Carr-Gregg, M., & Hutton, J. D. (1986). Vaginal examinations: women's experiences and preferences. New Zealand Medical Journal, 99, 8-10.
- Brotzman, G. L. (1999). Costs and outcomes of PAPNET secondary screening technology for cervical cytologic evaluation: a community hospital's experience. The Journal of the American Medical Association, 281(12), 1068-1069.
- Buckley, J. D., Harris, R. W. C., Doll, R., Vessey, M. P., & Williams, P. T. (1981). Case-control study of the husbands of women with dysplasia or carcinoma of the cervix uteri. Lancet, II, 1010-1015.

- Byles, J. E., & Sanson-Fisher, R. W. (1996). Mass mailing campaigns to promote screening for cervical cancer: do they work, and do they continue to work? Australian and New Zealand Journal of Public Health, 20(3), 254-259.
- Byles, J. E., Sanson-Fisher, R. W., Redman, S., Dickinson, J. A. & Halpin, S. (1994). Effectiveness of three community based strategies to promote screening for cervical cancer. Journal of Medical Screening, 1, 150-158.
- Byles, J., Sanson-Fisher, R., & Redman, S. (1996). Promoting screening for cervical cancer: realising the potential for recruitment by general practitioners. Health Promotion International, 11(4), 299-308.
- Carlson-Gielen, A., & McDonald, E. M. (1997). The PRECEDE-PROCEED planning model. In Glanz, K., Marcus-Lewis F., & Rimer, B. (Eds.), Health behaviour and health education: theory, research and practice. (2nd. Ed.). San Francisco: Jossey-Bass Publishers.
- Caserta, M. S. (1995). Health promotion and the older population: expanding our theoretical horizons. Journal of Community Health, 20(3), 283-293.
- Chavez, L. R., Hubbell, F. A., Mishra, S. I., & Valdez, R. B. (1997). The influence of fatalism on self-reported use of Papanicolaou smears. American Journal of Preventive Medicine, 13(6), 418-424.
- Cheek, J., Fuller, J., Gilchrist, S., Maddock, A., Ballantyne, A. (1999). Vietnamese women and pap smears: issues in promotion. Australian and New Zealand Journal of Public Health, 23(1), 72-76.
- Chomet, J., & Chomet, J. (1991). Smear tests. Cervical cancer its prevention and treatment. Glasgow: Thornsons. An imprint of Harper Collins Publishers.

Cockburn, J., Hirst, S., Hill, D., & Marks, R. (1990). Increasing cervical screening in women of more than 40 years of age: an intervention in general practice. The Medical Journal of Australia, 152, 190-193.

Cockburn, J., Murphy, B., Schofield, P., Hill, D. J., & Borland, R. (1991). Development of a strategy to encourage attendance for screening mammography. Health Education Quarterly, 6, 279-290.

Coleman, D. V., & Evans, D. M. D. (1988). Biopsy, pathology and cytology of the cervix. London: Chapman and Hall Medical.

Coleman, D., Day, N., Douglas, G. (1993). European guidelines for quality assurance in cervical cancer screening. Europe against cancer program. European Journal of Cancer, 29A(Suppl. 4), 1-38.

Coney, S. (1988). The unfortunate experiment. Auckland, New Zealand: Penguin Books.

Croyle, R. T., & Barger, S. D. (1993). Illness cognition. In Maes, S., Leventhal, H., & Johnston, M. (Eds.). International Review of Health Psychology. Chichester: JOHN WILEY & SONS.

Culpin, A., Gleeson, S., Thomas, M. M., Bekiaris, J. (1996). Evaluation of the 'Good Heart, Good Life' (Kalh Kardia, Kalh Zwh) project: a three year campaign to reduce smoking among the Greek community of Sydney's inner west. Health Promotion Journal of Australia, 6(2), 44-49.

Daly, J., Kellehear, A., & Gliksman, M. (1997). The public health researcher: a methodological guide. Melbourne: Oxford University Press.

Davies, C., & Brown, J. (1994). UK cervical cancer screening program: setting a research agenda. Journal of Medical Screening, 1, 249-254.

Davis, D. T., Bustamante, A., Brown, C. P., Wolde-Tsadik, G., Savage, E. W., Cheng, X., & Howland, L. (1994). The urban church and cancer control: a source of social influence in minority communities. Public Health Reports, 109(4), 500-507.

Denny, M. S., Koren, M. E., & Wisby, M. (1989). Gynaecological health needs of elderly women. Journal of Gerontological Nursing, 15(1), 33-38.

Dietrich, A. J., & Goldberg, H. (1984). Preventive content of adult primary care: do generalists and subspecialists differ? American Journal of Public Health, 74, 223-227.

Dignan, K. (1993). Testing times: women's health, preventive medicine. Nursing Times, 89(44), 28-30.

Dignan, M. B., & Carr, P. A. (1992). Program planning for health education and promotion. (2nd Ed). Philadelphia: LEA & FEBIGER.

Dobson, R. (8 August 1998). Health authority admits mistakes over smear tests. British Medical Journal, 317, 368.

Elkind, A., Earderly, A., Haran, D., Spencer, B., & Smith, A. (1989). Computer-managed call and recall for cervical screening: a typology of reasons for non-attendance. Community Medicine, 11(2), 157-162.

