QUALITY OF LIFE AND BARRIERS TO HEALTH CARE OF PROSTATE CANCER SURVIVORS RESIDING IN GAZA STRIP

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Nasser I. Abu-El-Noor

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Dissertation

Approved:	Accepted:
Advisor Dr. Raymond W. Cox III	Department Chair Dr. Raymond W. Cox III
Committee Member Dr. Sonia Alemagno	Dean of the College Dr. Chand Midha
Committee Member Dr. RaJade Berry-James	Dean of the Graduate School Dr. George R. Newkome
Committee Member Dr. Margaret Tonkin-Stephens	Date
Committee Member Dr. Kathleen Tusaie	

ABSTRACT

Prostate cancer is the second common type of cancer worldwide and in Palestine. The use of different treatment options helped prostate cancer survivors to get cured or to live for longer periods of time. Because of the several complications of treatment options, issues related to quality of life (QOL) became highly important in the decision of which option to use.

Many studies examined QOL of prostate cancer survivors and barriers to health care; but none was conducted in a developing country. The purpose of this study was to evaluate the level of QOL and to assess the barriers to health care as perceived by prostate cancer survivors who live in Gaza Strip.

The UCLA-PCI instrument was used to evaluate QOL. Barriers to health care were assessed by using a semi-structured interview. With a response rate of 97.98%, findings revealed that the scores of the general quality of life of prostate cancer survivors living in Gaza Strip were generally lower than those reported in the literature. The scores of Prostate-Specific Index fell within the range of scores reported in the literature. After calculating the t test, the differences between the results of this study and the results reported in the literature were found to be significant. The use of hormonal therapy and prostatectomy were found to be the most common treatment modalities used for treatment of prostate cancer in Gaza. Participants who were treated with prostatectomy reported higher scores of PCI QOL than those treated with hormonal therapy.

Participant reported several barriers to health care. These barriers were categorized under five major categories: 1) barriers due to unavailability, 2) organizational barriers, 3) geographical barriers, 4) socioeconomic barriers, and 5) barriers related directly to the blockage imposed on Gaza. Within each category several subcategories emerged.

Results served to recommend for several policy changes. The suggested health policy changes include: a) requesting physicians to inform patients about the pros and cons of different treatment modalities, b) introduce a prostate cancer screening policy, c) reconsider the referral policy to increase radiation therapy, and d) set policies designated to eliminate barriers to health care.

DEDICATION

This dissertation is dedicated to someone who is the closest to my heart in this universe. To my mother who was my biggest fan and biggest cheerleader. Mom, you are the breaths that I breathe and the candle that let the light for me during this long, long journey. You suffered a lot and tolerated a lot while I was away from you for more than three years at the time you needed me badly during your sickness and in spite of that, you were always supporting me and encouraging me to achieve my goal, I mean OUR goal. Mom, I love you so much. I love you more than anything else in this world. To you, mom, I dedicate this dissertation.

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LIST OF ABBREVIATIONS

ACS	American Cancer Society
ADT	Androgen deprivation therapy.
ANOVA	Analysis of variance
ASR	Age-standardized rate
ASR	The incidence age-standardized rate
AUA	American Urological Association
AUA	American Urological Association
DRG	Digital Rectal Examination
EORTC QLQ C30	European Organization for Research and Treatment of Cancer Core Quality of Life Questionnaire.
HPFS	Health Professionals Follow-Up Study
HPM	Health Promotion Model
HRQOL	Health related quality of life
HSR	Health Sector Review
ICRC	International Committee of Red Cross
I-CVI	Item content validity index.
KM	Kilometer
LDR	Low dose radiation
MoH	Ministry of Health

MOS	Medical Outcomes Study
NCI	National Cancer Institute
NGO	Non-governmental organizations
NIS	New Israel Shekel
PCBS	Palestinian Central Bureau of Statistics
PCI	Prostate Cancer Index
PCI	Prostate Cancer Index
PCOS	Prostate Cancer Outcomes Study
PLO	Palestinian Liberation Organization
PNA	Palestinian National Authority
PSA	Prostate-specific antigen
SBQ	Sexual Behavior Questionnaire.
SEER	Surveillance Epidemiology End Results
SF-36 v2	RAND 36-Item Health Survey v2
UCLA	University of California
UCLA	University of California, Los Angeles
UCLA-PCI	University of California Prostate Cancer Index
UN	United Nations
UNRWA	United Nations Relief and Work Agency
WHO	World Health Organization

CHAPTER I

INTRODUCTION

Because people live longer than ever before, the chances for people to develop chronic diseases including cancer, especially those types of cancers that appear at older ages such as prostate cancer among men, increase. Worldwide, the American Cancer Society (ACS) (2007a) estimates that the number of people who will be diagnosed with cancer will exceed 12 million new cancer cases in 2007 with approximately half of them residing at economically developed countries. According to the same report, an estimated 6.7 million will die from cancer in 2007, with approximately two thirds of them residing in developing countries (American Cancer Society, 2007a).

Most Common Types of Cancer

Prostate cancer is the second common type of cancer worldwide and it is the 6th leading cause of cancer –related deaths among men worldwide (American Cancer Society, 2007a). The three most common types of new cancer cases among men in developed countries are prostate, lung and bronchus, and colorectal cancers. Prostate cancer is ranked as the second most common cause of cancer-related deaths in developed countries (see Table 1-1). While the most common three types of new cases of cancer in developing countries are lung and bronchus, stomach, and liver, prostate cancer ranks as the 6th common type of cancer and the 6th common cause of deaths due to cancer in these countries (Table 1-1) (American Cancer Society, 2007a). The variation of the numbers of prostate cancer between developed and underdeveloped countries can be related to one of two reasons: increased detection and the fact that prostate cancer can be slow growing and therefore not detected until death from some other cause. To illustrate the variance of the incidence of cancer –including prostate cancer- and cancer related deaths between developed and underdeveloped courtiers, a comparison of cancer incidence and death related to cancer from Palestine and USA will be used). First, it could be due to the early screening of prostate cancer using prostate-specific antigen (PSA), which is used in early detection of prostate cancer in developed countries. Due to the use of PSA, incidence of prostate cancer increased rapidly between 1988 and1992, then declined sharply in the United states from 1992-1995 (American Cancer Society, 2007b). Additionally, the

Table 1-1: Comparing New Cases of Prostate Cancer and Deaths Related to Prostate Cancer Worldwide, Developed Countries and Developing Countries. (Source: American Cancer Society, 2007a)

	New cases		Deaths		%
	Rank	Cases	Rank	Cases	
Worldwide	2	782,647	6	253,906	32.4%
Developed Countries	1	566,841	3	143,834	25.4%
Developing Countries	6	194,914	6	106,537	54.7%

availability of other diagnostic technologies that help in early diagnosis of prostate cancer such as transrectal ultrasound and the improved techniques for prostate biopsy may have contributed to the increase in diagnosis over this period (Hoff & Pow-Sang, 2001).

Second, it could be due to the fact that prostate grows slowly and can go undetected. According to the American Cancer Society (2008), autopsy studies showed that many older men (and some younger men) who died due to other diseases also had prostate cancer that never caused a problem to them while they were alive and neither they nor their doctors were aware of. Furthermore, the American Cancer Society (2010) estimates that one man out of each six American men will develop prostate cancer during his life time.

The probability of developing invasive prostate cancer increases with age. The probability increases from 2.59% (1 in 39) between the ages 40-59 to 7.03% (1 in 14) at the ages 60-69 to 13.83% (1 in 7) at the age of 70 and older (American Cancer Society, 2007b). While prostate cancer is considered one of the most common cancers among males, the survival rates have improved in recent years. Between 1996 and 2002, the five-year relative survival rates for prostate cancer in the United States (the chance of living 5 years after being diagnosed with prostate cancer) was 99.9% at all stages of cancer and 100% if the cancer was local (American Cancer Society, 2007b).

In Palestine, according to the Ministry of Health (MoH) annual report (2006), a total of 1,623 (1,168 in the West Bank & 455 in Gaza Strip) new cancer cases were reported in 2005 with an incidence rate of 43.1 per 100,000 population, (49.2 per 100,000 in the West Bank and 32.7 per 100,000 in Gaza Strip). Of the reported new cases, 44.8% of them were males, and 55.2% were females.

The most common reported types of cancer among Palestinian males (Figure 1-1) in 2005 was lung cancer (13.8% of total new cancer cases among males) followed by prostate cancer (11.3% of total new cases among males with an incidence rate of 4.6 per 100,000 males). About 134 new prostate cancer cases were reported in the years 1998 and 1999. Most of the reported cases (110) were reported in West bank and the rest of cases (24) were reported in Gaza Strip (Ministry of Health, 2005). In general, 106 new prostate cancer cases (Table 1-2) were reported in Gaza Strep between the years 1995 and 2000. The majority (78.3%) of these cases were reported after the age of 60 (Table 1-3) with a peak incidence (25.5%) between the ages of 65-69. The total incidence rate of prostate cancer in Gaza Strip between 1995 and 2000 was 3.45 per 100,000 of the population (Najjar, Awad, & Thabet, 2002).

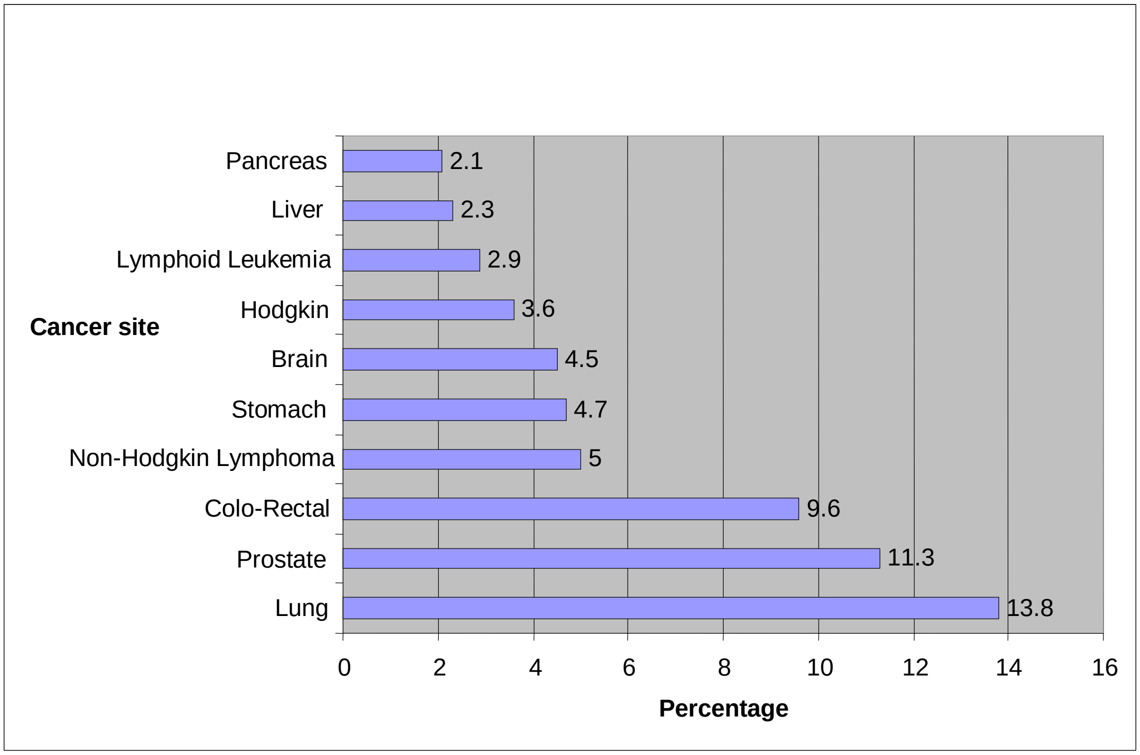


Figure 1-1: Common Types of Cancer among Males in Palestine. (Source: MoH, 2006)

Table 1-2: Distribution of New Prostate Cancer Diagnoses by Year in Gaza Strip, Palestine 1995-2000. (Source: Najjar, Awad, & Thabet, 2002)

Year	Number of Reported Cases
1995	16
1996	17
1997	28
1998	11
1999	13
2000	21
Total	106

Table 1-3: Incidence Rate of Prostate Cancer by Age Group in Gaza Strip, Palestine 1995-2000. (Source: Najjar et al., 2002)

Age group	**Cases**	**Percent**	**Rate per 100,000**
45-49	3	2.8	4.44
50-54	7	6.6	14.02
55-59	13	12.3	32.26
60-64	24	22.6	60.77
65-69	27	25.5	86.30
70-74	14	13.2	65.19
75+	18	17.0	76.02
Total	**106**	**100**	**3.45**

Of the total 1,048 deaths that occurred in 2005, malignancy was the third leading cause of death (10.3% of total death cases) in total population of Palestine after heart disease (21% of total death cases) and cerebrovascular diseases (11% of total death cases) (MoH, 2006). Cancer was the second leading cause of death among males (10.6%) and among the young population between the age of 20-59 years old (18.5%). The most common cause of death related to cancer among the total population was

Trachea, Bronchus & lung cancer which constituted 15.4% of all cancer-related deaths. Prostate cancer was the ninth leading cause of cancer-related deaths (5.3%) among the total Palestinian population and the second leading cause (9.5%) of cancer-related deaths among males (MoH, 2006).

In the United States, the number of people who were living with cancer in the year 2005 was estimated to be about 11.1 millions. About 1,479,350 new cases of cancer were estimated to be diagnosed in year 2009 (these numbers don’t include some types of skin cancer which are believed to be around one million new case) (American Cancer Society, 2009). Prostate cancer is the most common type of cancer diagnosed in men in the United States. Of the 1,479,350 new cases expected to be diagnosed in 2009, an estimated 192,280 new prostate cancer cases were expected to be diagnosed in 2009 (American Cancer Society, 2009).

Cancer is the second leading cause of death in the United States after heart disease. According to the American Cancer Society (2009), 25% of deaths occur in the United States due to cancer. Of the 562,340 expected deaths in 2007 due to cancer, about 27,360 of them were expected to be due to prostate cancer which is considered the second cause of cancer-related deaths in males after lung and bronchus cancer (American Cancer Society, 2009).

Treatment of Prostate Cancer

Depending on age, stage of cancer, and other disease conditions, treatment for prostate cancer may include surgical removal of the prostate gland (prostatectomy), radiation therapy, or watchful waiting (American Cancer Society, 2007b; Fleming, Wasson, Albertsen, Barry, & Wennberg, 1993) and watchful observation (Hoff & Pow-Sang, 2001). Hormonal or chemotherapy can be added to treatment regimen depending on the case (American Cancer Society, 2007b; American Cancer Society, 2009; Fleming, et. al, 1993).

In Gaza Strip, the most common type of primary treatment used to treat men with prostate cancer is surgical treatment. About 62.5% of total prostate cancer patients were treated surgically, 28.6% received chemotherapy, and 66.7% received hormonal therapy (Najjar et al., 2002). Men with prostate cancer do not have the advantage of being treated with radiation therapy as the Palestinians were denied by the Israelis to have this type of treatment. On some occasions, the Palestinian’s Minister of Health (MoH) refers some patients to receive radiation therapy treatment in neighbor countries such as Egypt. In the last 3 years (2007-20010?), due to the sanctions imposed on Palestinians in Gaza Strip after the 2006 elections and the partial or complete closure of the borders between Gaza Strip and Egypt, very few patients were referred to be treated outside Gaza Strip.

The use of each treatment modality has its own complications and side effects and each of the available treatment modalities has several long-lasting complications that may negatively impact the quality of life (Albaugh & Hacker, 2005). For example, the complications of radical prostatectomy include urinary symptoms and impotence due to trauma and removal of the neurovascular bundle adjacent to the gland (Woolf, 1995; Clark et al., 2003; Turini et al., 2003; Ward et al., 2004; Albaugh & Hacker, 2005).

Compared to surgical removal of the prostate, radiation therapy causes fewer sexual side effects (D’Amico et al. 1997), but still causes some erectile problems for men

(Potosky et al. 2004) and other urinary complications such as urinary incontinence and irritation (Brandeis, Litwin, Burnison, & Reiter, 2000). Radiation can also cause several bowel related complications such as frequency, urgency, diarrhea, fecal incontinence, pain during bowel movement, proctatitis, and blood in the stool (Sommers & Ramsey, 1999; Albaugh & Hacker, 2005).

Hormonal therapy commonly leads to sexual problems such as impotence; decreased libido, and erectile dysfunction; gynacomastia (increase breast size in men); weight gain, hot flashes, sleep disturbances, fatigue, altered mood and depression; and osteoporosis (Sommers & Ramsey, 1999; Potosky et al., 2002; Penson & Litwin, 2003; Turini et al., 2003; Albaugh, & Hacker, 2005). Melmed, Kwan, Reid, & Litwin(2002) further added that hormonal therapy is associated with diminished quality of life (QOL) because of subsequent deterioration in physical function and pain as measured by the domains in the SF-36 health assessment tool.

In spite of introducing no treatment, watchful waiting has its own psychological consequences. These consequences include stress, anxiety, and fear of the unknown (Chodak & Warren, 2006). On the other hand, men who choose watchful waiting may also report some bladder problems such as frequency, urgency, incomplete bladder emptying as the growing tumor will lead to obstruction of the bladder neck. Watchful waiting may also result in metastasizing to other organs including bone and severe bone pain and fractures will negatively impact their QOL (Chodak & Warren, 2006; Albaugh, & Hacker, 2005).

Chemotherapy therapy also has side effects that includes, but is not limited to, nausea, vomiting, alopecia (hair loss), diarrhea, bone marrow suppression (which affects the production of red and white blood cells therefore causes anemia and lowers the immune system of the patient) (Kalant, Grant, & Mitchell, 2007).

The diagnosis of cancer, treatment, and complications and side effects of treatment modalities can result in considerable suffering for the patients and affect their physical, psychological, and emotional well being. Such alteration of patients' well being will affect their quality of life. Survivals of prostate cancer in developing countries, including Gaza Strip, may not have the same quality of life as their counterparts in other parts of the world as they do not have the privilege of radiation therapy and have several barriers to health care whether due to availability of services or accessibility of health care. Therefore, prostate cancer may be diagnosed later, at more advanced stages requiring the use of more aggressive therapy such as hormonal and chemotherapy in their treatment regimen. Late diagnoses of their prostate cancer and the use of hormonal and/or chemotherapy may worsen their health related quality of life.

Policy Implications

Because the survival rate for prostate cancer is favorable regardless of the type of treatment, the treatment decision may depend on some specific health-related outcome that may affect the quality of life of the patient (Potosky et al., 2000). For men who live in Gaza Strip and are diagnosed with prostate cancer, the chances of getting treated with radiation therapy are small because of the blockade imposed against Gaza Strip for the last three years. The use of radiation therapy produces fewer complications than surgical treatments (Potosky et al., 2000) and the use of chemotherapy (in 28.6% of cases) and hormonal therapy (in 66.7% of cases) in patients who have prostate cancer in Gaza Strip (Najjar, et al., 2002) may produce additional side effects and complications for these patients. The lack of radiation therapy along with the presence of several barriers to health care may affect the quality of life for patients in this population.

The reported results about the level of quality of life of Gaza men who were diagnosed with prostate cancer were compared with the results of quality of life of prostate cancer survivors reported in the literature to examine if there was any difference in the scores of their quality of life. After examining the results of this study, several recommendations for policy makers were made. These recommendations included requesting treating physicians to discuss with their patients, the pros and cons of the different treatment options, plan to provide radiation therapy as a long strategic goal and to provide referrals for radiation therapy at the short term goal, form a plan for prostate cancer screening, and eliminating different barriers to health care.