Elkind, A. K., Haran, D., Earderly, A. & Spencer, B. (1989). Well you can come in but I am not having it. Health Visitor, 62, 20-21.

Ελληνική Ογκολογική Εταιρεία [Greek Oncological Society]. (26.3.1997). Πληθυσμιακοί έλεγχοι στους νομούς Ηλείας και Μεσσηνίας. [Population screening in Illia and Messinia provinces]. Αθήνα, Ελλάδα [Athens, Greece].

Ευρωπαϊκή Εβδομάδα Κατά του Καρκίνου. [European Week Against Cancer]. (1997). Έγκυρη διάγνωση των πιο συχνών καρκίνων της γυναίκας. Καρκίνοι μαστού και τραχήλου της μήτρας. [Early and accurate diagnosis of the most frequent female cancers. Breast and cervical cancer]. Paper presented in the European Week Against Cancer, 6-12 October 1997, Athens, Greece.

Fulton, J. P., Buechner, J. S., Scott, H. D., DeBuono, A., Feldman, J. P., Smith, R. A., & Kovenock, D. (1991). A study guided by the Health Belief Model of the predictors of breast cancer screening of women ages 40 and older. Public Health Reports, 106(4), 410-421.

Gifford, S. M. (1990). Culture and the provision of preventable health care: implications for medical education. Journal of Intercultural Studies, 11, 73-80.

Gil, V. E. (1995). The new female condom: attitudes and options of low-income Puerto Rican women at risk for HIV/AIDS. Qualitative Health Research, 5(2), 178-203.

Green, L. W., & Kreuter, M. W. (1999). Health promotion planning An educational and ecological approach. (3rd Ed.). Mountain View, California: Mayfield Publishing Company.

Gregory, S., & McKie, L. (1990). Smear tactics. Nursing Times, 86(19), 38-40.

Guest, C., Mitchell, H., & Piant, A. (1990). Cancer of the uterine cervix and screening of Aboriginal women. Australian and New Zealand Journal of Obstetrics and Gynaecology, 30(3), 243-247.

Gunguly, I. (1995). Promoting the health of women of non-English-speaking backgrounds in Australia. World Health Forum 16, 157-163.

Gyrd-Hansen, D., Holund, B., & Andersen, P. (1995). A cost-effectiveness analysis of cervical cancer screening: health policy implications. Health Policy, 34, 35-51.

Harokopos, V., & McDermott, J. (1996). Cervical screening: benefits and barriers. Journal of Health Education, 27(6), 351-356.

Havelock, C., Webb, J., & Queenborough, J. (1988). Preliminary results of a district call scheme for cervical screening organised in general practice. British Medical Journal, 297, 1384-1386.

Health Department of Western Australia. (1996). Agreed state/territory four year plan 1995/96 - 1998/99. West Australian cervical cancer prevention program for the prevention of cancer of the cervix. Western Australia: Women's Cancer Screening Service. Health Department of Western Australia Perth.

Hellas Media Network (1999). Review of the Greek-Australian census. [On-line]. Available <http://www.hellas.com.au/community/census/index.html>

Herbert, A., Stein, K., Bryant, T.N., Breen, C., & Old, P. (1996). Relation between the incidence of invasive cervical cancer and the screening interval: is a five-year interval too long? Journal of Medical Screening, 3, 140-145.

Herbst, A. L. (1990). The Bethesda system for cervical/vaginal cytologic diagnoses: a note of caution. Obstetrics & Gynaecology, 76(3), 449-450.

Heywood, A., Firman, D., & Ring, I. (1996). Factors associated with Pap smear taking in general practice: focusing public health initiatives. Australian and New Zealand Journal of Public Health, 20(3), 260-266.

Hiatt, R. A., Pasick, R. J., Perez-Stable, E. J., McPhee, S. J., Engelstad, L., Lee, M., Sabogal, F., D'Onofrio, C. N., & Stewart, S. (1996). Pathways to early detection in the multiethnic

- population area of the San Francisco Bay Area. Health Education Quarterly 23(suppl.), 10-27.
- Hill, D., Gardner, G., & Rassaby, J. (1985). Factors predisposing women to take precautions against breast and cervix cancer. Journal of Applied Social Psychology, 15(1), 59-79.
- Holly, A. E. (1996). Cervical intraepithelial neoplasia, cervical cancer, and HPV. Annual Review of Public Health, 17, 69-84.
- Honing, F. (1996). Cervical cancer screening project for women of non-English speaking background. Ishar Multicultural Centre for Women's Health, Western Australia.
- Hubbell, F. A., Chavez, L. R., Mishra, S. I., Valdez, R. B. (1996). Beliefs about sexual behaviour and other predictors of Papanicolaou smear screening among Latinas and Anglo women. Archives of Internal Medicine 156(20), 2353-2359.
- Hunt, L. (1998). The women's health specialty: curriculum implications. Women's Health Issues, 7(2), 116-120.
- Hurley, J. (1993). Cervical screening. The client's perspective on the adequacy of the service. Nursing Times, 89(44), 31-34.
- Iatridis, S. G. (1990). New developments related to competitive elements in health care in Greece. In: Casparie, A. F., Hermans, H. E.G.M., & Paelinck, J.H.P. (Eds.). Competitive health care in Europe: future prospects. Aldershot: Erasmus University Rotterdam.
- Ibbotson, T., Wyke, S., McEwen, J., Macintyre, S., Kelly, M. (1996). Uptake of cervical screening in general practice: effect of practice organisation, structure, and deprivation. Journal of Medical Screening, 3, 35-39.
- Ingham, R., & Bennett, P. (1990). Health psychology in community settings: models and methods. In Bennet, P., Weinman, J., &

- Spurgeon, P. (Eds.). Current developments in health psychology. Chur: Harwood academic publishers.
- Ινστιτούτο Κοινωνικής και Προληπτικής Ιατρικής [Institute of Social and Preventive Medicine] (1995). 1990-1995: Ινστιτούτο Κοινωνικής και Προληπτικής Ιατρικής [Institute of Social and Preventive Medicine]. Νέα Υγεία [New Health], 7, 6-7.
- Ishar Multicultural Centre for Women's Health. (1997). Cervical cancer screening project for women of non-English speaking background. Perth, Western Australia.
- Jameson, A., Sligo, F., & Comrie, M. (1999). Barriers to Pacific women's use of cervical screening services. Australian and New Zealand Journal of Public Health, 23(1), 89-92.
- Kahn, J. A., & Emans, S. J. (1999). Pap smears in adolescents: to screen or not to screen? Pediatrics, 103(3), 673.
- Karnaki, P. (1998). Cervical cancer mortality in Greek- Australian women. [Unpublished].
- Kant, A. C., Palm, B. T. H. M., Wentink, E., Van Weel, C. (1997). General practitioner based screening for cervical cancer: higher participation of women with higher risk? Journal of Medical Screening, 4, 35-39.
- Kingston, H. (1987). Cervical cancer screening and health checks for woman in rural practice using a practice nurse. The New Zealand Family Physician, 14, 137-138.
- Kirk, M. (1993). An Aboriginal perspective on cancer. Aboriginal and Islander Health Worker Journal, 17(3), 11-13.
- Kjaer, S. K. (1998). Risk factors for cervical neoplasia in Denmark. APMIS, 80 (SUPPLEMENTUM) 1-41.

- Kjaer, S. K., de Villiers, E. M., Dahl, C., Engholm, G., Bock, J. E., Vestergaard, B. F., Lynge, E., & Jensen, O. M. (1991). Case-control study of risk factors for cervical neoplasia in Denmark. I: role of the "male factor" in women with one lifetime sexual partner. International Journal of Cancer, 48, 39-44.
- Kloeble, A. S. (1999). Folate knowledge, intake from fortified grain products, and periconceptional supplementation patterns of a sample of low-income pregnant women according to the Health Belief Model. Journal of the American Dietetic Association, 99(1), 33-39.
- Kornfeld, J., Fleisher, L., Ter-Maat, J., Vanchieri, C., Hohenemser, L., & Stevens, N. (1998). Reaching minority and underserved population: impact of the cancer information service's outreach program. Part 3. Journal of Health Communication, 3(suppl.), 36-49.
- Kottke, T. E., & Trapp, M. A. (1998). The quality of the Pap test specimens collected by nurses in a breast and cervical screening clinic. American Journal of Preventive Medicine, 14(3), 196-200.
- Laara, E., Day, N. E., & Hakama, M. (1987). Trends in mortality from cervical cancer in the Nordic countries: association with organised screening programs. The Lancet, 1247-1249.
- Lane, D. S., Polednak, A. P., & Burg, M. A. (1992). Breast cancer screening practices among users of county-funded health-centres vs women in the entire community. American Journal of Public Health, 82, 199-203.
- Lazsano-Ponce, E. C., Buiatti, E., Najera-Aguilar, P., Alonso-de-Ruiz, P., & Hernandez-Avila, M. (1998). Evaluation model of the Mexican national program for early cervical cancer detection and proposals for a new approach. Cancer Causes and Control, 9, 241-251.

- Lesjak, M., Ward, J., & Rissel, C. (1997). Cervical screening of Arabic-speaking women in Australian general practice. Journal of Medical Screening, 4, 107-111.
- Leventhal, H., Nerenz, D. R., & Steele, D. J. (1984). Illness representations and coping with health threats. In Baum, A., Taylor, S. E., & Singer, J. E. (Eds.), Handbook of psychology and health: Vol. IV. Social psychological aspects of health. Hillsdale, New Jersey: Lawrence Erlbaum Associates, Publishers.
- Lupton, G., & Najman, J. M. (1995). Sociology health and health care. In Lupton, G., & Najman, J M. (Eds.). Sociology of Health and Illness. Australian Readings. (Second edition). Melbourne: Macmillan Education Australia PTY LTD.
- Lynge, E. (1989). Screening for cancer of the cervix uteri. World Journal of Surgery, 13, 71-78.
- Madden, R. (1996). Women's health. Catalogue NO. 4365.0. Canberra: Australian Bureau of Statistics.
- Maibach, E. W., Davis, S. W., Ter-Maat, J., & Rivera, N. (1998). Promoting cancer prevention and screening: the impact of the cancer information service. Part 7. Journal of Health Communication, 3(suppl.), 97-108.
- Mak, D., & Straton, J. A. Y. (1997). Effects and sustainability of a cervical screening program in remote Aboriginal Australia. Australian and New Zealand Journal of Public Health, 21(1), 67-70.
- Maliori, M., Moraitaki, K., Papoutsakis, G., Sokou, K., Trihopoulou, A., Tountas, G., & Tsamandouraki, K. (1995). Για την ανάπτυξη της προαγωγής και αγωγής υγείας [For the development of promoting and improving health]. Νέα Υγεία [New Health], 9, 4-5.
- McCormick, J. S. (1989). Cervical smears: a questionable practice? The Lancet, 2(8656), 207-209.