The budget of the Palestinian ministry of health is very limited. It was only 134,222,222 US dollars in 2004 excluding the expenditures for treatment abroad. The cost of treating 31,744 patients abroad was more than 58 million US dollars which constituted about 45.9% of the actual health expenditures at that year (Ministry of Health, 2005). The result of this study provides the Palestinian health policy decision makers with a background about the importance of establishing a radiation therapy center in Gaza Strip which can contribute to the improvement of quality of life of most of cancer patients including those who have prostate cancer and will save several millions of dollars that can be used in another venue to improve the overall health of the Palestinians.

Furthermore, the results of this study served to make recommendations for health policy makers in Gaza Strip to eliminate barriers to health care reported by participants. Eliminating or reducing any identified barriers will help to improve the quality of the services provided to prostate cancer men who live in Gaza Strip and will improve their quality of life.

Such issues are not as easy as they may sound as the Palestinian decision making regarding several issues is contingent upon the overall political situation in the area. The results of this study should inform Palestinian decision makers, along with the results of other similar studies in the event that what Kingdon (1995) called the “policy window” will open and they will have the opportunity to introduce their plans to improve the health status of the Palestinians. This window does not open often and when it does, it may stay open for only a short period of time. In fact, it is anticipated that the window will open with the inauguration of the new president for the United States who promised to work hard to bring peace to the Middle East.

The barriers to health care identified in this study will also be introduced to Palestinian health care decision makers for assessment and possible modification to the current health care system. Such changes will help men with prostate cancer and other categories of patient, to better utilize and access the health care system and consequently improve their quality of life.

Purpose of the Study

The purpose of this study was to evaluate the quality of life of prostate cancer survivors of men residing in Gaza Strip and to assess the barriers to health care they face through their treatment period. The results of this study should assist health care providers in counseling patients on the method of treatment for prostate cancer that offers the patient the best quality of life and help patients make their decision about the preferred treatment approach to their prostate cancer. The result of this study will help policy makers to evaluate the current policy or adopt a new policy toward the available prostate cancer treatment modalities to ensure better quality of life for prostate cancer survivors who live in Gaza Strip.

Furthermore, the study will help to identify the barriers that prostate cancer survivors face through their treatment journey. Identifying such barriers will help policy makers to change or manipulate current policies in an attempt to overcome these barriers. Additionally, the study seeks to provide information for health care providers to meet the concerns and needs of prostate cancer survivors through reporting quality of life issues.

The specific aims of this study are to:

1. Describe the level of perceived quality of life among men with prostate cancer who live in Gaza Strip.
2. Examine if there are any differences in the level of perceived quality of life among men with prostate cancer who live in Gaza Strip and receive treatment and men who finished their treatment.

3. Identify barriers to health care that face men with prostate cancer who live in Gaza Strip during their treatment period.

Problem Statement

A few decades ago, a diagnosis of cancer was usually associated with fear of death, disablement, and physical limitation from not only the cancer itself, but also from debilitating treatment and its complications. When a man is diagnosed with prostate cancer, additional fears of becoming impotent or infertile are other major concerns (D'Amico et al. 1997; Turini et al., 2003; Potosky et al., 2004; & Albaugh & Hacker, 2005). However, due to medical advancements in treatment and early diagnosis for most kinds of cancer, including prostate cancer, increasing numbers of patients are surviving those cancers, remain free from cancer for the rest of their lives, or live with less pain and/or physical limitations. To help these people live in a more decent life, quality-of-life issues should be considered for this vulnerable group of patients and barriers that impede the availability and accessibility to health care services should be overcome and eliminated to help them live through their experience of surviving cancer and its treatment and live in a better quality of life.

Therefore, assessing quality of life issues for prostates cancer survivors and identifying barriers to their health care will help them to access health care, improve quality of provided care, and help health care professionals to be more sensitive to their patients' needs and concerns to improve the quality of life for this vulnerable population. This issue is more evident in developing countries as they lack the medical advancements their counterparts in the developed countries enjoy (American Cancer Society, 2007a). When it comes to the Palestinian population in Gaza, quality of life for prostate cancer survivors and barriers to health care will be even more evident as this vulnerable population resides under blockade and economic sanctions since April 2006 which affects the drug supply and equipment needed for their treatment. Such blockage deprives patients, including prostate cancer patients, the opportunity to travel to Egypt or other countries to receive treatment. The impact of the blockade may affect the quality of life of this group of patients and contribute to several barriers to health care (World Health Organization: West bank & Gaza (2010)

Despite a relatively large number of studies that examined quality of life of prostate cancer survivors and barriers to health care in developed countries, little is known about the quality of life of prostate cancers and barriers to health care in the developing countries and none is known about the quality of life of prostate cancer survivors and barriers to health care among the Palestinian population of Gaza. This lack of knowledge stems from the fact that, to date, no research was performed to examine these topics in this particularly vulnerable population.

Conceptual Framework

The revised Health Promotion Model (HPM) was chosen to serve as the conceptual framework for this study. The original Health Promotion Model was initially introduced by Dr. Nola Pender in 1996 (Pender, 1996), and then revised in 2002 (Pender, Murdaugh, & Parsons, 2002). This model attempts to explain the complex biopsychosocial processes that motivate humans to practice activities that are directed toward enhancing their health and well-being (Pender, 1996, p. 51-52) rather than preventing disease occurrence.

Even though Pender (1996) recognizes that fear or threats to health may serve as motivators for people to avoid illness, she argues that such avoidance-oriented models of health behavior have limited usefulness when it comes to adolescents? and adults who see themselves as invulnerable to illness. In contrast to avoidance-oriented models of health behavior, the applicability of the Health Promotion Model is not limited to those who have fears or threats to their health and therefore it has the potential to motivate people toward promoting their health and wellness across the life span including those who do not have any apparent fears or threats to their health (Pender, 1996, Pender et al., 2002).

The revised Health Promotion Model is based on several assumptions that include (Pender et al., 2002:63):

1. Persons seek to create conditions of living through which they can express their unique human health potential.
2. Persons have the capacity for reflective self-awareness, including assessment of their own competencies.
3. Persons value growth in directions viewed as positive and attempt to achieve a personally acceptable balance between change and stability.
4. Individuals seek to actively regulate their own behavior.
5. Individuals in all their biopsychosocial complexity interact with the environment, progressively transforming the environment and being transformed over time.
6. Health professionals constitute a part of the interpersonal environment, which exerts influence on persons throughout their lifespan.
7. Self-initiated reconfiguration of person-environment interactive patterns is essential to behavior change." (Pender et al., 2002:63)

As the HPM attempts to “depict the multidimensional nature of the persons interacting with their interpersonal and physical environments as they pursue health” (Pender et al., 2002, p. 61), it integrates several constructs and propositions from the expectancy theory (Feather, 1982) and the social learning theory (Bandura, 1986). The theoretical statements derived from the HPM provide a basis for investigative work on health behaviors. The Health Promotion Model is based on the following theoretical propositions (Pender, et al., 2002, p. 63-64):

1. Prior behavior and inherited and acquired characteristics influence beliefs, affect, and enactment of health-promoting behavior.
2. Persons commit to engaging in behaviors from which they anticipate deriving personally valued benefits.
3. Perceived barriers can constrain commitment to action, a mediator of behavior as well as actual behavior.
4. Perceived competence or self-efficacy to execute a given behavior increases the likelihood of commitment to action and actual performance of the behavior.
5. Greater perceived self-efficacy results in fewer perceived barriers to a specific health behavior.
6. Positive affect toward a behavior results in greater perceived self-efficacy, which can in turn, result in increased positive affect.
7. When positive emotions or affect are associated with a behavior, the probability of commitment and action is increased.
8. Persons are more likely to commit to and engage in health-promoting behaviors when significant others model the behavior, expect the behavior to occur, and provide assistance and support to enable the behavior.
9. Families, peers, and health care providers are important sources of interpersonal influence that can increase or decrease commitment to and engagement in health-promoting behavior.
10. Situational influences in the external environment can increase or decrease commitment to or participation in health-promoting behavior.
11. The greater the commitment to a specific plan of action, the more likely health-promoting behaviors are to be maintained over time.
12. Commitment to a plan of action is less likely to result in the desired behavior when competing demands over which persons have little control require immediate attention.
13. Commitment to a plan of action is less likely to result in the desired behavior when other actions are more attractive and thus preferred over the target behavior.

14. Persons can modify cognitions, affect, and the interpersonal and physical environment to create incentives for health actions." (Pender et al., 2002, p. 63-64).

According to the revised HPM (Figure 1-2), there are three main constructs that influence human behavior toward health promotion. The first two sets of constructs are: individual characteristics (which include the following two constructs: prior related behavior and personal factors), and behavior-specific cognitions and affect (which includes the following six variables: perceived benefits of action, perceived barriers of action, perceived self-efficacy, activity-related affect, interpersonal influence, and situational influence). These two sets of constructs will lead to a "commitment to a plan of action" which will propel individuals toward embracing and practicing behaviors that promote their health unless if there were some "immediate competing demands and preference" that the individual can't avoid or resist intervenes. If the "commitment to a plan of action" was not derailed by the "competing demands and preference," the result will be the third variable, the "behavioral outcome" which includes the desired health-promoting behavior (Pender et al., 2002, p. 63-64).

The behavior-specific cognitions and affect constructs are considered of major importance and constitute a significant core for intervention by health care providers because they can be modified by specific interventions (Pender, et al., 2002, p. 63-64).

The HPM includes activities that are directed toward developing resources that enhance or maintain one's well-being. It can be inferred that there are two phases embedded in the model to promote health; the decision making phase and the action phase. The decision making phase includes factors that motivate individuals to maintain and enhance their health-promoting behaviors and indirectly influence patterns of their

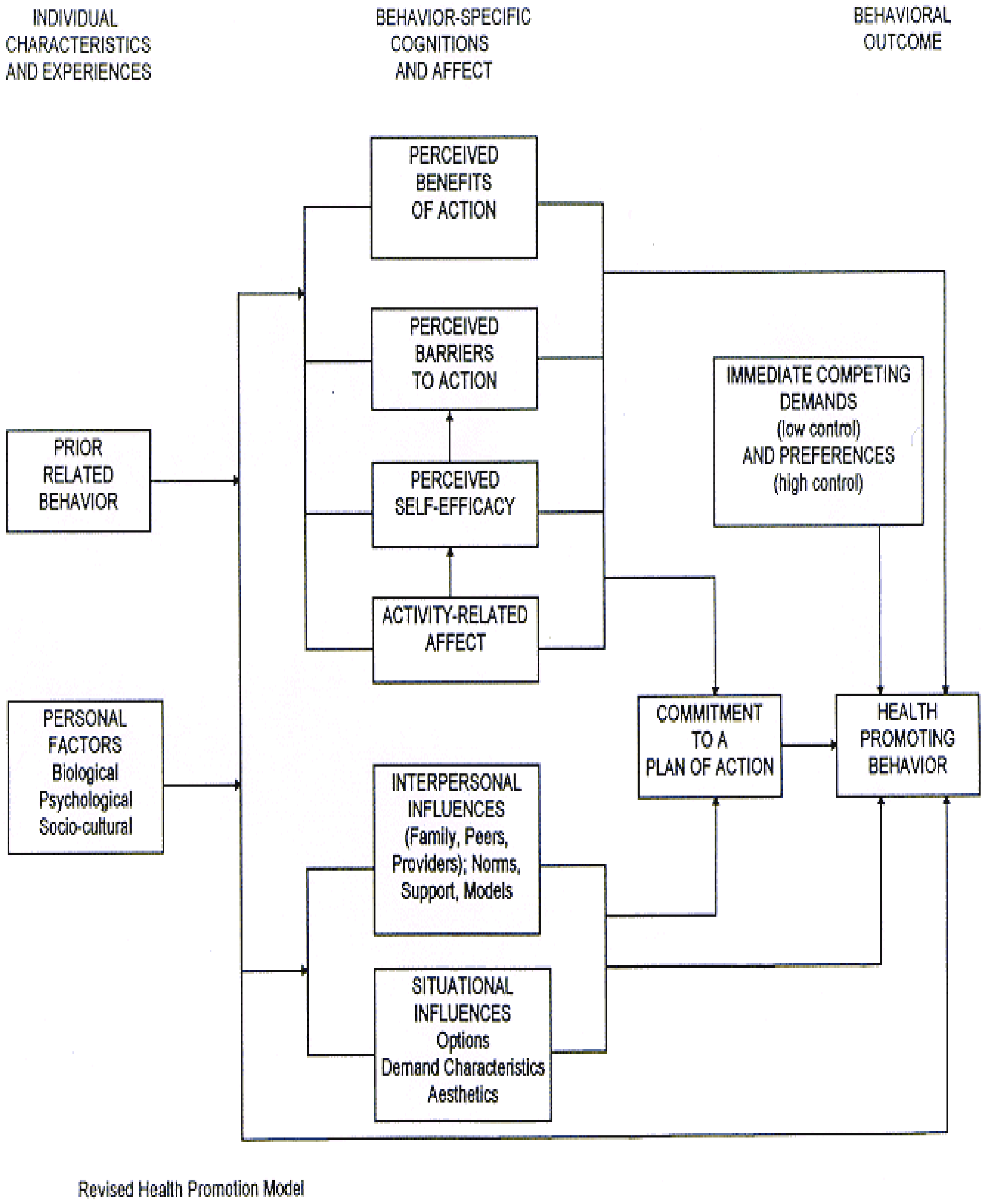


Figure 1-2: Revised Health Promotion Model. Sources: (Pender et al., 2006, p.50).

health behaviors while the action phase clarifies how barriers and cues to action trigger activities in health-promoting behaviors (Polit & Beck, 2004). Based on the revised Health Promotion Model (Pender et al., 2002), there are many factors involved in the patient's decision making about treatment options for prostate cancer, including psychological, socio-cultural, biological, and environmental factors, other's experience, barriers to health care, as well as prior related behavior. These and other factors will form how the patient thinks about and evaluates the benefits, obstacles, and complications of the different treatment options and in turn influence his decision about making the right choice of the available treatment options.

Assessing barriers to health care and quality of life for prostate cancer survivors of men residing in Gaza Strip will help in the decision making process by providing more information to those who will be newly diagnosed with prostate cancer. Those new cases will be better able to assess the perceived benefits, perceived barriers, and the perceived-self efficacy of each treatment option and how it will affect their quality of life. Assessing barriers to health care and evaluating the quality of life for people who had different methods of treatments will help to guide those newly diagnosed men to assess the perceived benefits, the perceived barriers, and the perceived self-efficacy of each treatment modality and make their decisions based upon the quality of life and the magnitude of barriers they are expecting from each treatment modality.

Other factors that may intervene in decision making include interpersonal influences and situational influences. Interpersonal influences include the effect of family, peers, friends, other men who received different treatment modalities, and health care professionals on their decision. Situational influences include the ability to pursue specific treatment modalities especially that most of the decisions to be made are suspended and depend completely on the political situation in the area. For example, if a patient chooses to receive radiation therapy, which is not available in Gaza Strip, and needs a referral to Egyptian, Israeli, or other hospitals outside Gaza Strip, he may not be able to have such a treatment for several months or years because of the Israeli closure of the borders of the Gaza Strip. Other choices for treatment will be affected by this blockade since the closure of borders affects the availability of hormonal and chemotherapy choices and affects the availability of instruments and anesthetic agents that are required for the surgical choice.

Since the Health Promotion Model proposes that health promotion involves activities directed towards enhancing or maintaining an individual's well-being, assessing quality of life for prostate cancer survivors of men residing in Gaza Strip and identifying barriers to health care will be of great benefit. Such assessments will also help those who are receiving treatment and those who already have received treatment. Knowing the factors that impact quality of life and identifying barriers to health care may lead to changes in current policies to reshape the environment to serve to enhance quality of life of prostate cancer survivors by eliminating those barriers to health care and factors that deter quality of life and enhance factors that improve quality of life of prostate cancer survivors.

Assessment of quality of life of prostates cancer survivors and identifying barriers to health care will also enhance the knowledge of health care professionals about the factors and behaviors that enhance quality of life and try to reinforce these factors and the barriers and factors that interfere with quality of life and try to avoid them and find suitable solutions to come over them. Assessing quality of life of prostate cancer survivors and identifying barriers to health care will help policy makers in Palestine to change current policies (or adopt new ones) that relate to treatment options available to treat prostate cancer and to overcome barriers to health care and improve the quality of life of life of prostate cancer survivors.

After going through the process of decision making about making the decision of treatment option or about health promotion after receiving treatment, the patient will chose the option that he thinks it will give him the best quality of life and will promote his health in his surrounding circumstances. The patient, then, will set an action of plan for health promotion. This plan, of course, will depend upon the situational factors that may enhance or disrupt his action plan.

Research Questions

This study addressed the following questions:

1. What is the level of the perceived quality of life of prostate cancer survivors who live in Gaza Strip?
2. Are there any differences of the perceived quality of life issues reported by prostate cancer survivors who live in Gaza Strip and currently receiving treatment and those who had finished their treatment?
3. What are the barriers to health care faced by prostate cancer survivors living in Gaza Strip during their treatment period?

Summary

Prostate cancer is the most common type of cancer among males in the developed countries and it is the second common type of cancer among males in Palestinian and in the world. There are several treatment modalities that are available to treat prostate cancer. Radiation and surgical removal of the prostate gland are the most common types of treatment. In Gaza Strip, surgical removal of prostate cancer is the most commonly used method of treatment. Hormonal and chemotherapy are used as adjunct methods for treatment. Radiation therapy is rarely used to treat prostate cancer patients of Gaza as up to the moment; there is no radiation therapy center available in Gaza. Some patients are referred to other countries to receive radiotherapy, which exhaust the already limited budget of the Palestinian ministry of health. Each of the available treatment modalities will have a different impact on the quality of life for prostate cancer survivors.

Assessing barriers to health care and the quality of life of prostate cancer survivors of men living in Gaza strip will help health care providers to identify and address the barriers they face, provide them with more information about the impact of each treatment modality on their quality of life, and inform their decisions about the method of treatment. The result will help Palestinian policy makers to change the related current policies or adopt new polices that will help to overcome barriers to health care and improve the quality of life of prostate cancer who reside in Gaza Strip.

CHAPTER II

LITERATURE REVIEW

This chapter involves several parts of literature review that that relates to the contents of this dissertation study. This involves a general background about Gaza Strip, the health care system and policy process in Palestine, the policy process and pathopysiology of prostates cancer. This is besides a review of the literature that relates to quality of life of cancer patients involving prostate cancer and finally literature that relates to barriers to health care.

A Preview about Gaza Strip

The territories of the Palestinian National Authority (PNA) (Figure A-1) consist of two geographically separated areas known as the West Bank and Gaza Strip. The Gaza Strip is a narrow strip of land that lies along the southeastern coast of the Mediterranean Sea. It is about 41 KM (about 25 miles) long and 6 to 12 KM (4-7.5 miles) in width. The geographical area of the Gaza Strip is estimated at 360 square kilometers (about 139 square miles) (Ministry of Health, 2004). In July, 2008, the population of Gaza was estimated to be 1,500,202 (Central Intelligence Agency, 2009).

In 1967 Israel occupied Gaza Strip and West Bank. After series of demonstrations against Israeli occupation, Israel with the Palestinian Liberation Organization (PLO) signed several agreements between September 1993 and September 1999 that resulted in interim self-government for Palestinians in Gaza and West Bank populated areas. Israel kept control on most of the land between the Palestinian cities. The Palestinian National Authority (PNA) became responsible for administering civilian issues such as education, health, and municipality in the Palestinian-populated areas of the West Bank and Gaza (Central Intelligence Agency, 2009).