- Mera, L. S. (1997). Pathology and understanding disease prevention. London: Stanley Thornes (Publishers) Ltd.
- Miller, A. B., Chamberlain, J., Day, N. E., Hakama M., & Prorok, P. C. (1990). Report on a workshop of the UICC project on evaluation of screening for cancer. International Journal of Cancer, 46, 761-769.
- Minichiello, V., Aroni, R., Timwell, E., & Alexander, L. (1990). In-depth interviewing. Researching people. Melbourne: Longman Cheshire.
- Mirotznic, J., Feldman, L., & Stein, R. (1995). The health belief model and adherence with a community centre-based supervised coronary heart disease exercise program. Journal of Community Health, 20(3), 233-248.
- Mirotznik, J., Ginzler, E., Zagon, G., & Baptiste, A. (1998). Using the health belief model to explain clinic appointment-keeping for the management of a chronic disease condition. Journal of Community Health, 23(3), 195-211.
- Mitchell, H., & Medley, G. (1991). Longitudinal study of women with negative cervical smears tests according to endocervical status. The Lancet, 337, 265-267.
- Moller Jensen, O., Esteve, J., Moller, H., & Renard, H. (1990). Cancer in the European Community and its member states. European Journal of Cancer, 26(1112), 1167-1256.
- Morrow, C. P., & Townsend, D. E. (1987). Synopsis of gynaecological oncology. (Third edition). New York: John Wiley & Sons.
- Morse, M. J., & Harrison, J. (1992). Social coercion for weaning. In J. M. Morse (Ed.). Qualitative health research. California: SAGE Publications.

- Munoz, N., & Bosch, F. X. (1992). HPV and cervical neoplasia: review of case-control and cohort studies. In Munoz, N., Bosch, F. X., Shah, K. V., & Meheus, A. (Eds.). The epidemiology of cervical cancer and human papillomavirus. International Agency for Research on Cancer: IARC Scientific Publications No. 119.
- Munoz, N., Crawford, L., Coursaget, P. (1995). HPV vaccines for cervical neoplasia. The Lancet, 345, 249.
- Murray, M., & McMillan, C. (1993). Health beliefs, locus of control, emotional control and women's cancer screening behaviour. British Journal of Clinical Psychology, 32, 87-100.
- Nahid, T (1993). Female genital mutilation: a call for global action. New York: Women Inc.
- Nicoll, P. M., Narayan, K. V., & Paterson, J. G. (1991). Cervical cancer screening: women's knowledge, attitudes and preferences. Health Bulletin, 49, 184-189.
- O'Connor, M. L., & Parker, E. (1975). Health promotion principles and practice in the Australian practice. Sydney: Allen & Unwin.
- Orlandi, M. A. (1987). Promoting health and preventing disease in health care settings: an analysis of barriers. Preventive Medicine, 16, 119-130.
- Papanicolaou, G. N. (1946). A general survey of the vaginal smear and its use in research and diagnosis. American Journal of Obstetrics and Gynaecology, 51, 316-342.
- Papanicolaou, G.N., & Traut, H. F. (1941). The diagnostic value of the vaginal smears in carcinoma of the uterus. American Journal of Obstetrics & Gynecology, 42(2), 193-206.
- Pasick, R. J. (1997). Socioeconomic and cultural factors in the development and use of theory. In Glanz, K., Marcus-Lewis F.,

& Rimer, B. (Eds.), Health behaviour and health education: theory, research and practice. (2nd. Ed.). San Francisco: Jossey-Bass Publishers.

Pasick, R. J., Sabogal, F., Adair-Bird, J., D'Onofrio, C. N., Jenkins, C. N. H., Lee, M., Engelstad, L., & Hiatt, R. A. (1996). Problems and progress in translation of health survey questions: the Pathways experience. Health Education Quarterly, 23 (supplement), 28-40.

Patton, Q. M. (1990). Qualitative evaluation and research methods. California: Sage Publications, Inc.

Paul, C., Bagshaw, S., Bonita, R., Durham, G., Fitzgerald, N., Jones, R., Marshall, B., & McAvoy, B. (1991). Cervical screening recommendations: a working group report. New Zealand Medical Journal, 104, 291-295.

Peters, R. K., Bear, M. B., Thomas, D. (1989). Barriers to screening for cancer of the cervix. Preventive Medicine, 18, 133-146.

Pierce, M., Lundy, S., Palanisamy, A., Winning, S., & King, J. (1989). Prospective randomised controlled trial of methods of call and recall for cervical cytology screening. British Medical Journal, 299, 160-162.

Price, J. H., Easton, A. N., Telljohann, S. K., & Wallace, P. B. (1996). Perceptions of cervical cancer and Pap smear screening behaviour by women's sexual orientation. Journal of Community Health, 21(2), 89-101.