In September 2005, Israel decided to withdraw its military soldiers and settlers from Gaza Strip and keeping control over all borders of Gaza Strip. This allowed it to control the entrance of all goods to Gaza including medical supplies. The only way Palestinians can leave Gaza Strip is through the borders with Egypt which was administered by Palestinians and monitored by Europeans. After the result of the 2006 elections which resulted in the win of the Islamic Resistant Movement (HAMAS) of the Palestinian Legislative Council, the international community lead by Israel and the United States refused to deal with a government lead by HAMAS and economic sanctions and blockade were imposed against Gaza Strip including the port between Gaza and Egypt. Sanctions and blockage were tightened after taking one Israeli soldier as a prisoner by some Palestinian fighters in June 2006. In June 2007, clashes between HAMAS and FATAH, the other major political group in Palestine, ended with HAMAS taking over all government and military institutions in Gaza (Central Intelligence Agency, 2009).

After that date, the Palestinians have two governments, one headed by HAMAS and resided in Gaza, and the other one appointed by President Abbas and resided in Ramallah at West Bank. As a result, sanctions and blockade against Gaza were severely tightened until Israel started to prevent fuel and electricity to get to Gaza. The port between Gaza and Egypt now is completely blocked. For further information about Gaza Strip, please refer to appendix A.

Health Care System and Health Policy in Palestine

The health care system in Palestine is relatively a novice system. It became independent from the Israeli system in 1994. For any health care system, there are several requirements that should be available to be a successful system.

Component of a Successful Health Care System

According to Janecka (2009), “a system consists of a large number of variable components engaged in ongoing relationships” (p. 2) to achieve a certain goal. Usually, systems have integrated subsystems and are internally adaptive to the surrounding environment to be successful. Failure of a system to adapt will result in chaos and therefore failure (Janecka, 2009). In its report issued in 2000, the World Health Organization (WHO) defined a health care system as “all the activities whose primary purpose is to promote, restore or maintain health” (p. 5). Further, WHO (2000) identified three fundamental objectives for health care systems. These objectives are: “improving the health of the population they serve; responding to people’s expectations; and providing financial protection against the costs of ill-health” (p. 8). Since these objectives are not always met, the result will be public dissatisfaction of their local health care systems (WHO, 2000).

For a successful health care system, it should incorporate all of its subsystems into the larger system (Janecka, 2009). A health care system consists of health care services, health care professionals, health organizations, and a government. The health care system has three integrated components: clients who need health services, professionals who provide health care services, and the public and private health care institutions that regulate, organize, finance, and coordinate these services (Library Index, 2009). Others added components to the health care system such as accessibility, affordability, equitability, sustainability, and good quality (Meadowcroft, 2008; WHO, 2000). For example, Meadowcroft (2008) mentioned that at the United Kingdom’s health care system, they tried to isolate the ability to access health care from the ability to pay and make it available to citizens regardless of their income, wealth, occupation, or contribution. Furthermore, Georgetwon University, Child Development Center (2009) added more components that relate to children health but can be applied to general health care systems. Besides access to health care services and treatment, these components include: management of health care data and information, coordination care, collaboration among systems, monitoring and evaluation, education and training, and funding strategies.

Given the fact that health care systems are the means to implement countries’ health care policies and approaching the nations’ health needs make them important

(WHO, 2006). Therefore, evaluating the performance of the health care system is a crucial issue. In order to evaluate any program, its goals and how they were implemented should be reviewed (Bamberger, Rugh, & Marby, 2006). Therefore, the performance of any health care system is evaluated through its achievement of its goals and how these goals were implemented (Roemer, 1991 as cited by WHO, 2000). Based on that, the WHO (2000) depicted the relationship between the function of a health system and its outcome in a figure that was revised in 2006. This figure (Figure 2-1) identifies that system functions (stewardship, resources creation, financing, and service delivery) determine the outcomes of the system. If these functions were implemented efficiently

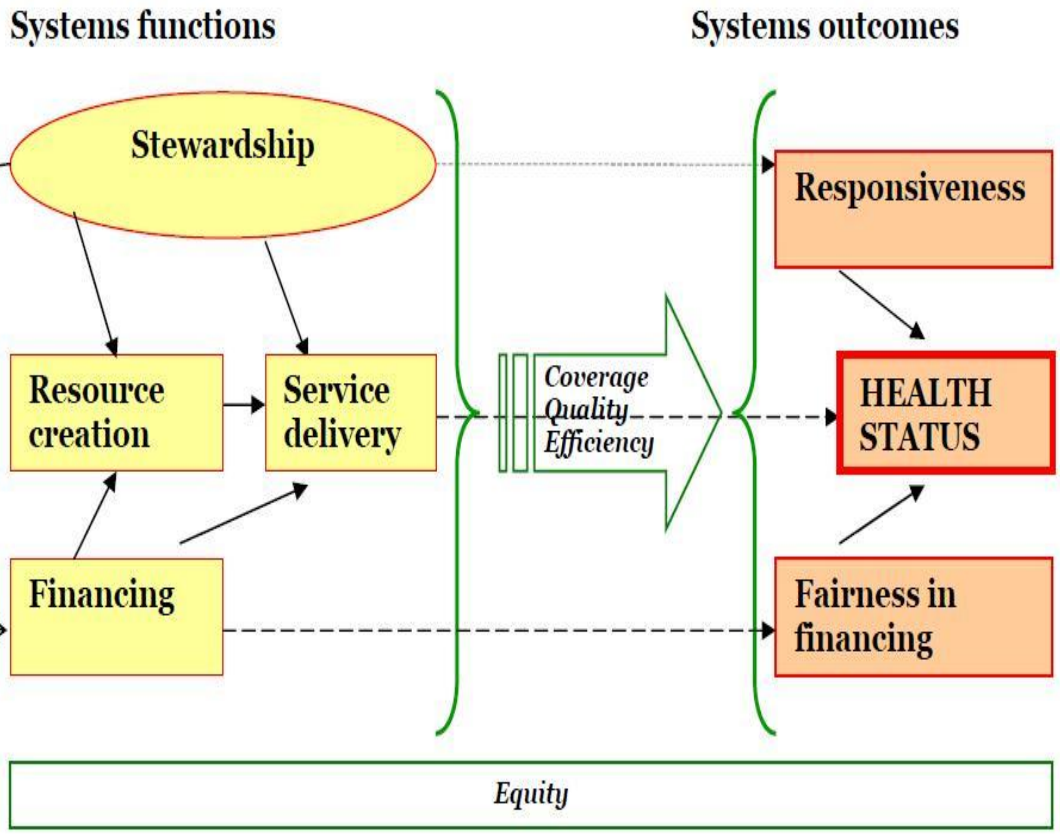


Figure 2-1: Health Systems Functions and Outcomes. Source: WHO (2006, p. 5)

and in good quality, the system will successfully provide the intended outcomes. The figure also assumes that equity is applied during the process of implantation.

Finally, WHO recommended an operational framework that consists of "five steps for integrated health care system strengthening at the country level. This framework includes the following (WHO, 2006, p.17):

“Building evidence for analysis of systems issues

⇩

Identifying the key systems constraint on national health goal.

⇩

Getting political support.

⇩

Developing a strategy for overcoming systems constraints.

⇩

Identifying a platform for advocacy and discussion”.

The Health Care System in Gaza

Before the establishment of the Palestinian National Authority (PNA) in 1994, the Palestinian health care system was highly connected to the Israeli system. The department of health was chaired by an Israeli officer assigned by the Israeli administration. A report by the WHO described the Palestinian health care system in 1989 as ‘disturbing’. The report referred this disturbance to the lack of a structured health care system and to the lack of independency from the Israeli system (World Health Organization, 2001).

The health care system in Gaza Strip consists of four main health providers: the Ministry of Health, the non-governmental organizations (NGOs), the United Nations Relief and Work Agency (UNRWA), and the private sector. The governmental health services are open to all Palestinians who hold health insurance. The UNRWA offers its services to the Palestinian refugees (people who were expelled from their cities and villages by Israelis in the war of 1948) who live in refugee camps (Ministry of Health, 2005).

The Ministry of Health is the principal health care provider in Gaza Strip and Palestine (MOH, 2006). Furthermore, it is responsible for ensuring a well-governed health system in Palestine. Besides providing health care, the MoH is responsible for regulation and legislation, public health activities, surveillance, human resources development, and financing (World Health Organization, 2005). It runs 12 out of the 24 hospitals available in the Gaza Strip and 1,548 beds out of a total of 2,053 beds. The rest of the available beds are operated by 10 non-governmental organizations (NGOs) and two private hospitals (Ministry of Health, 2006). The ratio of beds to population is 14.2 beds per 10,000 people. Of the 2,053 beds available in Gaza, only 50 beds are designated for oncology patients (Ministry of Health, 2006). These beds are distributed between the two major hospitals: Dar-Al-Shifa Hospital and the Gaza European Hospital.

The most common type of health insurance available in Gaza Strip is the governmental health insurance as there were 178,076 families (about 1.17 million of the population) covered in 2006 by the governmental health insurance (Ministry of Health, 2006). Governmental health insurance covers the total expenses of treatment for hospitalized patients. There is a little copayment for outpatients (i.e. about 75 American cents per each prescribed drug and about 25 cents for each laboratory test). Children under the age of three are treated freely if their parents don't have a health insurance and patients with chronic diseases, including cancer, do not pay the co-payment for the prescribed drug. Any patient presented to the emergency room is not denied treatment even if he/she doesn't have a health insurance.

The budget of the Palestinian Ministry of Health is very limited. It was only 134,222,222 US dollars in 2004 excluding the expenditures for treatment abroad (Ministry of Health, 2005). Because some care, especially tertiary care, is limited or not available in Palestine, patients who need such care are referred by the MoH to receive such care at one of the neighboring countries such as Egypt, Jordan, or Israel and in some other cases to some European countries (The RAND Palestinian State Study Team, 2007). The cost of referring patients to receive treatment abroad is expensive and consumes a huge portion of the already limited budget for the MoH. For example, the cost of treating 31,744 patients abroad was more than 58 million US dollars which constituted about 45.9% of the actual health expenditures for 2004 (Ministry of Health, 2005). The majority of patients referred to treatment abroad are patients who needs eye surgery, who have heart disease, and patients with cancer. In most cases, the health insurance covers the total cost of treatment abroad or at least it covers a big portion of the cost depending on the financial capacity of the patient. Given the limited budget, the MoH worked on reducing the number of referrals by expanding the Palestinian health care capacity and by inducing more restrictive criteria for referrals abroad (The RAND Palestinian State Study Team, 2007).

Criticism for the Palestinian Health Care System

To evaluate the performance of the Palestinian health care system, it was reviewed by several organizations in response to the donor countries requests who wanted to ensure that the money they donate produces some enhancement of the system. Examples of these reviews are the study conducted by the RAND Palestinian State Study Team between September 2002 and May 2004 (The RAND Palestinian State Study Team, 2007) and the Health Sector Review (HSR) which was conducted in 2003-2005 and was reported on by Dr. Yehia Abed (Abed, 2007).

The RAND Palestinian State Study Team (2007, p. 227) identified several minimal components for a successful health care system that they used as the base to review the health care system in Palestine. Besides effective governance and sufficient financial resources, these criteria included (The RAND Palestinian State Study Team, 2007, p. 227):

- maintain an effective and well-regulated public health system
- provide reasonable access to high-quality preventive and curative services for all Palestinians
- maintain high-quality programs for training health professionals
- achieve health outcomes at the population level that meet or exceed international guidelines, such as those recommended by the World Health Organization (WHO)
- be effective, efficient, and financially viable
- contribute to peace and encompass the possibility of cooperation with neighboring countries on issues of common interest.

The RAND review concluded that the Palestinian health system starts with many strengths, such as a health care system that included the high value placed by the society on health; the availability of highly qualified, motivated, and experienced health care professional in many areas including administration, management, research, clinicians and public health workers; plans for national health system developments; a strong base for nongovernmental and governmental institutions; and a relatively healthy population. In spite of those strengths, the same report included several issues of concern. These concerns included the poor coordination and implementation of health policies and programs between Gaza Strip and West Bank and between the nongovernmental and the governmental sectors of the health care system, the under-qualification of many health care providers, the weakness of the licensing and continuing education system, and deficits in operating the budget of MoH and the governmental health insurance system (The RAND Palestinian State Study Team, 2007).

Furthermore, both the RAND and HSR review reported several issues and pitfalls of the health care system in Palestine that are of great concern. Some of these pitfalls were included in both reports and some were only reported in one of the two reports. For example, the HSR (Abed, 2007) mentioned that the donors and other local stakeholders were dissatisfied with the performance of the MoH especially in issues related to efficiency, effectiveness, and sustainability of the health care sector and the inability of the PNA to prioritize health services and interventions. Further, the report included that "budget allocations were made with little reference to the size and type of priorities, inputs-outputs matching or inefficiency concerns" (p. 9) and that planned activities were unrelated to the available budget. In fact, the report added that there was often little relation between actual expenditures of the MoH and the allocated budget. The HSR attributed such inadequacy of budgeting to the lack of necessary tools for economic and financial analysis that would help in improving the utilization of the available scarce resources. The HSR also reported about other inefficiencies within the Palestinian health care system. For example, the report stated that the employment process has a number of inefficiencies. A lack of qualified staff and clinical and non-clinical qualifications were also reported. Additionally, some activities of health care schools (medical, dental, and nursing) did not meet the international standard for that field.

The RAND report described the Palestinian health care system as lacking a systematic process at the national level to ensure that development of health care system is matching the goals of the national health plan. The report gave the example that the only two plans developed in 1994 and 1999 are similar in structure, approaches, and aims to illustrate the inadequacy of the health care system to meet its objectives. To illustrate the inefficiency of the health care system, the report added that most of the goals of the first plan were not met and were repeated in the second plan (The RAND Palestinian State Study Team, 2007). The second plan was supposed to cover the period between 1999 and 2003 and up to this moment, a new national health plan is not issued.

Both reports concluded that there was a great shortage in many areas especially those related to management, planning, budgeting, procurement, accounting, and data analysis. For example, the RAND report mentioned that the MoH had deficits in "exercising its managerial authority over the health system" and that there was a lack of coordination between the four main health care providers in Palestine and within the MoH offices in Gaza and West bank especially in areas related to health policy development and implementation (The RAND Palestinian State Study Team, 2007, p. 245). The report also mentioned that the health care system lacks a consistent national process that reviews the new projects to insure the adequacy of developing a new, efficient infrastructure for the health care system. Additionally, both reports added that the system lacked modern standards for minimal enforcement for accreditation of health care facilities and health care professionals including physicians, nurses, and pharmacists. And in fact, when these standards were available, they were not enforced adequately.

Another issue that both reports included was the quality of health services. Dissatisfaction was mentioned by both reports about the provided health services by both clients and providers. In fact, the RAND report included that the clients input was limited in the planning process and that clients described the health services provided by the MoH as inferior compared to services offered by neighbor countries and the private sectors. Therefore, people who can afford treatment in a neighbor country or within a private facility will mostly do so. Such perceived inferiority of the provided services contributed to the increase in requests for referrals for treatment abroad. The HSR reported that there was a weak enforcement of the referral system for treatment abroad. The report further added that some cases that could be treated locally or at a lower tier are sometimes treated at a higher tier which would leave negative impact on the quality and efficiency of the entire health care system. Finally, a report by the World Health Organization (2005) indicated that there is an inadequate, incomprehensive reporting system for health information with insufficient data analysis capacity at the central level. Such inadequate availability of data will deter the health planning and policy development activities along with research and evaluation.

The RAND report mentioned that the Palestinian health care system, as many other health care systems, function much better at the planning and policy making level than at the implementation level that contributed to the lack of achievement of the many health care plans and objectives. The gap between policy development and policy implementation was reported heavily in the literature. In fact, Shafritz and Russell (1997) mentioned that the bureaucracy of implementation may distort the goals of the program or the policy. The report further added that the MoH had limited success to develop, implement, and enforce policy for the entire Palestinian health care system because of the fragmentation of decision making between Gaza Strip and West Bank (The RAND Palestinian State Study Team, 2007).

Both, the RAND report (The RAND Palestinian State Study Team, 2007) and the HSR report (Abed, 2007) had attributed these inefficiencies to several reasons. For example, the HSR report attributed such inefficiencies to the poor coordination between the PNA, the MoH, the Palestinian health organizations and the international community and to the lack of resources. The RAND report added that the deficits could be attributed to lacking of the necessary statuary authority or lacking the political ability or will to exercise this authority, especially that most of the ministries at the NPA were suffering from a weak level of authority over their sectors, inefficient management practices such as being autocratic and adopting non-participatory process in policy and decision making. Further, the World Health Organization (2005) added more reasons for the inefficiency of the Palestinian health care system. One reason could be the high dependence of the Palestinian health care system on external donations which made up to 48% of the total health expenditures which might also be a cause for lack of long-term sustainability. Another reason could be the fragmentation of responsibilities. An example was provided by the WHO report included the method used for collecting health-related information as data were collected by both the MoH and the Palestinian Central Bureau of Statistics (PCBS).

Finally, both the RAND and HSR reports, in addition to other literature, made recommendations that may contribute to reform of the Palestinian health care system. Some of these recommendations included: strengthening coordination between different health care providers and stakeholders, between Gaza Strip and West Bank, and between primary, secondary, and tertiary levels in regard of integrating health planning and health policy development, reviewing and upgrading standards for accreditation of health care facilities and health educational programs, and licensing of health care professionals; adopting a gate keeping process for referrals for treatment abroad and enforcing more rigorous, restrictive referral system and developing the local capacity to limit the number of referrals; developing policies that contribute to the development of human resources, financing of health care programs, development of research and evaluation programs, development of a health information system, and improving health promotion and disease prevention activities; explicitly assigning the responsibility for implementation of policy decisions to the appropriate stakeholders along with continuous monitoring and providing incentives for successful performance. Furthermore, a report by the World Health Organization (2005) recommended the improvement of a fully comprehensive and integrated health information reporting system that could contribute to the improvement of health policy, planning, research and evaluation of the Palestinian health care system. The World Health Organization (2000a) further recommended the improvement of human resources as a fundamental issue for reforming, developing, and improving any health care system. Besides planning and training, human resources development may include developing effective continuing education programs including designing special postgraduate programs that meet the health care needs of the country, and introducing new trends of health management.

Health Policy and Health Reform in Palestine

Public policy is defined as “a set of actions taken by a government to control the system, to help solve problems within it or caused by it, or to help obtain benefits from it” (Walker 2000, p. 13). A policy is a statement enabling or constraining execution of some type of action by one or more actors in relation to various aspects of some situation. (Uszok, et al., 2003, p. 2). Shafritz & Russell (1999) added that any policy is a decision and that the policy may include taking no actions toward a certain issue. Furthermore, Guy Peters (2004) concluded that anything done by the government is labeled as ‘Policy.’ According to Peters (2004), a policy then has three levels. The first level is policy choice, which is the decision made by decision makers. The second level is the policy output which represents the programs designed to achieve the goal of the policy choice. The third level is policy impact which is the effect of the policy and the programs on the citizen.

Based on the above definitions, health policy is defined as “the way nations, states, cities, and communities distribute resources to competing interventions and competing populations based primarily on anticipated benefits. Health policy reflects the values of the society or community in terms of how and to whom health resources are distributed” (Patrick & Erickson, 1993, p. 419). A health policy could also be defined as “a program of action whose aim is to improve health conditions of the people” (Neema, 2005, p. 2). Adding to those definitions, Garvin and Eyles (2001) included that health policy should be adaptive to the situations and circumstances to the local health needs and objectives. The objective of public health policy is usually set to meet the community needs of maintaining, promoting or restoring of the community’s health (Gunning-Schepers & Stronks, 1999).

Following the Oslo Peace Accord in 1993, the Palestinian Ministry of Health (MoH) was established and started to operate from Gaza Strip. The MoH inherited a devastated and fragmented health care system to start with. The Palestinian health care system was heterogeneous with respect to its organizations and its actors as there were four health care providers working independently of each other (Barghoutis and Lennock, 1997 {as cited by Mataria, et al., 2004} and Barghouti and Diabes, 1996 {as cited by Mataria, et al., 2004}). Prior to the establishment of the MoH, the Palestinian Health Council was established and one of its goals was to produce a strategic national health plan. The first strategic national health plan was produced in 1994 while the second plan was produced in 1999 by the MoH. One of the major objectives of the MoH was to provide comprehensive health care services and to promote an equitable and efficient utilization of health care services to the Palestinian population (Ministry of Health, 1999). Most of the objectives produced in the first national plan were not met and therefore were repeated in the 1999 national strategic plan (The RAND Palestinian State Study Team, 2007). In fact, most of the objectives of the second national plan which were supposed to cover the period between 1999 and 2003 were partially implemented. This could be related to the deteriorating situation after the start of the second uprising in 2000 (World Health Organization, 2005). The WHO (2005) further added that the delay for developing a new strategic health plan is a good indication for the limited capacity of the MoH for policy development.

The donor countries provided a substantial assistance to help in rebuilding the ailing health care system. Activities to reform the ailing health care system were directed at setting up ministerial structure, developing a national health care information system, reviewing and promoting the governmental health insurance system, providing training in certain health areas such as women's health, and helping the four sectors that provide health care to act in participatory planning and collective policy development for the Palestinian health care system (Giacaman, Abdul-Rahim, & Wick, 2003). In spite of these achievements made by the MoH, Giacaman, et al. (2003) mentioned that it was evident that quality of care was not improved nor were the most important health needs addressed.

The attempts of the MoH to reform the existing health care system were met with many obstacles. Some of the obstacles to health sector reform included the ongoing conflict in the area, the weakened Palestinian institutions and state structures, the limited capacity of the MoH to implement reforms, the functioning nature of the NPA which is characterized by authoritarianism and dependence, and the policy vacuum, as there is a lack of general development policy (Giacaman et al., 2003). The WHO further added that the geographical separation and the dispersal of the Palestinian population between West Bank and Gaza Strip contributed to the lack of a unified health policy authority (World Health Organization, 2001). Such separation also contributed to lack of communication and coordination within the two entities of the MoH (World Health Organization, 2005). Another reason that was added by Abed (2007) is the lack of the necessary tools for financial and economic analysis that could be used to improve the use and allocation of the scarce resources within the public sector.

Another issue that Giacaman et al. (2003) considered as an important impediment to the health reform was the donors' policies and practices. Giacaman et al. included that donor countries have their own preferences that may not match the actual needs of the Palestinians and that their approaches and mechanisms are neither flexible nor adaptive to the reality on the ground. Because of donors' inflexibility; requirements for rapidly measurable outcomes; and time limits, quick fixes solutions were adopted. Such quick fixes and swiftness of developing plans to meet the requirement of the donor countries contributed to the lack of sustainability of the Palestinian health care system, constituted a major threat for proper and adequate health policy development, and created more fragmentation than cooperation (Giacaman et al., 2003). The consequences of such lack of coordination in policy development and implementation slowed progress in achieving the goals of the strategic national health plans, decreased the viability of the health care system, and undermined the public confidence in the health care system and organizations especially those operated by the MoH (The RAND Palestinian State Study Team, 2007).

Because of the several obstacles that face the Palestinian health care system along with the instability of the political and economic situations within the area, the health policy and planning capacity in Palestine were described as weak and limited (World Health Organization, 2005). In fact, WHO (2005) further described the MoH’s attitude toward recognizing the needs for change as lukewarm. On the other hand, The RAND Palestinian State Study Team (2007) report mentioned that the success of the MoH to develop, implement, and enforce policy for the health system as a whole is limited and that the MoH had limited success in taking control of its managerial authority over the health system. The RAND report related such limited success to several presumed reasons; MoH lacking resources or expertise for implementation of effective planning and coordination at the national level, lacking the necessary statutory authority, lacking the political will or ability to exercise such authority, and the concentration and domination of the planning process and/or policy development within the hands of a small number of stakeholders or specific personalities.

Several examples were reported in the literature to illustrate the weakness of the planning and policy making process within the Palestinian health sector. For example, Abed (2007) mentioned that the referral system for treatment abroad is weakly enforced as there were some cases that received treatment at a higher level (was treated abroad) that could have received treatment at a lower level (within the MoH’s facilities) of care. Such lack of policy enforcement had a negative impact on the efficiency and quality of the care provided. WHO (2005) gave the example of the limited regulatory system within the health sector as there is virtually no regulation, accreditation, or licensing for the private health sector operating within the Palestinian territories. In fact, the lack of effective licensing policies extends to the licensing of the health care providers including physicians, nurses, pharmacists, and health education facilities (Abe, 2007 & The RAND Palestinian State Study Team, 2007A draft of Patients' Bill of rights was produced more than15 years ago by the Palestinian Council of Health which has not been adopted by the policy making authorities (The RAND Palestinian State Study Team, 2007).

The RAND report (The RAND Palestinian State Study Team, 2007), the HSR (Abed, 2007), and the WHO report (World Health Organization, 2005) made some recommendations to improve the areas of policy development and policy implementation. The major recommendation in the three reports was to enhance the coordination between the different governmental and nongovernmental stakeholders of health and between the West bank and Gaza Strip regarding strengthening the integration of planning, policy development, and policy implementation. Other recommendations evolved about adopting specific policies such as those relating to accreditation and regulation of facilities offering health care and health education institutions, licensing and certification of health care professionals, and referral policy for treatment abroad.

Prostate Cancer Screening Policy in Gaza Strip

One of the primary prevention tools for prostate cancer is screening (Harris & Lohr, 2002). In fact, early detection through screening was described by Brawer (1995) as the only feasible possibility to reduce cancer-related mortality. The other two possibilities for reducing cancer-related mortality are improving therapy and reducing incidence. Prostate cancer population screening or mass screening was defined by Aus, et al., (2005) "as the examination of asymptomatic men" who are at risk (p. 548). The goal of early detection of prostate cancer is to identify men who are asymptomatic and to detect the disease in the early stages since treatment will be most likely to be effective (Harris & Lohr, 2002; Frankel, Smith, Donovan, & Neal, 2003; American Urological Association (AUA), 2009). The AUA added that there are two widely used tests in prostate cancer screening; Prostate-Specific Antigen (PSA) and Digital Rectal Examination (DRG). DRE is done by inserting a lubricated finger in the rectum to feel the size prostate gland. Enlarged prostate could be a sign for prostate cancer. PSA is a blood test that measures the level of Prostate-Specific Antigen which is normally produced in small amounts by the prostate gland. The level of PSA increases in the case of prostate cancer. Since the PSA test was approved by U.S. Food and Drug Administration in 1986, it was used widely to screen for prostate cancer (Lin, Lipsitz, Miller, & Janakiraman, 2008).

Although screening using PSA test may help in detecting prostate cancer in the early stages, an issue of concern is that PSA level is increased not only in the case of prostate cancer, but its concentration may be affected by other conditions such as age, prostate size, prostatitis, benign prostatic hyperplasia, ejaculation, prostate biopsy, or surgery (Frankel, et al, 2003; Lin, et al., 2008). In spite of the fact that PSA detects most prostate cancers, in some cases, it may give false negative results (American Urological Association, 2009). Furthermore, PSA is not diagnostic for prostate cancer. The only way to confirm prostate cancer is through biopsy which in turn when it is done can cause some complications such as discomfort, bleeding and rarely sepsis. Because of that, there is a debate about the use of PSA in prostate cancer screening, since if the result was positive, it will be accompanied by anxiety and some patients will go for unnecessary biopsy, which has several complications (Frankel, et al., 2003). In fact, in an extensive review of the literature, Harris & Lohr (2002) and Ilic, O'Connor, Green and Wilt, (2007) did not find direct evidence that connect screening to reduced mortality; nor did they find sufficient evidence to either confirm or refute the use of routine use of mass screening for prostate cancer. The fact that some prostate cancers detected by screening are clinically unimportant and that the survival rate for patients with prostate cancer could reach to 10 years if it was not detected adds to the debate (Frankel, et al., 2003; Ilic, et al., 2007).

On the other hand, Brawer (1995) argues that since the level of PSA is elevated in most of cases of clinically diagnosed prostate cancers, it will serve as an incentive for the role of screening for early detection of prostate cancer. Furthermore, several studies reported that screening for prostate cancer contributed to decreasing the number of deaths due to prostate cancer. For example, Bartsch et al. (2001) reported on a study performed in Austria where free PSA offered freely for men aged 45 to 75 years in the state of Tyrol. The study reported that there were 22 fewer deaths in 1998 and 18 fewer deaths in 1999 than expected related to prostate cancer among men aged 40 to 79 years. Further, the study reported that there was a significant drop of mortality rate due to prostate cancer compared to the rest of Austria.

In another study performed in Quebec to assess the impact of prostate cancer screening on mortality related to prostate cancer, more than 46,000 men aged 45 to 80 years were randomized between screening and no screening groups; Labrie et al. (1999) found that there were 137 death reported due to prostate cancer between 1989 and 1996 among the 38.005 unscreened men. On the other hand, there were only 5 deaths reported among the 8,137 screened men. The death rate was calculated to be 48.7 per 100,000 in the unscreened group and 15 per 100,000 among the screened group with a 3.25 odds ratio in favor of participants in the screening group.

After eleven years of initiating the Quebec study, Labrie et al. (2004) reported that there was a 62% reduction of a cause-specific mortality rate among the group of men who participated in the screening group. In their conclusion, Labrie et al. (1999) concluded that if PSA screening was started for men at the age of 50, results would identify those who are at higher risk for prostate cancer. Coupled with the treatment for localized prostate, the approach of early diagnosis and treatment will contribute to decreasing mortality rate due to prostate cancer, which therefore will improve quality of life for men who are diagnosed early with the disease.

In spite of the ongoing debate about the efficiency of screening for prostate cancer, the American Cancer Association (ACA), (2007) and the American Urological Association (AUA), (2009) recommend that prostate cancer screening be done for men starting at the age of 50 years. And for those who are at higher risk such as those who have a family history and African Americans, the ACA recommends to start testing at the age of 45 years while the AUA recommends starting screening at the age of 40.

In Palestine, there is no policy regarding screening for prostate cancer and therefore, PSA and DRE are not routinely done for men who are 50 years or older. DRG and PSA test are done when a patient complains of urinary problems in an attempt for a primary diagnosis of prostate cancer.

A Brief Overview of the Policy Process

Policy making in general and health policy in particular is a very important issue for any society. Walker (2000, p. 13) defined public policy as “a set of actions taken by a government to control the system, to help solve problems within it or caused by it, or to help obtain benefits from it.” Weimer and Vining (1999) think that policy is a client-related advice relevant to decision making and informed by social values. Further, Gupta (2001) added that policy involves advising those who govern. Scott (2005) thinks that policy is a value-based and needs a value-creating advice and that a value-adding policy requires a good policy framework and research-based evidence. The starting point of any policy process is agenda setting. Gupta (2001) and Shafrtiz and Russell (1999) started their policy process or policy cycle with agenda setting. According to Gupta (2001), the policy process has six components: agenda setting, policy formulation, policy adoption, policy implementation, policy evaluation, and policy change or policy termination (Figure 2-2). In a similar way, Shafritz and Russell (1999) included five steps of the policy process which are agenda settings, policy decision or non-decision, policy implementation, policy regulation and feedback.

Gupta (2001) mentioned that the policy cycle will not start if the agenda was not clear and unless an issue captures the government’s attention. He mentioned that there are so many problems or issues that loom and move around in the society that do not capture the attention of policy makers and therefore will not be included in the agenda setting and therefore, will not be resolved. He also added that not everything needs the government's attention.

Therefore, it is hoped that introducing the results of this study to the health policy makers in Gaza Strip will work as a motivator for them to improve QOL of prostate cancer survivors and to eliminate the barriers they face in utilizing health care services. Also it is hoped that the health decision makers to be politically astute and use the chances when policy windows open (Kingdon, 1995). Policy windows may open for short times, such as when there is a chance that the Israelis decide to let medical supplies to enter Gaza or some humanitarian organizations will succeed to bring some drugs and

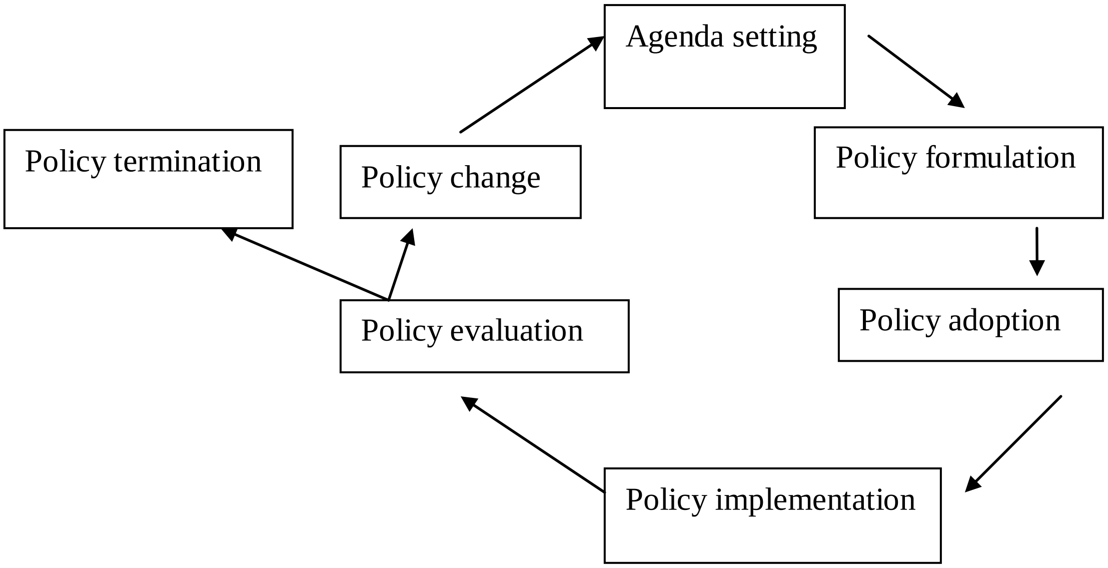


Figure 2-2: Gupta Policy Process. Source: Gupta (2001)

medical supplies through the sea or the Egyptian borders. In such occasions, MoH staff need to request exactly what is missing in their drug and medical supply stores so that some supplies will not duplicate and expire while setting on the shelves and other drugs and supplies will be missing.

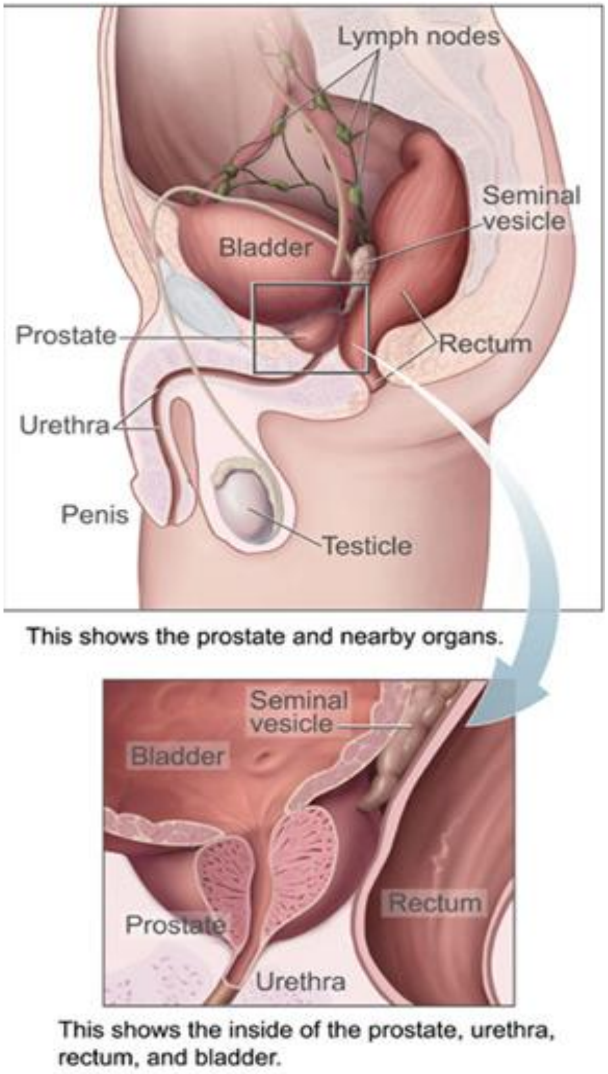
Anatomy of Prostate Gland and Pathophysiology of Prostate Cancer

The prostate gland (Figure 2-3) is a single chestnut-shaped gland about the size of the peach pit (about 4 centimeters across and 3 centimeters thick) and encircles the proximal part of the urethra, just inferior to urinary bladder (Marieb & Hoehn, 2007; Shier et al., 2007). The prostate gland secretes alkaline thin, milky secretions that work to neutralize the acidic fluids containing the sperm cells which remain relatively immobile in the acidic secretions of the epididymis. Prostatic secretions also enhance the motility of sperm and work to neutralize the vaginal acidic secretions (Shier et al., 2007).

Prostate cancer is one of the most common cancers in males. It is the second most common cancer worldwide and the most common cancer among American males (American Cancer Society, 2007a). The incidence age-standardized rate (ASR) is higher in the westernized countries (the highest ASR is in the United States followed by Sweden) and lowest in Asian countries (McCance & Huether, 2006). This could be related to the fact that adults in United States and western countries consume more red meat and fats and fewer amount of fruits and vegetables (Nelson, De Marzo, & Isaacs,

2003) and to the fact that there is more screening for Prostate-Specific Antigen (PSA) which helps in early diagnosis of prostate cancer (Bartsch et al. 2001).

According to the National Cancer Institute's (NCI) Surveillance Epidemiology End Results (SEER) report, it is estimated that about 186,320 American men will be diagnosed with prostate cancer and about 28,660 men will die of cancer of the prostate in 2008. According to the same report, the incidence and death rates (Table 2-1) are much



This shows the prostate and nearby organs.

This shows the inside of the prostate, urethra, rectum, and bladder.

Figure 2-3: Anatomy of Prostate Gland. Source: Wikipedia, 2009.

higher among black Americans (Ries, Melbert, & Krapcho, 2008). While the majority of prostate cancer among American men occurs after the age of 55 years (Table 2-2), the median age for the occurrence of prostate cancer between the years 2001 and 2005 was estimated to be 68 years (Ries et al., 2008). By the age of 85, about one in six American men will have prostate cancer during their lifetime and 3% will die from it (McCance & Huether, 2006). While the incidence of prostate cancer is relatively high, the good news is that the widespread use of preventive measures such as screening for Prostate-Specific Antigen, a protein that increases in the presence of prostate cancer, and digital rectal examination along with the availability of different treatment modalities that are used early to treat prostate cancer helped to decrease the age-adjusted death rate (Bartsch et al., 2001).

Table 2-1: Incidence and Death Rates of Prostate Cancer in The USA According to Race/Ethnicity. Source: NCI's SEER report ((Ries et al., 2008).