Quilliam, S. (1990). Positive smear. The emotional issues and what can be done. Health Education Journal, 49(1), 19-20.

Quinn, M., Babb, P., Jones, J., & Allen, E. (1999). Effect of screening on incidence of and mortality from cancer of the cervix in England: evaluation based on routinely collected statistics. British Medical Journal, 318(7188), 904.

- Reid, G. S., Robertson, A. J., Bissett, C., Smith, J., Waugh, N., & Halkertson, R. (1991). Cervical screening in Perth and Kinross since introduction of the new contract. British Medical Journal, 303, 447-450.
- Reid, S., Simpson, J., & Britt, H. (1997). Pap smears in general practice: a secondary analysis of the Australian Morbidity and treatment survey 1990 to 1991. Australian and New Zealand Journal of Public Health, 21(3), 257-264.
- Report of the Evaluation Steering Committee. (1995). The interim evaluation of the organised approach to preventing cancer of the cervix 1991-95. Canberra: Australian Government Publishing Service.
- Roberts, E., Cook, G. A., Walsworth-Bell, J. P., & Barrow, S. (1995). Setting standards for cervical screening fail-safe mechanisms: a target based on an audit of cytopathology laboratory records. Journal of Medical Screening, 2, 102-104.
- Robertson, A. J., Reid, G. S., Stoker, C. A., Bissett, C., Waugh, N., Fenton, I., Rowan, J., & Halkerston, R. (1989). Evaluation of a call program for cervical cytology screening in women aged 50-60. British Medical Journal, 299, 163-166.
- Ronis, D. L., Kaiser, M.K. (1989). Health beliefs and breast examination behaviours: Analysis of linear structural relations. Psychology and Health, 3, 259-285.
- Ross, S. K. (1989). Cervical cytology screening and government policy. British Medical Journal, 299, 101-104.
- Sala, M., Dosemeci, M., & Zahm, S. H. (1998). A death certificate-based study of occupation and mortality from reproductive cancers among women in 24 US States. Journal of Occupational and Environmental Medicine, 40(7), 632-639.

- Sato, S., Makino, H., Matsunaga, G., & Yajima, A. (1998). False negative rate in mass screening for cervical cancer. Acta Cytologica, 42(3), 836-837.
- Savage, A. S., & Clarke, A.V. (1998). Older women's illness representations of cancer: a qualitative study. Health Education Research, 13(4), 529-544.
- Schwartz, M., Savage, W., George, J., & Emohare, L. (1989). Women's knowledge and experience of cervical cancer screening: a failure of health education and medical organisation. Community Medicine, 11(4), 279-289.
- Shepherd, J. C., & Fried, R. A. (1995). Preventing cervical cancer: the role of the Bethesda system. American Family Physician, 51(2), 434-439.
- Sherlaw-Johnson, C., Gallivan, S., & Jenkins, D. (1999). Withdrawing low risk women from cervical screening programs: mathematical modeling study. British Medical Journal, 318(7180), 356.
- Shield, P., Daunter, B., & Wright, R. (1987). The Pap smear revisited. The Australian & New Zealand Journal of Obstetrics & Gynaecology, 27(4), 269-283.
- Shroff, K. J., Corrigan, A. M., Bosher, M, Edmonds, M. P., Sack, D., & Coleman, D. V. (1988). Cervical screening in an inner-city area: response to a call system in general practice. British Medical Journal, 297, 1317-1318.
- Sigurdsson, K. (1993). Effect of organised screening on the risk of cervical cancer. Evaluation of screening activity in Iceland, 1964-1991. International Journal of Cancer, 54, 563-570.
- Singer, N. (1995). Understanding sexual risk behaviour from drug users accounts of their life experiences. Qualitative Health Research, 5(2), 237-249.

- Skrabanek, P. (1987). Cervical cancer screening. The Lancet, 1(8547), 1432-1433.
- Slattery, M. L., Abbott, T. M., Overall, J. C., Robison, L. M., French, T. K., Jolles, C., Gardner, J. W. & West, D. W. (1990). Dietary vitamins A, C, and E and selenium as risk factors for cervical cancer. Epidemiology, 1, 8-15.
- Slattery, M. L., Overall, J. C., Abbott, T. M., French, T. K., Robison, L. M., & Gardner, J. (1989a). Sexual activity, contraception, genital infections, and cervical cancer: support for a sexually transmitted disease hypothesis. American Journal of Epidemiology, 130, 248-258.
- Smith, A., Elkind, A., & Eardley, A. (1989). Making cervical screening work. British Medical Journal, 298, 1662-1664.
- Stahlberg, D. & Frey, D. (1996). Attitudes: structure, measurement, and functions. In M. Hewstone, S. Wolfgang, & M. G. Stephenson (Eds.), Introduction to social psychology. Oxford: Blackwell Publishers.
- Standing, P., & Mercer, S. (1984). Quinquennial cervical smears: every women's right and every general practitioner's responsibility. British Medical Journal, 289, 883-886.
- Straton, J. A. Y. (1994). Recruitment for cervical screening: a review of the literature. Department of Public Health. The University of Western Australia, Perth: Australian Government Publishing Service.
- Straton, J. A. Y., Sutherland, G. J., Hyndman, J. C. G. (1995). Cervical cancer screening for hospital inpatients: report of an intervention study. Australian Journal of Public Health 19(3), 288-293.
- Strecher, V. J., & Rosenstock, I. M. (1997). The Health Belief Model. In Glanz, K., Marcus-Lewis, F., & Rimer, B. K. (Eds.), Health

behaviour and health education: theory, research, and practice. (2nd Ed.). San Francisco: Jossey-Bass Publishers.