Race/Ethnicity	Incidence Rate	Death Rate
All Races	163.0 per 100,000 men	26.7 per 100,000 men
White	156.7 per 100,000 men	24.6 per 100,000 men
Black	248.5 per 100,000 men	59.4 per 100,000 men
Asian/Pacific Islander	93.8 per 100,000 men	11.0 per 100,000 men
American Indian/Alaska Native	73.3 per 100,000 men	21.1 per 100,000 men
Hispanic	138.0 per 100,000 men	20.6 per 100,000 men

Table 2-2: Incidence of Prostate Cancer in the USA According to Age. Source: NCI's SEER report ((Ries et al., 2008).

Age group	**Percentage**	**Median Age**
Under age of 20	Approximately 0.0%	68 years
20 - 34	Approximately 0.0%	
35 - 44	0.6%	
45 - 54	8.6%	
55 - 64	28.0%	
65 - 74	36.1%	
75 - 84	22.0%	
85 + years	4.7%	

Risk Factors for Prostate Cancer

There are several risk factors that may contribute to the development of prostate cancer. These factors include the following:

1. Age: the chance for prostate cancer increases with age as it is considered the disease of the elderly. More than 70% of prostate cancers are diagnosed after the age of 65 (Held-Warmkessel, 2007 and Munden, 2007).
2. Racial and ethnic factors: incidence rate and death rate are much higher among African Americans than among Whites. Native Americans and Asians have the least incidence for prostate cancer (Held-Warmkessel, 2007 and Munden, 2007).

3. Family history and genetics: the chance to develop prostate cancer increases if there is a family member having the disease. Chances will be much higher if that family member was a first-degree (brother or father) family member (Held-Warmkessel, 2007). Besides that, some investigations in the last few decades identified some genes that are associated with prostate cancer (Nelson, et al., 2003).
4. Diet: incidence of prostate cancer increases with diet high in saturated fats (Munden, 2007), high fat-diet, high-calorie diet, and high consumption of red meat (Held-Warmkessel, 2007).
5. Hormones: androgens are needed to promote prostate growth; therefore, incidence is higher among men who receive androgen steroids as anabolic agents or for medical purposes (McCance & Huether, 2006).
6. Smoking: long history of tobacco smoking may increase the risk for prostate cancer (Held-Warmkessel, 2007).
7. Occupational and exposure history: men who work as farmers and those who are exposed to pesticides are at higher risk to develop prostate cancer (Held-Warmkessel, 2007).
8. Sexuality: incidence of prostate cancer may increase with sexually transmitted diseases such as syphilis, gonorrhea, and human papillomavirus types 16 or 18 (Held-Warmkessel, 2007).
9. Vasectomy: it was identified as a possible risk factor (McCance & Huether, 2006).

Clinical Manifestations of Prostate Cancer

Usually, prostate cancer goes asymptomatic and symptoms appear with advanced cases (McCance & Huether, 2006). Usually, symptoms are due to obstruction of urinary flow (Figure 2-4). The symptoms usually develop progressively and include: slow urine stream, hesitancy, incomplete bladder emptying, dysuria (difficulty in urination), frequency and nocturia (frequency of urination during night time) (McCance & Huether; 2006 and Munden, 2007). Prostate cancer may also cause rectal obstruction and difficulty in deification. In later stages, when cancer is metastasized to other organs, patients may have severe symptoms depending on the site of metastasis such as bone pain, pathologic fractures, enlarged lymph nodes, liver enlargement, edema of lower extremities, and mental confusion (McCance & Huether, 2006).

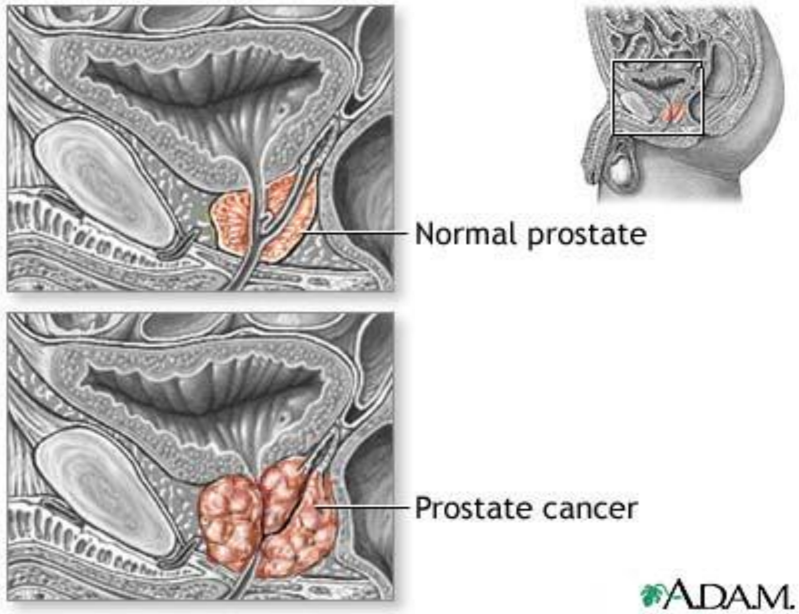


Figure 2-4: Comparison of Normal Prostate and Prostate Cancer. Source: UCLA Health System, 2009.

Usually, the diagnosis of prostate cancer is suspected after patients complain of urinary symptoms. Confirmation of the diagnosis is based upon rectal digital examination followed by elevated blood level of PSA which therefore prompt immediate medical attention to initiate proper treatment (Visser, et al., 2003). To confirm diagnosis, a tissue biopsy and microscopic tissue examination of the prostate will help to distinguish between benign and malignant masses of the prostate (Munden, 2007).

Treatment Options and their Complications

There are different treatment options to treat prostate cancer. The choice of the treatment option depends on several factors that include: the anticipated effect of treatment for a given patient, risk factors, patient's preference, patient's concerns about complications, risk for complications of surgical procedure and anesthesia, patient's age, life expectancy, other health problems, stage of tumor, and expected side effects and complications (Held-Warmkessel, 2007; McCance & Huether, 2006).

Treatment options include:

- no treatment (watchful waiting);
- surgical treatment (includes total prostatectomy, transurethral resection of the prostate, or cryotherapy);
- nonsurgical treatments such as radiation therapy, (Munden, 2007);
- hormone therapy, or chemotherapy;
- and any combination of these (Held-Warmkessel, 2007; McCance & Huether, 2006).

Treatment options are not free from complications as each treatment modality has it own complications. Complications of surgical interventions include urinary incontinent, urethral stricture, and impotence. These are in addition to the ordinary complications for anesthesia and surgery (Lu-Yao, McLerran, Wasson, & Wennberg, 1993).

Complications of radiation therapy include impotence; incontinence; frequent bowel movement; painful hemorrhoids; strictures; and acute cystitis, proctitis, and enteritis (Held-Warmkessel, 2007). Complications of hormonal therapy may include psychological effects, loss of libido, hot flashes, impotence, osteoporosis, gynecomastia (enlargement of breasts), and breast tenderness (Held-Warmkessel, 2007). Finally, the complications of chemotherapy may include fatigue; anemia; leukopenia (decreased count of white blood cells); thrombocytopenia (decreased count of platelets); nausea and vomiting; alopecia (hair loss); phlebitis (inflammation of veins), thrombosis (formation of blood clots inside blood vessels); and drug and dose dependence (Held-Warmkessel, 2007).

The prognosis and survival rates for prostate cancer have improved greatly in the past five decades. Nowadays, about 85% of prostate cancer cases are discovered in the early stages while the malignancy is still localized in the region. In these stages, the 5-years survival rate is 100% and it declines at 10 years to 84% and to 56% at 15 years (American Cancer Society, 2007a).

Quality of Life and Cancer

In the past few decades, advances in medicine and medical technology have enabled many patients to survive once considered fatal conditions such as cancer. As these people now live longer, a desire to understand their experiences, how the disease, its complications, and related treatments impact their lives has evolved. Such a desire has led researchers to examine and evaluate patients’ experiences and their responses toward their diagnoses and the related treatment; QOL specifically, has become an important determinant of healthcare outcomes (Ferrans, 2005). These efforts have resulted in the development of quality of life (QOL) and health related quality of life (HRQOL) concepts and the development of several scales that measure them (Head, 2007). In fact, providers of cancer care have been front-runners in the evaluation of QOL as they recognized the need to assess outcomes more broadly than response to the tumor and length of survival (Ferrans, 2005).

Definitions of Quality of Life

The concept of QOL has proven to be difficult to define in the last few decades. In mid 70s, Campbell (1976) defined QOL as "a person's own sense of well-being, as derived from his or her current experience of life as a whole" and he perceived that “the quality of life lies in the experience of life” (Campbell, 1976, p. 118). Further, he added that when a person conceptualizes his/her well-being, that individual will compare his/her perception at the present situation with a situation that he/she aspires to, expect, or feels that he/she deserves. If the perceived life matches with the aspired-to life, the result will be satisfaction, otherwise dissatisfaction will be the result. Further, he added that the major determents of well-being are psychological factors which are subjective to that individual’s judgment (Campbell, 1976).

In med 80s, Caiman (1984) tried to offer a definition of the concept of QOL and referred it as the “gap” between the individual's expectations and experience (Calman, 1984). He called for QOL assessment based upon the patient's own list of problems and priorities and the estimation of the "gap" followed by the development of a plan for modifying QOL in which the patient is fully involved (Caiman, 1984). Ferrans (l996) offered a definition of QOL, reflective of characteristics of multidimensionality and subjectivity of QOL. In her attempt to define QOL, Ferrans (1996) stated that, "the essence of quality of life lies in the experience of life" (p. 295) and that the person is the only proper judge of his/her own quality of life since people differ in what they value. Further she added that each person will value his/her QOL based upon his/her own experience (Ferrans, 1996). Based upon that, Ferrans (1990, 1996) defined quality of life as “a person’s sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her” (Ferrans, 1990, p. 15 and Ferrans, 1996, p. 296)

The World Health Organization Quality of Life (WHOQOL) Group (1993, p.153) and (1996, p. 17) defined quality of life as:

> individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept, incorporating in a complex way a person’s physical health, psychological state, level of independence, social relationships, personal beliefs and relationship to salient features of the environment.

The concept of QOL is a general concept that can be applied to evaluate several dimensions of life. To distinguish between QOL in its more general sense and the requirements of clinical medicine and clinical trials, the term health-related quality of life (HRQOL) is frequently used in order to remove ambiguity (Fang & Hao, 2003).

In health care research, modified definitions of quality of life have included: "the degree of satisfaction with present life circumstances perceived by the person" (Young & Longman, 1983, p. 220), "patients' appraisal of and satisfaction with their current level of functioning compared to what they perceive to be possible or ideal" (Cella & Cherin, 1988, p. 70), and "a personal statement of the positivity or negativity of attributes that characterize life" (Padilla, Ferrell, Grant, & Rhiner, 1990, p. 108). These definitions stress the patients' appraisal of the advantages and disadvantages of the available treatments modalities and therefore provide information on whether or not the consequences of the disease and the complications of treatments are tolerable or not (Cella & Tulsky, 1990).

It can be noticed from the provided definitions that the concept of QOL has a subjective nature since it reflects one's individual feelings toward his/her own life. Such a way to look at QOL applies to survivors of prostate cancer as the whole experience of cancer is very personal. Therefore, the concept of QOL, including prostate cancer survivors, depends upon the unique experiences of each individual (Ferrans, l996). Therefore, it is important to consider individuals' differences and how they are satisfied with their own lives. Therefore; according to Caiman's (1984) and Cella & Cherin's (1988) definitions, a good quality of life is obtained when the hopes of that individual are fulfilled or when he/she perceives and judges his/her current status as adequate according to his/her own judgment and evaluation of his/her own status. While poor QOL exists when those hopes are unmet based upon the experience of that individual, or un met based upon the standards that he/she considers as ideal. Similarly, Cella & Cherin (1988) linked the reality of experience with the desired ideal in defining QOL as the patient's appraisal of and satisfaction with his/her current level of functioning compared to what he or she views as ideal. In cases of chronic diseases or life-threatening conditions, patients are faced with the necessity of adjusting to their new health conditions. According to Sprangers & Schwartz (1999), a ‘response shift’ takes place during the process of adaptation for a chronic disease or life-threatening conditions. This ‘response shift’ involves changes in patient’s internal standards, values, and the way he/she conceptualize his/her QOL.

Indeed, the concept of QOL was generally described as multidimensional by several scholars. These dimensions include individuals’ perceived physical health, psychosocial wellbeing, social or socioeconomic resources, functional ability, spiritual well-being, and satisfaction with life (King, 2006; Dunn et al., 2006). According to Fairclough (2002), besides being influenced by individuals’ physical and social environment, QOL is also influenced by emotional and existential reactions to that environment. To Fang and Hao (2003), HRQOL encompasses 5 major domains “physical status and functional abilities, psychological status and well being, social interactions, economic and/or vocational status factors, and religious and/or spiritual status” (p. 196).

Measuring Quality of Life

Since QOL concept is subjective, it is difficult to measure, but in general, the individual of concern will be the best source of information about the level of his/her QOL (Aaronson et al., l999) and therefore, his/her perspective has equal validity to that of the practitioner when it comes to monitoring the effects and outcomes of disease and treatment (Leplege & Hunt, 1997).

While the assessment of quality of life is valued, the difficult task is to measure a subjective concept with components that cannot be directly observed such as social functioning and spirituality (Bottomley, 2002). In his book, measuring the effect of cancer of quality of life, Osoba (1991) outlined several reasons for developing quantitative measures, and he acknowledged that many feel that QOL is far too subjective to evaluate via a standardized measure, but he believed that rigorous psychometrics could result in valuable tools to measure quality of life.

What seems interesting is that patients' expectations are always changing as they adjust to disease (Carr, Gibson, & Robinson, 2001). Fang and Hao (2003) argued that QOL means different things to different people and it varies according to the person's current situation. In case of chronic diseases, including cancer, patients develop psychological adaptation to their condition (Muldoon, Barger, Flory, & Manuck, 1998) which will lead to changes in the way they perceive their lives and therefore their QOL. In fact, such adjustment to disease will lead to a shift in their responses to QOL assessment over time as their expectations have changed which often contribute to difficulties in interpreting data (Varricchio, 2006).

Quality of Life among Men with Prostate Cancer

The literature has extensively evaluated the quality of life of prostate cancer survivors, both who received different modalities of treatment and those who did not. The results showed several key elements that affect QOL of prostate cancer survivors that can be divided into two categories; physical and non-physical categories. The physical category covers areas such as urinary, bowel, and sexual functions, while the non-physical category covers areas such as body image, emotional and social issue, and other issues that impact quality of life of prostate cancer survivors.

Impact of Physical Outcomes on Quality of Life

The Prostate Cancer Outcomes Study (PCOS) was one of the largest and most popular studies that evaluated health-related quality of life (HRQOL) in prostate cancer patients. The PCOS was initiated by the American National Cancer Institute (NCI) in 1994. The purpose of this study was to "investigate variations in the initial treatment of prostate cancer, and to describe HRQOL outcomes in a large, heterogeneous cohort of newly diagnosed prostate cancer patients treated in community medical practices" (Potosky et al., 1999, p. 1917).

A total of 11,137 men, diagnosed with a biopsy-proven prostate cancer between the beginning of October, 1994 and the end of October, l995 in 6 of the Surveillance and Epidemiology End Results (SEER) cancer registries were eligible for the PCOS. A pre-specified sampling design was used to ensure adequate representation of eligible patients and a sufficient number of minority participants. Of the total number sampled (n=5,672), 62% of participants (3,486) completed survey questionnaires about their HRQOL at 6, 12 and 24 months after initial diagnosis. The PCOS survey instrument was designed to focus on urinary, bowel, and sexual dysfunctions. Selected scales from the Medical Outcomes Study (MOS) were included; however, to "…minimize respondent burden and to focus on disease-specific function, we excluded three scales of the SF-36 [physical and social function scales and general health perceptions]" (p. 1721). The five scales which were included focused upon bodily pain, depression/anxiety, vitality, role limitations related to physical health, and role limitations related to emotional health (Potosky et al., 1999). In their commentary at the PCOS, Potosky et al. indicated that the huge data collected in this study should "provide important new information concerning the diagnosis and management of prostate cancer in the United States to benefit patients, clinicians, and policy makers" (p. 1723).

Several studies reported on findings from this large (PCOS) database. Stanford et al. (2000) used a sample of 1291 Black, White, and Hispanic participants from the PCOS who had localized prostate cancer and were treated with prostatectomy. The objective of the study was to "measure changes in urinary and sexual function in men who have undergone radical prostatectomy for clinically localized prostate cancer" (p. 354). Age of participants ranged between 37 and 79 years. They had a radical prostatectomy surgery within a six months period after being diagnosed with prostate cancer. Measurement of sexual and urinary functions were performed at six, twelve, and twenty-four months after the initial diagnosis. The results revealed that 20.5% of participant regained full urinary control after 6 months and 31.9% regained full control after 2 years of diagnosis. About

40% of participants reported occasional urinary leakage and about 7% reported frequent urinary leakage, while 1.6% reported that they did not have any urinary control after two years. At the end of the two year assessment, the level of urinary bother was improved and only 8.7% of participants reported that urinary incontinence was a moderate or a big problem. The results also showed that about 60% of participants reported that they did not have hard erection enough to have penetrating sex and the rest of them had no erection at all. Furthermore, about 42% of participants reported that their impotence bothered them moderately to severely 18 months (2 years after diagnosis) after having the surgery.

Another study that used the data from the PCOS was Potosky et al. (2000). Potosky and his colleagues used the data from PCOS to compare HRQOL for 1591 patients aged between 55 and 74 years who had participated in the PCOS and were treated either by radical prostatectomy or external radiation. After adjusting for estimates of differences (such as age at diagnosis, baseline functions, and socioeconomic factors) between the group that received radical prostatectomy and the group who received external beam radiation, the results showed that 9.6% of the patients who had radical prostatectomy had experienced urinary incontinence compared to 3.5% of those who had radiation therapy. Urinary incontinence was defined as “having no control or frequently leaking or dripping urine” (Potosky et al. 2000, p. 1586). About 13.8% of patients who had radical prostatectomy reported leakage of urine compared to 2.3% of patients received radiation therapy. More patients from the radical prostatectomy reported having more urinary frequency and reported that they were bothered by their urinary function than patients from the radiation therapy group. When asked about their bowel elimination function, more patients who received radiation therapy reported that they had bowel dysfunction than patients received radical prostatectomy. When asked about their sexuality, 79.6% of patients who had radical prostatectomy reported impotence compared to 61.5% of the patients receive radiation therapy. Sexual bother was reported by more younger patients (55-59 years) who had radical prostatectomy (59.4%) than patients received radiation therapy (25.3%) from the same age group. When compared the HRQOL for the two groups, Potosky et al. (2000) reported that they did not observe statistically significant differences among the two groups in the five examined domains. In spite of that, the researchers reported that more patients from the radiation therapy group (22.7%) said that their overall health was fair or poor compared to 11.5% of radical prostatectomy group.

Penson et al. (2003) used the data of the PCOS in order to determine if there is a "relationship between primary treatment, urinary dysfunction, sexual dysfunction, and general health-related quality of life (HRQOL) in prostate cancer" (p. 1147). A sample of 5,672 men with prostate cancer was randomly selected from the 11,137 who originally participated in the PCOS. Participants had received 4 methods of treatment: radical prostatectomy, radiation therapy, hormone ablation therapy, and watchful waiting. Participants were surveyed at 3, 6, 12, and 24 months after receiving treatment. After controlling for covariates, the researchers assessed the effect of the four treatment modalities on the general HRQOL after two years of initiating treatment. The results showed that in spite that participant reported urinary and sexual bothers, there were no statistically significant differences in the general health-related quality of life outcomes among participants in the four groups.

Reis, Netto, Reinato, Thiel, and Zani (2004) compared the impact of urinary incontinence and erectile dysfunction QOL and the willingness to undergo treatment again in patients treated by radical retropubic prostatectomy and patients treated with low dose radiation (LDR) brachytherapy. Self-reporting questionnaires were mailed to a 158 patients who had clinical localized prostate cancer and were treated by either with radical prostatectomy or LDR brachytherapy between July 1992 and November 2001. The questionnaire consisted of 11 questions; five to assess sexual function, four to assess urinary continence, and 2 to assess satisfaction with treatment and willingness to receive the same treatment again. With a response rate of 43% (n = 56), results indicated that: 84.8% of the prostatectomy group and 23.07% in the brachytherapy group reported some degree of erectile dysfunction, 17.6% patients treated by prostatectomy and 9.5% treated with brachytherapy suffered from urinary incontinence. As both treatment modalities affected sexual function and urinary continence, Reis et al. (2004) concluded that they negatively impacted levels of quality of life. In spite of reported treatment-related morbidity and impact on QOL, most patients (88.2% of prostatectomy group and 95.5% of the brachytherapy group) would elect to have the same treatment performed again (Reis et al., 2004). This reinforces Pender's Health Promotion Model (Pender, 1996 & Pender et al., 2002) that people will follow health promoting behaviors that maintain or enhance their well-being by extending their lives.

Namiki et al. (2004) assessed health-related quality of life (HRQOL) of Japanese men with localized prostate cancer after a radical retropubic prostatectomy in order to assist Japanese urologist in their discussion about treatment options with their patients who are diagnosed with prostate cancer. The study was a longitudinal survey of HRQOL that started with a 104 participants who had a radical retropubic prostatectomy after being diagnosed with localized prostate cancer. 32 participants dropped out or became ineligible for the study as they received adjunct treatments such as hormonal or radiation therapy. Namiki et al. (2004) used RAND 36-Item Health Survey 1.2 (SF-36) to assess the general HRQOL and the University of California, Los Angeles Prostate Cancer Index (PCI) to assess the specific prostate cancer HRQOL. The participants were interviewed before surgery and at 3, 6 & 12 months after the surgical procedure (Namiki et al., 2004).

The results of this study revealed that patients who had a retropubic prostatectomy experienced significant decline in some domains such as the physical domain as participants reported role limitations due to body pain and physical problems after three months of the surgical procedure. But Namiki et al. (2004) reported that most of these problems had significantly improved at the 6-month interview. The scores for mental health status were also decreased after the surgical procedure but had recovered to the base line after one year. Furthermore, the results of this study revealed that most of the participants suffered from urinary bother within the first three months after surgery. However these symptoms started to disappear and participants, especially younger participants, started to report improvements after 6 and 12 months, but it did not came back to the baseline before the surgery. In regard to bowel elimination, no problems were reported by participants regarding this domain. Finally, participants reported that they had a substantial score of sexual dysfunction and deterioration of sexual bother, especially those who are relatively younger patients whose scores were much worse. In spite of that, the majority of participants reported good general HRQOL. The researchers related that to the fact that the majority of the participants were older (mean for age was

66.6 years) than participants in other related studies. Therefore, Namiki et al. (2004) suggested to urologic surgeons to discuss this issue in more details with younger patients during preoperative counseling related to treatment options.

In another study, Shrader-Bogen et al. (1997) mailed self-administered questionnaires to 354 men who received either prostatectomy or radiotherapy in a cross-sectional study in order to identify and compare their self-reported QOL and side effects of treatment 1-5 years after treatment. With a response rate of 86.4 (n =306), only 274 of them met the eligibility criteria to participate in the study. Forty eight percent of participants were treated with prostatectomy while the other 52% received radiotherapy. The results of Shrader-Bogen's et al. (1997) revealed the following: a) adverse changes in bowel function (such as diarrhea, urgency, and bleeding with bowel movement) were reported more frequently by patients who received radiotherapy than those who received prostatectomy, b) after adjustment for age, patients treated with prostatectomy reported significantly more treatment-related urinary symptoms and side effects (such as leaking, increased leaking with coughing or sneezing, and greater use of protection) than patients received radiotherapy. The only urinary symptom that was reported more frequently by radiotherapy patients was nocturia, c) patients treated with prostatectomy had significantly worse sexual dysfunction than radiotherapy patients as a side effect to treatment. About 70% of the prostatectomy patients were unable to have an erection and an additional 15% were unable to have a sufficient erection for vaginal penetration. On the other hand, 50% of the radiotherapy patients were unable to achieve erection and an additional 27% were unable to have a sufficient erection for vaginal penetration. This difference in ability to achieve erection between the 2 groups was statistically significant even though the radiotherapy group was 9 years older than the surgery group, d) about 69% of the prostatectomy patients reported that they were “not very satisfied” or “not at all satisfied with their sexual function compared with 62% of the radiotherapy patients, e) prostatectomy patients reported more effect of sexual function on their overall QOL than radiotherapy patients, but after adjustment for age, this difference was no longer significant.

Using a control group (n = 2412), Bacon et al. (2002) studied 1201 men who were diagnosed with prostate cancer between 1993 and 1998. Both groups were recruited from participants of the Health Professionals Follow-Up Study (HPFS). Men participated in the control groups were free from diseases that may affect their QOL such as cancer, cardiovascular disease, diabetes, stroke, renal failure, and Parkinson’s disease and they were age-matched with their counterparts in the treatment group. Bacon et al (2002) used three common scales (the Medical Outcomes Study Short Form–36 Health Status Survey (SF-36), the Cancer Rehabilitation Evaluation System–Short Form (CARES-SF), and the University of California at Los Angeles (UCLA) Prostate Cancer Index) to evaluate QOL. The findings showed that bowel symptoms had the greatest effect on QOL, followed by sexual and urinary symptoms.

The result of Bacon et al. (2002) reflected that sexual symptoms were strongly associated with QOL and reductions in QOL were particularly evident for men who had some sexual function before being diagnosed with prostate cancer. Sexual bother had the greatest effects on the physical function, vitality, and mental health domains of QOL.

Although urinary symptoms were significantly affecting QOL, they were the least predictive of QOL after cancer diagnosis and their effect were more evident on men who had moderate to severe urinary symptoms before diagnosis. Urinary symptoms had the greatest impact on the physical function, general health, vitality, and mental health domains of QOL and to a lesser degree on the domains of the psychosocial and marital interaction domains. Bowel symptoms (rectal urgency, loose or liquid stools, crampy pain, and bowel movement distress) were the greatest area that impacted level of QOL, especially the role and social functioning domain. In general, psychosocial domains of QOL were just as strongly impacted as were the physical domains of quality of life (Bacon et al., 2002).

Although the literature suggests that there are issues concerning urinary and sexual functioning after a radical prostatectomy, Litwin, Melmed, and Nakazon (2001) came to the conclusion in their longitudinal study after a radical prostatectomy that urinary and sexual function continue to improve even beyond two years postoperatively. Therefore, patients who have had a radical prostatectomy should be encouraged that recovery may continue for months after surgery.

Impact of Non-Physical Issues on Quality of Life

The previous part of the literature examined QOL of men who had received treatment for prostate cancer and how the complications of their treatment impacted their quality of life. Other scholars took another path of examining the effect of treatment and its complications on prostate cancer survivors and how they impact their body image which in turn affects QOL.

In an ethnographic, qualitative study, Oliffe (2005) explored men's experiences of impotence following prostatectomy as a treatment from prostate cancer and how such experiences affected their perceived masculinity. A total of 15 Anglo-Australian men with localized prostate cancer who were treated with prostatectomy were recruited for this study. Participating men were heterosexual and had current female partners at the time of the study. The average age for participants was 57 years and all of them were sexually active and had no erectile dysfunction before the interviews. An in depth analysis of the contents of the semi-structured interviews reveled that participants and their partners had focused on survival and traded life with impotence. One participant expressed his feeling: "If you are alive you can do whatever you can do; if you are dead then you can't do anything. So the first objective is to be alive" (Oliffe, 2005, p. 2252).

In spite of this trade off, many participants tried several means such as vacuum erection devices, Viagra, and penile injection to try to get erection in an attempt to have penetrative sex and felt disappointed and worthless when they were not succeeding to have penetrating sex. Many of them also showed surprise and distress at the reduction of the penis size after the surgery. Regardless of these findings, participants reveled that their impotence did not affect their masculinity and they perceived their impotence as part of the nature of aging (Oliffe, 2005).

In a qualitative study conducted in Sweden by Hedesting, Sandman, Tonic, and Widmark (2005), 10 patients with localized prostate cancer and treated with external radiation therapy were recruited. Participants were 60-70 years old and were not having any chronic diseases that may affect their health outcomes and quality of life. They had received the radiation therapy 6 months to three years prior to the interview. The aim of the study was to “gain deeper understanding of how men live after external beam radiotherapy of local prostate carcinoma” (Hedesting et al., 2005, p. 310). Analysis of the interviews showed 4 themes: to “bear the emotional experience of the illness alone, a sense of being exposed, striving for a sense of having control in a new life situation, and striving to reconcile with a new life situation” (p. 312).

Men reported that they did not initiate talks about their disease- related emotions and thoughts including those related to their prognosis and future. Participants who had waning erection ability described their experience as being mutilated. In general, men felt emotionally distressed of getting their bodies exposed especially in the presence of female care providers and reported a sense of being exposed when asked about their waning sexual function (Hedesting et al., 2005).

In an attempt to examine the impact of hormonal therapy on patients with prostate cancer and how they cope with body changes and how it will affect their spousal relationships, Navon and Morag (2003) interviewed 15 Israeli patients who have received hormonal treatment for their prostate cancer. Participants had received continuous hormonal therapy ranging from six months to three years. Participant reported that some changes had occurred to their appearance and affected their body image and their emotional status. Examples for these changes were diminished sexual organs, development of breasts, disappearing of their chest and limbs hair, and gaining wait at their hip and buttocks areas. These were besides reporting having the experience of hot flashes. Such feminization characteristics resulted in disturbance of body image and resulted in feelings of revulsion, self-loathing and disgust with their appearance. One participant reflected:

> I started developing breasts and gaining weight, particularly in the backside, like a woman. My penis has shrunk, it's dead in fact…so since the treatment, I started feeling self-abhorrence. Hot flashes have set in, like in menopausal women. . . . I feel revolted, it's dirty and unpleasant. It makes me feel different from other people. I find it hard to look at my body. It makes me hate myself (p. 1382).

While tried to convince themselves that these physical changes were worthy sacrifices to stay alive, all participants tried to conceal their physical changes from others and used loose clothes to camouflage their enlarged breast and buttocks and their hairless legs. Nevertheless, these changes had a great impact on their body image. One participant descried his feelings:

> Whenever I saw my body, I wondered, 'Who am I? A woman? A man?' It's a very confusing situation. I believe I'm neither one thing nor another; that's the only way I can think about myself without becoming confused. To tell the truth, at first, every time I looked at myself, I became depressed. I know that it makes no sense, but it was only when I took the mirror out of the room that I stopped thinking about my appearance. As time went on, I developed all sorts of methods for consoling myself. Each time that my body's appearance disgusts me anew, I tell myself that the main thing is I'm alive. Being alive is worth it all. . . . Even concerning the size of my organ, I tell myself: 'Well, it means that the disease has shrunk (p. 1383).

At the spousal relationships, in spite that many participants reported that they continued to have good relationships with their wives; some reported that they became repugnant to their wives because of their appearance and their impotence. Such feelings of rejection from wives had its negative impact on participants' emotions (Navon & Morag, 2003).

In a similar qualitative study, Harden et al. (2002) interviewed 6 focus groups of 22 men with prostate cancer and 20 of their spouse-caregivers with the goal to "explore the experiences of couples living with prostate cancer, the impact of the illness on their quality of life, their ability to manage symptoms, and their suggestions for interventions that would help them to improve their daily experiences." (p. 701). Two groups consisted only of patients, another two groups consisted of spouse-caregivers only, and the last two groups consisted of mixed patients and spouse caregivers.

Four major themes came out of the analysis: enduring uncertainty, living with treatment effects, coping with changes, and needing help. Beside living and coping with changes due to treatment effect (urinary symptoms, sexual dysfunction, hormonal change, and weight gain) participants reported struggling with treatment choices (in many cases, information were not understood by patients and/or their families), interruptions of life patterns, emotional distress (Harden et al., 2002).

According to Harden et al (2002), the effects of treatments had a great emotional impact on patients and their spouses-caregivers especially those related to sexual dysfunction and side effects of hormonal therapy (such as fluctuations in mood {feeling depressed and crying easily} and hot flashes). The male group participants mentioned their feelings of being incomplete and grieved the loss of an integral part of their marriage. One man said:

> You go to sleep holding hands; it’s the best you can do. You sleep in the same bed, and you’re afraid to hold each other because somehow you feel like you are starting something that you can’t finish, and she’s the same way (Harden et al., 2002, p. 705).

Sexual dysfunction and changes due to hormonal therapy posed a serious threat to men’s identity and sense of masculinity and therefore their body image. One man summarized his feelings:

> You don’t have that [sexual] power anymore. It’s sad fooling yourself. . . . I used to go out with female friends and tease them . . . say anything so I would feel masculine. That was the power I had. Now I can’t flirt anymore . . . because of that medicine [hormones] (Harden et al., 2002, p. 705).

Besides men's feeling of losing the "sense of power", women reported a decreased sense of femininity or sexual attractiveness as their husbands showed less interest in them as a result of the effects of the hormones (Harden et al., 2002).

In an attempt to explore how prostate cancer and its treatment affect men's bodies, their roles, and sense of masculinity, Chapple and Ziebland (2002) conducted unstructured interviews with 52 men from the United Kingdom who suffered from prostate cancer. Findings showed that many men were hesitant to disclose their suffering and to consult their doctors, because "boys don't cry" and it is not "macho" to do so and they perceived it as a threat to their masculinity. Chapple and Ziebland (2002) argued that such a perception reinforces the notion that "masculinity" is a social construction.

However, while prostate cancer and the side effects of surgical and radiotherapy treatments sometimes led to serious complications such as impotence and incontinence, the use of hormonal therapy was reported to have an additional, sometimes profound effects on libido, energy, ability to work, breast enlargement, body shape and competitiveness. These side effects reduced some men's sense of masculinity (Chapple & Ziebland, 2002).

Participants perceived that loss of body control over urination and bowel movement causes embarrassment for them. Along with their inability to work (due to treatment-induced fatigue), they perceive such lack of control to affect their masculinity and their body image. A man summarized his feelings about urinary incontinence:

> I experienced this pain in the bladder and trouble passing water and passing water far too often to get involved in doing anything else and this obviously lead to a lack of confidence and you don't feel like leaving home (….) (Chapple & Ziebland, 2002, p. 828).

While many of the interviewed men denied the effect of being impotent (as they saw themselves as getting old for having sex), one participant described the effect of impotence on him:

> Yes, yes I mean I feel that I've lost all masculinity, I am not a man any more. I mean I am just not. I mean if I was just walking with my wife, very slowly these days, and somebody accosted her I would sort of run away. I have no masculinity left (Chapple & Ziebland, 2002, p. 834).

Chapple and Ziebland (2002) concluded that the physical body as well as the culture should be considered when trying to explain what it means to be masculine, and how illness may affect men's sense of masculinity.

In a longitudinal study performed in Australia with the aims to compare effects of different pharmacological treatments on HRQO and to "examine the role of appraisal and coping in HRQOL" in patients with non localized prostate cancer, Green, Pakenham, Headley, & Gardiner, (2002, p. 401) randomly assigned 65 men with non localized prostate cancer into four groups. The first group did not receive any treatment. The other three groups received three different types of hormonal therapy. The mean age for participants was 75.5 years at the beginning of the study. Another group of volunteers from the community who had no prostate cancer and was matching the patients groups in age, marital status, general health and occupational status was included in the study. A base line assessment using different scales that measure HRQOL, existential satisfaction, coping, and self-efficacy was followed by another assessment after a six months period.

Findings showed that patients who were receiving hormonal therapy reported significantly worse deterioration of sexual dysfunction than those who did not receive treatment and the community volunteers groups. On the other hand, there were no differences between the five groups concerning the existential, emotional, social, cognitive and physical functions. Findings also reported that those who received hormonal therapy had lower HRQOL in issues related to sexual, subjective cognitive function, and social roles, but they had higher HRQOL in other issues such as urinary functions. Furthermore, Green's et al. study reported that regression analysis revealed that medical, appraisal, and coping variables had an association with HRQOL and that higher self-efficacy was associated with better HRQOL.

Another longitudinal study (Andel & Kurth, 2003) aimed to examine the impact of immediate androgen deprivation therapy (ADT) upon health-related quality of life (HRQOL) in asymptomatic men with lymph node positive prostate cancer and compared it with the HRQOL of men who did not receive therapy revealed similar findings (Andel & Kurth, 2003). 91 men with histologically proven lymph node positive prostate cancer participated in the study. These patients were showing no symptoms at the time of diagnosis. While most of them received hormonal therapy, 18 patients chose to receive no therapy. A cross-sectional survey was performed by completing extended self-administered questionnaire at 6 months after initial diagnosis and subsequently every 12 months. The questionnaire included the European Organization for Research and Treatment of Cancer Core Quality of Life Questionnaire (EORTC QLQ C30), a global measurement of QOL (the Selby Uniscale), the c), the Sexual Behavior Questionnaire (SBQ) and self-constructed questions about the occurrence of hot flushes.

The used scales covered several dimensions of QOL. The EORTC QLQ-30 covered the areas of physical function, role function, emotional function, social function, and global health status/QOL. The Selby Uniscale measures one's energy level in comparison to others and the SBQ measures issues related to relationships and sexuality.

Data were collected approximately 6 months after the initial diagnosis and subsequently every 12 months. At the 6 months and 18 months after the initial diagnoses questionnaires, men receiving ADT had statistically significant differences with respect to the areas directly related to hormonal treatment. They reported more erectile dysfunction, decreased sexual interest, activity, and pleasure and more frequent hot flashes. At the times related to emotional functions and HRQOL, men received ADT had reported statistically significant levels of being more emotionally distressed and worse HRQOL. However, these statistically significant differences disappeared at the questionnaires done 18 months after the initial diagnoses (Andel & Kurth, 2003).

Barriers to Health Care and Utilization of Health Care Services

According to the Oxford Dictionary (2009), the ward barrier means “an obstacle that prevents movement or access” or “an obstacle to communication or progress.” The term barriers to health care was defined by (American Medical Student Association, 2009) as “obstacles within our health care system that prevent vulnerable patient populations from getting needed health care, or that cause them to get inferior health care compared to advantaged patient populations”. On the other hand, multiple authors of the major modes of health-related behaviors defined barriers to health care as “beliefs the individual holds concerning the costs associated with taking a health action” (Cummings, Becker, & Maile, 1980 as cited by McCullock-Melnyk, 1988, p. 196).

The literature reported many barriers to health care utilization which can be grouped into several categories. The American Medical Student Association mentioned four groups of barriers to health care; a) Geographic barriers, b) Cultural barriers, c) Socioeconomic barriers, and d) Organizational barriers. On the other hand, Health System Problems, Choice Regional Health Network (2009) identified six categories of barriers to health care: a) perceptions on the value of insurance; b) financial barriers; c) primary care and treatment barriers; d) health status improvement; e) consumer knowledge of the system; and f) customer service. Finally, McKinlay (1972) reviewed the literature related to the utilization of health services and came out with six approaches that explain the utilization behavior for health services: a) the economic approach, b) the sociodemographic approach, c) the geographic approach, d) the sociopsychological approach, e) the sociocultural approach, and f) the organizational approach.