Strecher, V. J., Champion, V. L., & Rosenstock, I. M. (1997). The Health Belief Model and health behaviour. In Gochman, D. S. (Ed.). Handbook of health behaviour research: Vol I. Personal and social determinants. New York and London: Plenum Press.

Suarez, L., Nichols, D. C., Pulley, L., Brady, C. A., & McAlister, A. (1993). Local health departments implement a theory-based model to increase breast and cervical cancer screening. *Public Health Reports*, 108(4), 477-483.

Sutherland, G. (1992). Cervical cancer screening services in Western Australia. Western Australia: Women's Cancer Prevention Unit, Health Department of Western Australia.

Temple-Smith, M. J., Banwell, C. L., Gifford, S. M., & Presswell, N. T. (1995). Promoting health beyond recruitment: beliefs and attitudes to breast and cervical cancer screening services among Italian-born women in Melbourne. Health Promotion Journal of Australia, 5(2), 31-36.

Thornton, J., & Chamberlain, J. (1989). Cervical screening in the workplace. Community Medicine, 11(4), 290-298.

Tsolidis, G. (1995). Greek-Australian families. In Hartley, R. (Ed.). Families & cultural diversity in Australia. NSW: Allen & Unwin and The Australian Institute of Families Studies.

Tsoulis, E. (1998). Between the ceiling and the sky. Australia: Flamingo an imprint of Harper Collins Publishers.

Υπουργείο Υγείας, Πρόνοιας και Κοινωνικών Ασφαλίσεων, Ελληνική Δημοκρατία [Minister of Health, Welfare, and Social Security, Hellenic Republic]. (18.3.1993). Δωρεάν διενέργεια των εξετάσεων κολποτρααγγηλικών επιχρισμάτων κατά Παπανικολάου (TEST PAP). [Free Pap test screening services]. Αθήνα Ελλάδα [Athens, Greece].

- Van Den Brink-Muinen, A. (1998). Principles and practice of women's health care. Women's Health Issues, 8(2), 123-130.
- Vellozzi, C. J., Romans, M., & Rothenberg, R. B. (1996a). Delivering breast and cervical cancer screening services to underserved women: part I. Literature review and telephone survey. Women's Health Issues, 6(2), 65-73.
- Vellozzi, C. J., Romans, M., & Rothenberg, R. B. (1996b). Delivering breast and cervical cancer screening services to underserved women: part II. Implications for policy. Women's Health Issues, 6(4), 211-220.
- Verreault, R., Chu, J., Mandelson, M., & Shy, K. (1989). A case-control study of diet and invasive cervical cancer. International Journal of Cancer, 43, 1050-1054.
- Walsh, J., & McPhee, S. (1992). A systems model of clinical preventive care: an analysis of the factors influencing patient and physician. Health Education Quarterly, 19, 157-175.
- Ward, J., & Sanson-Fisher, R. (1992). Pap smear tests in general practice. Australian Family Physician, 21(4), 465-466.
- Ward, J., & Sanson-Fisher, R. (1997). Accuracy of the women's recall of the opportunistic recruitment for cervical cancer screening in general practice. Australian and New Zealand Journal of Public Health, 21(3), 335-356.
- Ward, J., Donnelly, N., & Holt, P. (1998). Impact in general practice of the policies of the organised approach to preventing cancer of the cervix. Australian and New Zealand Journal of Public Health, 22(3), 336-341.
- Ward, J., Gordon, J., & Sanson-Fisher, R. (1991). Strategies to increase preventive care in general practice. The Medical Journal of Australia, 154(15), 523-531.

- Warden, J. (29 August 1998). Moves to end cervical screening failures in England. British Medical Journal, 317, 558.
- Waxler-Morrison, N., Doll, R., & Hislop, T. G. (1995). The use of qualitative methods to strengthen psychosocial research on cancer. Journal of Psychosocial Oncology, 13, 177-191.
- Weisberg, E. (1991). National cervical cancer screening policy. New Doctor, 56, 21-24.
- Weller, D. (1997). Cancer screening in general practice. Australian Family Physician, 26(5), 517-525.
- Western Diagnostic Pathology. (nd). Pap smears. Additional tests. [Brochure].
- Wilkenstein, W., Jr. (1990). Smoking and cervical cancer-current status: a review. American Journal of Epidemiology, 131, 954-957.
- Williams, G. A., Abbott, R. R., & Taylor, D. K. (1997). Using focus group methodology to develop breast cancer screening programs that recruit African American women. Journal of Community Health, 22(1), 45-57.
- World Health Organisation (1986). Control of the cervix uteri. Bulletin of the World Health Organisation, 64(4), 607-618.
- World Health Organisation (1996). Cervical cancer control in developing countries: memorandum from a WHO meeting. Bulletin of the World Health Organisation, 74(4), 342-351.
- World Health Organisation. Report of the director general. (1998). Life in the 21st century. A vision for all. Geneva: World Health Organisation.