Regardless of the number of approaches and categories of barriers to health care, the literature in the USA had reported extensively on these barriers. In her extensive review of the literature, McCullock-Melnyk (1988) concluded that the following barriers were the most often ones that were reported in the literature: cost (direct cost and cost of lost work), time lag to the appointment, waiting time, travel time, availability of transportation, proximity to the health care providers, issues related to health insurance coverage, lack of primary health care providers, provider/consumer ratio, prior negative experience, and differences between provider and patient in regard to cultural and social characteristics. The Center for Universal Design and The North Carolina Office on Disability and Health (2009) added that communication skills and the pattern of communication between providers and clients, especially those who are disabled, is a major barrier to health care that could lead to frustration among that vulnerable group of clients.

Others reported on specific barriers to specific groups of patients or clients. For example, Beckman, Buford, and Witt (2000) found that the most common barriers for pregnant women to seek prenatal care were long waiting time in spite of having a previous appointment and the cost of getting care. Margolis, Carey, Lannon, Earp, and Leininger (1995) identified limited availability of health care providers, lack of transportation, lack of continuity of care, and lack of belief in getting benefit from preventive care services as the major barriers to health care for underserved children.

Based upon the data from the Medical Expenditure Panel Survey Household Component, Weinick, Zuvekas, and Drilea (1997) found that inability to afford health care services was reported by about 60% of families as the major barrier for family members to receive the needed health care. The second major barrier (reported by about 20% of families) to health care was health insurance-related issues such as the refusal of health insurance companies to approve, cover, or pay for the care; having preexisting health conditions that the insurance doesn't cover; inability to obtain required referrals for care; and refusal of some physicians to accept some family's insurance plans. Other barriers reported by families included problems related to transportation, child care limitation, physical barriers, time-related barriers, issues related to lack of information, and sometimes refusal of services. Finally, Weinick et al. (1997) added that there were some variations of barriers among families with different health and demographic characteristics including perceived health status, race/ethnicity, and health insurance status.

Regarding Palestine and Gaza Strip, there are no specific studies that aimed to address the issue of barriers to health care. Nevertheless, some reports about the health care system in Palestine include some of the barriers to heath care in general. In a report prepared to the WHO, Dr. Abed (2007) included several barriers to health care. For example, the report included issues such as lack of coordination in health policy making between Gaza Strip, West Bank, governmental section, and nongovernmental organization and the inability of the Palestinian National Authority (PNA) to prioritize the provided health services and intervention. Such lack of coordination and inability for prioritizing health services impacted negatively the efficiency, effectiveness and sustainability of the provided health services. This in return affected the level of satisfaction of many donors which in return may affect the amount of money they donate to the MoH. Knowing that about 50% of the budget of MoH comes from donating courtiers reflects the impact of reducing the donated money on the availability of many services provided by the MoH. Also, Abed (2007) included that there is a lack of several services and he attributed this lack to the inability of the MoH to finance such services. Other barriers reported by Abed included the great shortage of qualified personnel in areas of health management, planning, budgeting, accounting, and data analysis. The lack of qualified personnel was attributed to the inefficiency in the employment process, inadequate licensing system for health care professionals, and to the fact that schools for health care professionals don’t meet the international standards. Such shortage in availability of provided health services and lack of qualified personnel affected the quality of provided health services and lead to client and staff dissatisfaction (Abed 2007).

Most of the barriers reported by Abed (2007) were repeated in another report prepared by the RAND Palestinian State Study Team (2007) which also included some criticism about the lack of standards for referring patients to be treated abroad. The RAND report along with a report prepared by the World Health Organization (2005) included that the Palestinian health system lack a health information system that includes data base that would be of benefit for future health planning and health-related policies.

One of most frequently models used to explain the utilization of health services is Anderson Model. The model was initially developed by Dr. Ronald Anderson in the 1960's as part of his dissertation (Anderson, 1995). The initial model tried to help in providing reasons for families' use of health services, defining and measuring equitable access to health care, and assisting in developing policies to provide equitable access to health care services. As things in health care arena changed rapidly after developing the

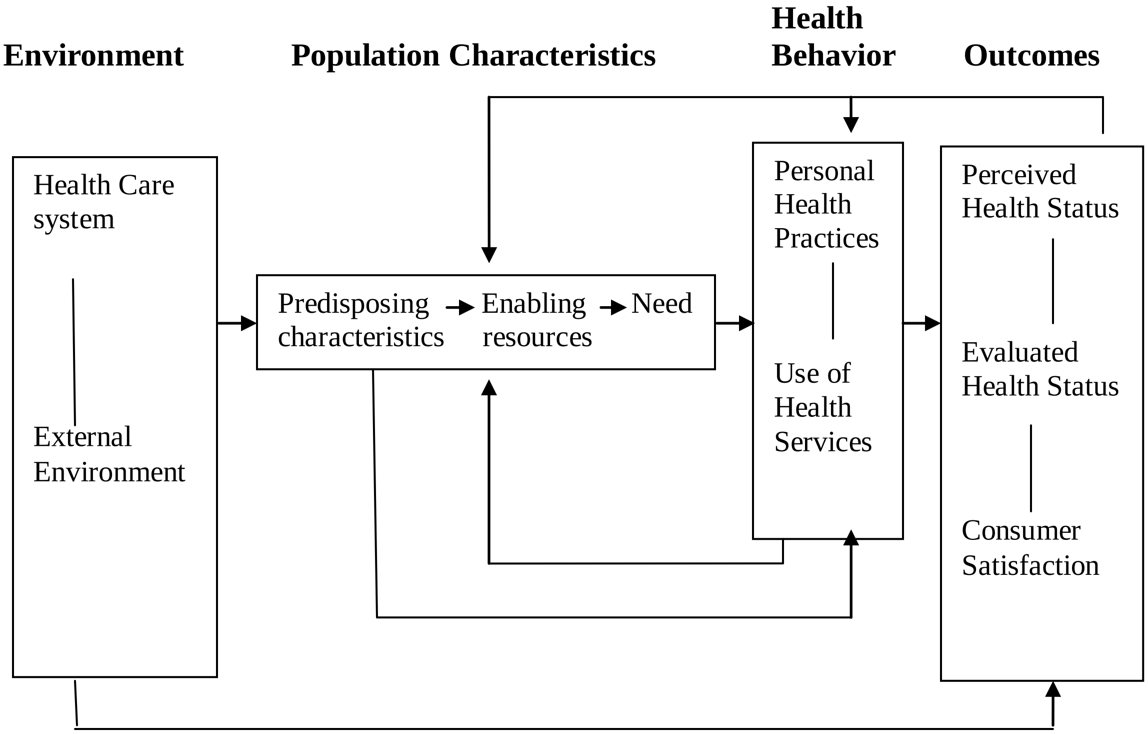


Figure 2-6: Revised Behavioral Model (Anderson, 1995, p.8).

initial model, the model was revised up to four times (Figure 2-6 represents the fourth revised model). The model hypothesized that the use of available health services is determined by several factors that include societal, health services, system, and individual factors (Figure 2-7). The individual factors include individual's predisposition to use health services, enabling factors that impede or enable use of services, and individual's need for the services (Anderson and Newman, 2005). For example, predisposing factors include factors related to demographic, social structure, and belief variables.

Demographic variables include sex, age, marital status, and past illness. Social structure variables include level of education, occupation, race/ethnicity, family size, and religion. Finally, beliefs variable includes values about health and illness, attitude toward available health services, and knowledge about the disease. Enabling factors include factors that relate to family and community. Family variable includes income, availability of health insurance, type and access to available sources. Community variable includes issues related to ratios of health professionals and facilities to a given population, price of provided services, region of country, and urban-rural character. Finally, the need factor includes the individuals' perceived level of illness or evaluated level of illness.

In order to promote health services, Anderson (1995) thinks that a factor should be mutable and therefore will be a point for policy change. Some factors included in the model are un-mutable such as age, sex, race and ethnicity. Others are mutable such as beliefs, level of education and offered health services. Therefore, Anderson (1995) thinks that enabling the use of health services is a high mutable policy variable that will enable clients to utilize health services and it can be inferred that removing the barriers to health care utilization is a high mutable policy variable too. Such an assumption motivates

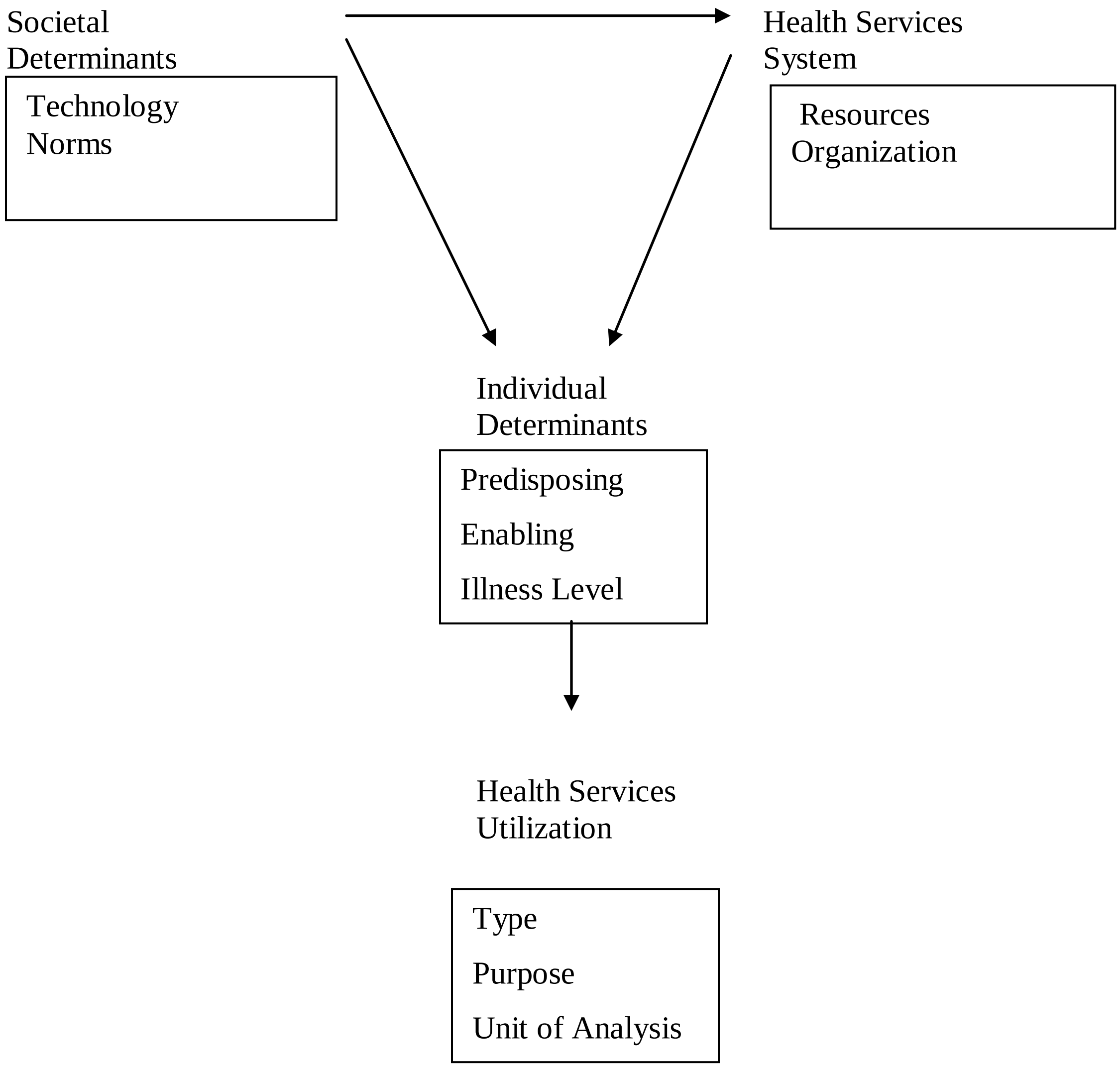


Figure 2-7: Factors Influencing Utilization of Health Care Services. (Source: Anderson & Newman, 2005, p. 4)

health olicy makers to design policies and programs to provide services that are not available and to overcome the barriers that hinder the utilization of the available health services.

Summary

Prostate cancer is one the most cancers that affect men especially when they get older. Several risk factors such as age, ethnicity, and diet increase the chance to develop prostate cancer. When discovered while localized, prostate cancer is curable, while it is not if discovered in advanced stages. Then the goal of treatment becomes palliative rather than curative. Several treatment options including prostatectomy, radiation therapy, hormonal therapy, and watchful waiting are available to treat prostate cancer. Each of the available treatment options has its pros and cons and the consequences of treatment usually affect the level of QOL of prostate cancer survivors.

In spite of the numerous definitions of quality of life, they all have something in common which is that quality of life is subjective and it can be perceived differently by different people who have the same physical conditions. The literature about quality of life of patients having prostate cancer have reported that there were several domains that impacted the quality of life of prostate cancer survivors. The physical domains included dysfunction in the urinary, sexual, and bowel elimination which were reported to affect men’s quality of life. Other issues that were reported to have an effect on quality of life were related to body image, emotional statues, social roles and relationship with spouses.

In spite of the abundance of literature about quality of life of patients having prostate cancer, the researcher observed that the reported literature came from developed countries such North America, Europe, Australia, Japan, and Israel. Unfortunately, the researcher could not find any study that had evaluated QOL of prostate cancer survivors in any developing country. Such lack of literature about the QOL of prostate cancer survivors in the developing countries raises the question if there are any differences of QOL of prostate cancer survivors among those who live in the developed courtiers and those who live in the developing countries.

The same issue was noticed about the literature about barriers to health care. There are several studies that were conducted in the USA and reported about the barriers to health care, but there were no studies that reported about the same topic in the developing countries. Nevertheless, the available literature categorized barriers to health care under several categories that range from 4-6 categories. Among the categories of barriers to health care were those related to economic, cultural, geographical, organizational, time-related factors, and factors related to customer service.

CHAPTER III

METHODOLOGY

This chapter aims to discuss the methodology employed for this dissertation study. It presents the study design, participants sampling and setting, definition of study constructs, the instrument used to measure quality of life and its validity and reliability, data analysis, and ethical considerations.

Study Design

The design for this study is a cross-sectional, descriptive design that contains both quantitative and qualitative approaches. This design will help in describing the study variables at a certain, fixed point of time. The advantage of cross-sectional design is that it is practical, simple, economical, and easy to conduct (Polit and Beck, 2004, Neuman, 2006). Because data in cross-sectional designed are collected at fixed points of time, results may be ambiguous or misleading. Other limitation of cross-sectional design is the inability to infer changes over time (Polit, and Beck, 2008). On the other hand, in this design, the investigator will have less "ability to establish an in-depth development of the phenomena being studies" (LoBiondo-Wood and Haber, 2006, p. 246).

The study included both the quantitative and qualitative approaches in data collection. The use of both quantitative and qualitative approaches strengthens the design and reduces any weaknesses in either approach (Patton, 2002 and Punch, 2005). It will also provide richer and more in-depth data that will reduce biases of the use of a single method (Neuamn, 2006 & Creswell, 2003) and will add to the richness of the study. Furthermore, Neman (2006) argues that the use of triangulation method will make the study fuller and more comprehensive and one method will cover for the limitations of the other (Creswell, 2003). For example, quantitative data gives the researcher hard data and when used with qualitative data it answers the question why.

Participants, Sampling, and Settings

The study population for this study included all male adult patients who had been diagnosed with prostate cancer and received, currently receiving treatment, or did not receive any treatment for prostate cancer and reside in Gaza Strip. The number of patients who had been diagnosed with prostate cancer between the years of 1995 and 2000 was 106 cases (Najjar et al, 2002). Unfortunately, there were no available data about the actual number of patient diagnosed with prostate cancer in Gaza. The number of patients who are living with prostate cancer in Gaza Strip is estimated to be around 250 to 300 patients. All prostate cancer patients living in Gaza Strip were recruited to participate in this study whether they were receiving treatment or not at the time of data collection between August and November, 2009.

The sampling frame for this study included all male patients who were diagnosed with prostate cancer and live in Gaza Strip prior to and during the data collection process. This included patients who were receiving treatment and who had finished their treatment at the time of data collection took which took place between August and November, 2009. The plan was to obtain contact information about patients who were diagnosed with prostate cancer and live in Gaza Strip from the Palestinian National Cancer Registry. But access to all prostate cancer was not possible because cases diagnosed after 2007 were not registered at the Palestinian Cancer Registry due to political chaos that prevails in the region. Further, it was not possible to obtain a list of prostate cancer patients from the Palestinian Cancer Registry due to the high bureaucracy that prevails at the governmental systems. Therefore, the researcher had to go to the oncology outpatient clinics at the two centers providing oncology treatment in Gaza Strip (Shifa Hospital and Gaza European Hospital) and identified a list of 171 patients who were receiving treatment at the time of data collection or had previously received treatment at one of the two centers.

The process of identifying participants was much easier at Gaza European Hospital as it has a computerized system which helped the researcher to identify cases that were diagnosed with prostate cancer by punching the diagnosis into the system. The process was much more complicated at Shifa Hospital as the researcher and his assistant had to manually examine the medical records of all oncology patients that were available at the registrar office to identify patients who had been diagnosed with prostate cancer.

Participants were interviewed, privately, at one of the health care facilities that offer treatment for prostate cancer, when they came to receive their treatment, at their homes (when participants preferred to), or at other convenient places to the participants. In the event where it was difficult to reach to some participants in person, they were interviewed over the phone. According to Babbie (2001), interview survey usually has a high response rate. He described a response rate of 80-85% of interview survey as a "completion rate" (p. 258). Babbie added that another advantage of this method for data collection is decreasing the numbers of "don't knows" and "no answers" (p.258).

The questionnaire was not sent by mail to the patients for three reasons. First, it was expected that a relatively sizable proportion of participants will not be able to read and write as the latest available data about the level of illiteracy in 2002 revealed that the level of illiteracy was 13.2% among male Palestinians 55-64 years old and was as high as 59.4% among male Palestinians over the age of 65 years (Palestinian Central Bureau of Statistics, 2009). Such high percentage of illiteracy might affect the adequacy of data and response rate if questionnaires were to be mailed to participants. Second, the postal system in Gaza Strip is not well developed as there are no postal codes and the majority of streets have no names which would make the mailing process very hard. Third, the availability of the interviewer will help to answer any inquiry by participants if they need any clarifications about any item of the questions involved in the questionnaire.

Definition of Study Constructs

Constructs of interest for this study are defined as follows:

Prostate Cancer Survivor: any adult male patient who had been previously diagnosed with prostate cancer and live in Gaza Strip regardless if he received, is currently receiving, or didn’t receive treatment at all for prostate cancer.

Quality of Life: Ferrans’ (1990, 1996) definition of quality of life was used as the operational definition for QOL for this study. She defined QOL as “a person’s sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her” (Ferrans, 1990, p. 15 and Ferrans, 1996, p. 296).

Barriers to health care: any obstacle within or outside the Gazan health care system that patients with prostate cancer who reside in Gaza Strip think that it prevents them from getting needed health care.

Instrument

The questionnaire used (Appendix A for the Arabic Version and B for the English version) in this study to measure quality of life of prostate cancer survivors was based on the University of California Prostate Cancer Index (UCLA-PCI), including the RAND 36-Item Health Survey v2 (SF-36 v2) Health-Related Quality of life (Appendix C). The UCLA-PCI was developed by a group of researchers at the University of California, Los

Angeles (UCLA) to measure health-related quality of life (HRQOL) in patients who were diagnosed and treated for prostate cancer. A permission from Dr. Litwin (Appendix D) was obtained to translate and use the instrument for the purpose of this study. Besides addressing HRQOL issues related to prostate cancer, the instrument also addresses the general HRQOL as those patients may have other co-morbidities or health related issues that may impact their quality of life. The index consists of three parts : (a) the RAND 36-Item Health Survey v2 (SF-36 v2), items 1-11; (b) the UCLA Prostate Cancer Index, items 12-28; and (c) the Socio-demographic data, items 29-34 (Litwin, 1994). The researcher used the qualitative approach to assess the barriers to health care using a semi-structured interview technique.