- Young, C., & Coles, A. (1992). Women's health, use of medical services, medication, lifestyle and chronic illness. Some findings from the 1989-90 National Health Survey. In Donovan, J., D'Espaignet, E., Merton, C., & Van Ommeren, M. (Eds.). Immigrants in Australia: a health profile. Canberra: Australian Government Publishing Service.
- Zhang, Z. F., Parkin, D. M., Yu, S. Z., Esteve, J., & Yang, X. Z. (1989). Risk factors for cancer of the cervix in a rural Chinese population. International Journal of Cancer, 43, 762-767.
- Zunzunegui, M. V., King, M. C., Coria, C. F., & Charlet, J. (1986). Male influences on cervical cancer risk. American Journal of Epidemiology, 123, 302-307.

12. Who advised you to have a Pap test?
13. What do you think is the purpose of a Pap test?
14. What were your reactions to the examination?
15. What are your feelings when undergoing the examination?
16. What are your reactions to the person administering the test?
17. Would you go to your GP for a Pap test? Why?
18. Has your GP explained the purpose of a Pap test?
19. Does your GP explain the results of your Pap test?
20. Who would you prefer to do the Pap test?
21. Are you aware of any women among your family or friends who have cervical cancer?
22. What do you know about the causes and treatments of cervical cancer?
23. Do you think that cervical cancer is a preventable disease?
24. What do you believe women should do to prevent cancer of the cervix?

Ερωτήσεις

1. Που γεννηθήκατε;
 - Ελλάδα
 - Αυστραλία
 - Κάπου αλλού
 - Παρακαλώ διευκρινίστε:
2. Ποια είναι η μητρική σας γλώσσα;
 - Ελληνικά
 - Αγγλικά
 - Κάποια άλλη
 - Παρακαλώ διευκρινίστε
3. Ποιο είναι το έτος γεννήσεως σας; 19...
4. Είστε
 - Παντρεμένη
 - Χωρισμένη
 - Χηρεμένη
5. Για ποια πράγματα όσο αφορά το τεστ Παπανικολάου μιλάτε με τους γνωστούς και φίλους σας;
6. Τι πληροφορίες και τι συμβουλές σας έχουν δώσει όσο αφορά το τεστ Παπανικολάου;
7. Από που έχετε πάρει αυτές τις πληροφορίες;
8. Ποιος κατά την γνώμη σας θα πρέπει να κάνει τεστ Παπανικολάου; Γιατί;
9. Έχετε κάνει ποτέ τεστ Παπανικολάου; Γιατί;
10. Ποιος σας συμβούλεψε να κάνετε το τεστ
11. Όταν ήρθατε στην Αυστραλία κάνατε συχνά τεστ Παπανικολάου
12. Πριν έρθετε στην Αυστραλία είχατε κάνει τεστ Παπανικολάου;
13. Ποιος σας μίλησε για πρώτη φορά για το τεστ Παπανικολάου;
14. Ποιος πιστεύετε κατά την γνώμη σας ότι είναι ο σκοπός ενός τεστ Παπανικολάου;
15. Ποιες είναι οι αντιδράσεις σας προς την γυναικολογική εξέταση;
16. Ποια είναι τα συναισθήματα που σας δημιουργούνται κατά την εξέταση;
17. Πως αντιδράτε προς το άτομο που κάνει την εξέταση;
18. Θα θέλατε να κάνει την εξέταση ο προσωπικός σας γιατρός; Γιατί;
19. Ο γιατρός σας, σας έχει εξηγήσει τον σκοπό του Παπ τεστ;
20. Ο γιατρός σας εξηγεί τα αποτελέσματα του τεστ σας;
21. Ποιος θα προτιμούσατε να κάνει την εξέταση;
22. Έχετε υπ'οψη σας κάποιες κυρίες στον οικογενειακό σας κύκλο που να είχε καρκίνο στον τράχηλο της μήτρας;
23. Ποιος πιστεύετε ότι είναι ο καλύτερος τρόπος να προληφθεί ο καρκίνος στον τράχηλο της μήτρας;
24. Τι πιστεύετε ότι πρέπει να κάνουν οι γυναίκες για να μην δημιουργήσουν καρκίνο του τραχήλου της μήτρας;

Appendix B

Informed Consent

Dear Participant:

My name is Panagiota Karnaki. I am a Master's student of Health Science at Edith Cowan University, Perth, Western Australia. I am in Australia from Greece in order to complete my studies. I am conducting a study about cervical cancer screening among Greek women in Perth. I will be interviewing about 10 women in the area of Perth.

I would like to conduct an anonymous individual interview with you. The interview does not aim at testing your knowledge. It aims at investigating the difficulties Greek, and Australian born Greek women have in regards to having a Pap test, and also to examine their opinions about the usefulness of the test, and ways in which the procedure can be improved so as to become easier to them. Your opinions will be important in examining strategies to improve the present screening program in Perth.

The interview will last for approximately one hour and will be held at a location of your convenience, at your home or public area. The information you provide will remain confidential. Your name will be known only to me and will not be mentioned anywhere in my study. **It would help me a lot if I could have your permission to tape our**

conversation. I am expected by my university to keep the information from these interviews for five years as evidence that I did conduct research. The tapes will be kept in a locked cupboard and will be listened to only by the researcher and the secretary responsible for transcribing the tapes. Tapes will be identifiable by a number and thus names will not be revealed to either the secretary or translator. Transcribers and translators will sign confidentiality statements in order to protect the content of the interviews.

If you agree to the interview please complete the consent form and return to me as soon as possible at the following address:

Address:

40 Student Housing

Edith Cowan Drive, Joondalup, 6027

Perth, WA

Or call: (08) 94002040

Hope to hear from you

Yours,

Panagiota Karnaki

Edith Cowan University

Perth, Western Australia

Γράμμα ενημέρωσης

Αγαπητή Κυρία,

Το όνομα μου είναι Παναγιώτα Καρνάκη. Είμαι φοιτήτρια στον κλάδο επιστημών υγείας στο Edith Cowan University, Perth, Western Australia. Έχω έρθει στην Αυστραλία από την Ελλάδα για να τελειώσω τις σπουδές μου στον τομέα της προαγωγής υγείας.

Η έρευνα που κάνω αναφέρεται στις συνθήκες και τις γνώσεις των Ελλήνων γυναικών όσο αφορά το test Πανανικολάου. Στα πλαίσια της έρευνάς αυτής θα προσπαθήσω να πάρω συνέντευξη από Ελληνίδες κυρίες στην περιοχή του Πέριθ.

Θα ήθελα αν συμφωνείτε να συζητήσω μαζί σας, ανώνυμα, γύρω από θέματα που αφορούν το test Πανανικολάου. Η συζήτηση δεν θα έχει το χαρακτήρα test. Στοιχεί από την έρευνά να επηρεάσει τις συνθήκες και τυχόν δυσκολίες που αντιμετωπίζουν οι Ελληνίδες κυρίες όσο αφορά το συγκεκριμένο test, την γνώμη τους για το test και να επηρεάσει το test τους οποίους θα μπορούσε να γίνει καλύτερη και ευκολότερη για αυτές η διαδικασία.

Με λίγα λόγια θα ήθελα να διεξάγω μαζί σας μια συνέντευξη. Η συνέντευξη θα διαρκέσει περίπου μισή ώρα και θα λάβει μέρος όποιος είναι βολικά για εσάς. Η συζήτηση μας θα παραμείνει απόρρητη. Το όνομα σας θα είναι γνωστό μόνο σε έμένα και δεν θα υπάρξει γραμμένο πουθενά. Θα ήταν επίσης μεγάλη βοήθεια εάν είχα την άδεια σας να πραγματοποιήσω την συζήτηση μας. Το Πανεπιστήμιο μου με υποχρεώνει να κρατήσω το περιεχόμενο των κασετών για ορισμένο διάστημα. Αυτό γίγνε για να υπάρχει απόδειξη ότι πραγματικά έκανα την έρευνα μου. Μετά από ένα ορισμένο χρονικό διάστημα οι κασέτες καταστρέφονται. Οι κασέτες θα βρισκονται κλειδωμένες σε ειδική θύρα στην οποία θα έχω πρόσβαση μόνο εγώ. Για να μπορώ να ξεχωρίσω τις συζητήσεις θα αριθμήσω τις κασέτες με νομίσμα.

Εάν συμφωνείτε να πάρετε μέρος σε αυτήν την συζήτηση παρακαλώ γράψτε μου στην παρακάτω διεύθυνση:

Panagiota Karnaki
Unit 40 – Student Housing
Edith Cowan University
100 Joondalup Drive
Joondalup 6027

Το τηλέφωνό μου είναι **9400 20 40**
 Ευχαριστώ πολύ.

Καρινάκη Παναγιώτα

Appendix C

Consent form

I, _____, have read the information and understand all aspects of your study.

- I agree to participate in this study. I agree to take part in the interview and realize that I can withdraw at any time.
- I can stop the interview at any time.
- My responses to this study will not be identifiable.
- I have the right to check the tape recordings of my responses.
- My name will not be revealed in the event of this study being published

Participant:

Investigator:

Thank you very much for your participation.

Panagiota Karnaki

Φόρμα Συμφωνίας

Εγώ η _____ έχω διαβάσει και κατανοήσει όλες τις πτυχές της έρευνας

- ♦ Συμφωνώ να πάρω μέρος στην έρευνα και ξέρω ότι έχω το δικαίωμα να σταματήσω και να αποχωρίσω οποιαδήποτε στιγμή.
- ♦ Οι απαντήσεις μου θα παραμείνουν ανώνυμες.
- ♦ Έχω το δικαίωμα να ελέγξω τις κασέτες με τις συζητήσεις οποιαδήποτε στιγμή.
- ♦ Το όνομα μου δεν θα αναφερθεί πουθενά σε περίπτωση που η έρευνα δημοσιευθεί.

The participant

The investigator

Ευχαριστώ πολύ για την συμμετοχή

Παναγιώτα Καρνάκη

Appendix D**Confidentiality Statement**

I agree to translate from Greek language into English audiotaped interviews conducted for the research project of Panagiotia Karnaki. None of the participant's names are to be made available to me, and I agree that any other personal details revealed through the interviews will be held confidential.



Fotini Zachariades