Semi-structured interview allowed participants to talk about whatever issues they think that they were barriers to health care and allowed them “to tell their stories in the manner they chose” (Green, McSweeney, Ainley, Bryant, 2009, p. 50). In this technique, the interviewer asks a predetermined questions and probes participants’ when necessary to enhance the depth and richness of their responses (Holstein & Gubrium, 1997 and Patton, 2002). Further, Willig, (2001, p. 22) thinks that this technique will “generate novel insights for the researcher” and enable him/her to “maintain control of the interview” and the original research questions.

The RAND 36-Item Health Survey was originally produced and published by the RAND researchers and now it is used as the principal tool to measure general HRQOL (Litwin, 1994). The SF-36 is a Short-Form health survey with multiple purposes (Ware, 2000) and was described as the most widely evaluated tool that assesses health outcome for patients regardless of their age, diseases, or type of treatment (Garratt, Schmidt, Mackintosh, & Fitzpatrick, 2002). The SF-36 was designed to satisfy the minimum psychometric standards that are necessary for group comparisons. In response to some deficiencies identified in the original version of SF-36, a second version (SF-36 v2) was introduced in 1996. Improvements were introduced to make it shorter, more simple, less ambiguous, and more comprehensible and readable by patients, which would increase response rate (Ware, 2000).

The SF-36 v2 consists of 36 items that assess the eight health domains considered by the medical outcomes study to represent the most frequently used concepts in relevant health surveys and those that are affected by several diseases and treatment (Ware, 2000). These domains cover the following areas: physical functioning, role physical (role limitation due to physical health problems), bodily pain, general health, vitality (energy/fatigue), social functioning, role emotional (role limitation due to emotional problems), and mental health (psychological distress and psychological well-being). It also includes an item in which the patient makes a statement about the evaluation of their health status (Ware & Sherbourne, 1992; Ware, 1993; and Ware 2000). The scores recorded for each scale range from 0 to 100, with the higher scores referring to a better QOL.

The second part of the instrument is the UCLA Prostate Cancer Index (UCLA-PCI). It is a self-administered questionnaire that contains 20 items that quantifies and covers six health-related domains that are prostate-specific to HRQOL. These domains are urinary functions and bother (six items), bowel functions and bother (five items), and sexual functions and bother (nine items). The urinary, bowel, and sexual scales focus on the problems of urinary incontinence, bowel difficulties, and sexual difficulties respectively while the bother scales focus on how much these patients are troubled by these dysfunctions. The UCLA-PCI is available for public at the Patient-Reported Outcome and Quality of Life Instruments Database (2009) and at the University of Kentucky Department of Surgery (2009) websites.

The third part of the instrument, which contains six items, is pertaining to demographic data and brief medical history. Besides including information about age, ethnicity, level of education, occupational, and marital status, it includes a 12-items medical conditions check list. This check list has a list of 12 other diseases or health-related conditions that were selected based on the comorbidity index. The list includes the following: diabetes, heart attack/chest pain, stroke, amputation, circulation problems in legs or feet, asthma/emphysema/breathing problems, stomach ulcer/irritable bowel, kidney disease, major depression, seizures, alcoholism/alcohol problems, and drug problems. The participants need to check each item in the list as present or absent.

In the original instrument, the items for SF-36 v2 and UCLA-PCI are answered using a Likert scale or yes/no answers. But the instrument is accompanied by scoring instructions for each item (appendix E). The final score is converted to scores that range from 0 to 100, with higher scores meaning better health states and HRQOL.

Validity and Reliability of the UCLA-PCI Including SF-36

The UCLA-PCI including the SF-36 showed to be valid and reliable. To test the validity and reliability of the instrument, after conducting a four focus groups discussion (n=50) of patients who have prostate cancer and their spouses, Litwin et al. (1998)

conducted a cross sectional study with 245 participants who had prostate cancer in the control group and 273 participants who had no prostate cancer in the comparison group. Litwin et al assessed the psychometric properties of the instrument by measuring test-retest reliability, internal consistency reliability, and construct validity. They further compared the performance of the instrument with other established instruments that measure cancer-related HRQOL. The results showed that the test-retest reliability of the instrument ranged from 0.66 to 0.93. The internal consistency of the instrument ranged from 0.65 to 0.93. Furthermore, the results showed that the items targeted the function and the bother of the three main domains (urinary, bowel, and sexual functions) correlated substantially with one another: urinary ($r = 0.71$), bowel ($r = 0.65$), and sexual ($r = 0.73$) with a $p < 0.001$, indicating that the UCLA-PCI demonstrated good psychometric properties and performed well in this patient population and interpreted the high response rate among participants as an indication for how easy the use of the instrument was by the participants.

Besides Litwin’s et al. (1998) study, several other studies reported that the UCLA-PCI was reliable and valid to be used in elderly men patients who have been diagnosed with early or late prostate cancer (Litwin et al., 1995, Lubeck, Litwin, Henning, & Carroll, 1997, Litwin & McGuigan 1999, Litwin, McGuigan, Shpall, & Dhanani, 1999, and Saigal, Gornbein, Reid, Litwin, 2001). For example, Saigal et al. (2001, p. 407) reported that the PCI has shown to be both valid and reliable with “test retest reliability intraclass correlations of 0.77 in five of six scales and alpha coefficients of 0.65–0.93 in populations of older men with and without prostate cancer”.

On the other hand, several studies reported about the validity and reliability of the SF-36 as a solo instrument that measures general HRQOL (Ware & Sherboure, 1992; McHomey, Ware, & Raczek, 1993; Ware, Snow, Kosinski, & Gandek, 1993; Benjamin-Coleman & Alexy, 1999; Sneed, Paul, Michel, Vanbakel, & Hendrix, 2001; Walters, Munro & Brazier, 2001). For example, the reliability of the SF-36 was established in a study based on the Medical Outcome Survey (N=3445) showed that the coefficient for the instrument ranged from 0.77 to 0.92 (Ware, et al., 1993). Reviewing several studies that examined the reliability and validity of SF-36, Sneed et al. (2001) reported that its reliability and validity were well documented. For example, the median scale reliability across 14 reviewed studies exceeded 0.80-0.91. Furthermore, Sneed et al concluded that "the SF-36 was better able to differentiate physical and emotional aspects of QOL" in their sample (p. 332). In another study aimed to the validity and reliability of the SF-36 tool, using 1980 participants (response rate = 83%), Brazier et al. (1992) reported that the SF-36 was reliable as Cronbach's alpha was > 0.85 and reliability coefficient was more than 0. 75 for all domains except social functioning domain. Brazier et al. further added that their study provided evidence of the construct validity of the instrument.

Translation and Modification of the Instrument

The first part of the study, the SF-36 v2, was translated into the Arabic language and showed to be reliable and valid. In their study, Sabbah, Drouby, Sabbah, Retel-Rude, and Mercier (2003) used a random sample of 524 Lebanese who were 14 years and older and living in urban and rural areas of the southern part of Lebanon. The SF-36 was translated into Arabic then back translated into English. Some expressions were modified due to cultural differences. Words used to measure distance such as miles, yards, blocks were replace by words using the metric system. Words like playing golf and bowling were translated to activities such as gardening and sport activities to refer to moderate activities. The result of Sabbah's et al. (2003) showed that the translated version of the SF-36 had acceptable internal consistency with a Cronbach's alpha >0.70 and factor analysis results showed that the factor correlation of the Arabic version were comparable to that found in the original SF-36. A permission to use the Arabic version of the SF-36 in this study was obtained from the main researcher, Dr. Ibtissam Sabbah (Appendix F).

The second part of the instrument which relates to prostate-specific QOL (UCLA-PCI) was also translated into the Arabic Language and some modifications were considered to fit into the cultural and religious variability pertaining to the people living in Gaza Strip. Examples of modifications included omitting "anal intercourse" when translating item 16 as it is not religiously or culturally accepted.

The demographic and brief medical part of the instrument was replaced by another that describes the population of Gaza and was placed at the beginning of the questionnaire. Also, some additional questions were added to the instrument to address issues that were not included in the initial instrument. Examples of these questions include; when the patient was diagnosed with prostate cancer and what type of treatment did he receive. Finally, an open question was also added to help the investigator to assess the barriers to health care that faced men who have prostate cancer.

The instrument was translated by the principal researcher and then was reviewed by two experienced nurses, who had at least five years of nursing experience and had good command of both the English and the Arabic languages. Conceptual rather the literal meaning was the goal of translation. After translating the instrument into the Arabic language, it was then back translated into the English language by a third bilingual nurse. Back-translation is a standard procedure for translating a research questionnaire from English to other languages (Kim et al., 1995).

The instrument used in this study was proven to be valid and reliable as mentioned in the previous section. Before using the instrument in this study, the content validity of the translated instrument was examined. Five expert nurses, who have at least 10 years of experience, were asked to evaluate the content relevance (to both general quality of life and prostate-specific quality of life) of each item of the instrument and the entire instrument as a whole. They were asked to rank each item on a four point scale where 1= not relevant, 2= somewhat relevant, 3= quite relevant, and 4= highly relevant. Then each item was dichotomized where any item that was rated 1 or 2 was considered not relevant and any item rated 3 or 4 was considered relevant (Polit and Beck, 2006). Then, item content validity index (I-CVI) of these ratings was calculated by figuring out the proportion of items that were rated as relevant by all five experts. According to Polit and Beck, an I- CVI of 80% or above indicates a good content validity. The response of the five nurses revealed the following: two nurses reported all items as highly relevant. The other three nurses reported that, with the exception of 2-5 items rated as somewhat relevant, all of the items were highly relevant. When the response for each item was dichotomized, all items were labeled as relevant and therefore, the I-CVI was 100% for each item which reflects a good content validity (Polit and Beck, 2006).

Pilot Testing

After translating the instrument, it was introduced to ten patients who were randomly selected from the list of patients identified by the researcher and were diagnosed with prostate cancer to evaluate its clarity and to determine whether it was friendly and easy to understand. The pilot study also investigated the following: (1) how long it takes to complete the questionnaire; (2) whether participants felt they had enough opportunity to share their views; (3) suggestions for changes; (4) other comments.

Participants in the pilot study reported that it was friendly to use the instrument and that the items were easily understood. Only one suggestion was addressed about the wording of questions. That was about another Arabic expression to the English expression “sexual intercourse” to help less educated people to more understand what meant by this item. Other than that, participants in the pilot study did not suggest any changes in the wording of the instrument. The suggestion was taken into consideration and was added into bracket. Finally, the average time to answer the questionnaire was between 25-40 minutes.

Data Analysis

The Statistical Package for Social Science (SPSS), version 16, was used to compute and analyze the quantitative data. All responses provided by participants were entered into a personal computer. The responses then were recoded using the accompanied scoring instructions (appendix E) to convert the Likert scale points into scores that ranged between 0 and a 100.

The accuracy of the data entered into the SPSS was ensured by double checking of 25 completed questionnaires and comparing the data entered into the computer with the original data and examining. No errors related to data entry were found. The researcher also checked that all data fell within the accurate range for each item. Running frequencies for all items revealed that there were not missing data as the researcher had reviewed each questionnaire while interviewing participants for missing data. None of the participants had refused to answer any item of the questionnaire.

Data analysis procedures included basic descriptive statistics to describe the sample. Because the study was a descriptive study, the data were analyzed using descriptive statistics (mean, range, standard deviation, and percentage) and frequency distribution tables and occasionally t test.

Normality of continuous variables distribution was assessed using skewness and kurtosis (i.e. Fisher measure of skewness). When the Fisher measure of skewness was calculated for the continuous variables, it was found that some results exceeded the ± 1.96 (the critical value of significance at an alpha of 0.05). Fisher measure of skewness is calculated by “dividing the measure of skewness by the standard error for skewness” (Munro, 1997, p. 42). Examples for results of skewness that exceeded the critical value are the skewness for time elapsed after diagnosis (Table 4-7), skewness of scores for PCI QOL for participants who were receiving treatment (Table 4-15), and score of bodily pain and general health (Table 4-16 A).

Several authors, such as Tabachnick and Fidell (1997) mentioned that sample size may affect Fisher's measure of skewness and may result in large critical values with moderately large samples which have normal distributions. Field (1009, p.134) further added that "as our sample gets bigger then, we can be more confident that the sampling distribution is normally distributed" .Tabachnick and Fidell suggested that in a sample size of a 100 cases or more (such as in the case of this study) not to worry about the statistical significance of skewness. Although Tabachnick and Fidell did not provide guidelines about an acceptable degree of departure from the zero to be used in large studies, depending on the result of several computer simulation studies, Kline (1998) provided a rule of thumb of using an absolute skewness value of more than 3 to assume non-normality of data. In the case of this study, none of the variables that had a Fisher's measure of skewness was three or more.

The qualitative part of the research question, particularly the part related to exploring the barriers to health care, was analyzed through careful reading of the responses provided by the respondents. Data analysis consisted of identifying, coding, and categorizing patterns found in data (Bryne, 2001). In this study the researcher used thematic analysis which is considered a way of seeing, as well as a process of coding qualitative information (Bryne, 2001). Throughout data coding, the researcher began with determining labels, defining the concern of each theme, describing how to know when each theme occurred, describing any qualifications or exclusions to identify themes, and determining some positive and negative examples to eliminate the possibility of confusion when looking to the themes (Bryne, 2001). Besides that, codes and categories were developed from the gathered information and the investigator did observe how frequently these codes and categories appeared in the data base to establish the patterns of these categories and codes. Then the investigator identified the major themes and subthemes that came from the data. When appropriate, quotes were used. Finally, the identified themes were analyzed by using direct interpretation.

Ethical Considerations

Prior to contacting the participants, all materials and procedures were submitted to the Internal Review Board (IRB) at the University of Akron and an approval to conduct the study was issued (Appendix H). Then after approval, a similar package was submitted to the Palestinian Ministry of Health and obtained their approval (Appendix I) for conducting this study, recruiting participants from the two government oncology centers, and seeking the cooperation of the employees in these two centers. A third approval was obtained from the Helsinki Committee (Appendix J) which is an independent committee in Gaza Strip that approves health related studies conducted in Gaza Strip. After getting the approvals to conduct the study from the IRB at the University of Akron, the Palestinian Ministry of Health, and Helsinki Committee; the investigator contacted the participants and a written consent (Appendix K) was obtained from each participant after explaining the purpose of the study. In case the participant was illiterate or interviewed over the phone, after consulting with the IRB at the University of Akron, a verbal consent was obtained to participate in the study. Prior to obtaining the verbal consent, the interviewer read the consent form to each participant and in case he had any question, the interviewer had answered those questions. The investigator explained to each participant that his participation is voluntary and that he had the right to refuse to participate or to withdraw from the study at any time. All participants were assured of confidentiality and anonymity and were assured that no direct physiological, psychological, or socioeconomic risks or manipulations would be associated with this study. The investigator did secure the confidentiality of the participants and did not include their names on any documents or reports. Completed data sheets were entered into a computerized data file in the researcher’s personal computer that was assigned a secured password. Data collection sheets and the computerized data entries were only accessible by the principle investigator and will be destroyed two years after the completion of the study.

Summary

The design used for this study was a cross-sectional design that used both quantitative and qualitative approaches in data collection. All patients diagnosed with prostate cancer who live in Gaza Strip were asked to participate in the study. The instrument used to measure quality of life of prostate cancer men living in Gaza Strip was based on the UCLA-PCI instrument which is a valid and a reliable instrument. The part that measures the general health-related quality of life was translated into the Arabic Language by a group of researchers from Lebanon. After translating the PCI-related QOL part, a pilot testing for the instrument was done to ensure the easiness of its use by target population. Approvals from the IRB at the University of Akron and from the Palestinian Ministry of Health were obtained prior to conducting the study. After data were collected, the SPSS package was used for data analysis. The data produced were mainly descriptive to fit the purpose of the study.

CHAPTER IV

RESEARCH FINDINGS AND DISCUSSION

This chapter outlines the results of data analysis performed to answer the research questions regarding quality of life of prostate cancer survivors living in Gaza Strip and the barriers to health care they faced during their treatment time. Quantitative approach was used to analyze data related to quality of life. Results were presented in tables and were related to relevant literature. Qualitative approach was used to analyze data related to barriers to health care. A descriptive model was generated to depict barriers to health care reported by participants.

Description of the Sample

The target population for this study was all participants who were diagnosed with prostate cancer and live in Gaza Strip. The sample frame included prostate cancer patients who were receiving treatment and patients who had already finished their treatment at the time of data collection between August and November, 2009. Access to all patients diagnosed with prostate cancer in Gaza Strip at that time was not possible because cases diagnosed after 2007 were not registered at the Palestinian Cancer Registry. Further it proved impossible within the time parameters of this study to obtain a list of prostate cancer patients from the Palestinian Cancer Registry. Therefore, data were obtained by going to the oncology outpatient clinics at the two centers providing oncology treatment at Gaza Strip (Shifa Hospital and Gaza European Hospital). In this way a list of 171 patients who were receiving treatment at the time of data collection or had previously received treatment was created.

The process of identifying prostate cancer patients was much easier at Gaza European Hospital as the center has a computerized information system which helped the researcher in identifying patients who had been diagnosed with prostate cancer by entering the diagnosis into the system. The process was much more complicated at Shifa Hospital as all of the available medical records for all oncology patients that were available at the registrar's office had to be examined manually to identify patients who were diagnosed with prostate cancer.

Of the 171 cases identified with prostate cancer, the addresses or the telephone numbers of six cases could not be identified. In nine cases, the patients had died. Furthermore, 3 cases were out of the country, and one patient was hospitalized due to a serious illness. This reduced the sampling frame to a 152 cases. All of these participants were receiving treatment at the time of data collection except seven of them. When these patients were approached (either personally or by telephone), all of them agreed to participate in the study and completed the items of the questionnaire except one participant. Therefore, the respondents were 151 out of 152 participants with a response rate of 99.34% for this group of participants.

To recruit more participants, especially of those who were not receiving treatment at the time of data collection, the snow ball technique was used. After interviewing participants, they were asked to refer other patients who were diagnosed with prostate cancer that they knew. The result was identifying a new list of 54 patients. All of the new referred cases were from those prostate cancer survivors who were not receiving any treatment at the time of data collection. All participants were approached either personally or by telephone. Of the 54 new cases, six were found to be dead and one was outside the country. Of the remaining 47 cases, 44 agreed to participate in the study and the other three participants refused to be involved in the study. The final total number of participants was 195 (151 from the first group and 44 from the second group) out of 199 with a final response rate of 97.98%.

Such a response rate is considered a very high response rate. Similar studies that used the UCLA-PCI instrument to evaluate QOL of men who had prostate cancer reported response rates that ranged between 53.1 to 93% (Litwin et al.,1995; Litwin et al., 1998; Litwin and McGuigan, 1999; Madalinska et al., 2001; Karakiewicz et al., 2003; Jo, Junichi, Tomohiro, Yoshinari, and Masato, 2005; Shikanov et al., 2008; Wakatsuki et al., 2008; Inoue et al., 2009). The high response rate in this study could be related to the fact that participants were approached directly, either in person or by telephone, which provided participants with details about the purpose of the study and gave them a chance to answer their questions which encouraged hesitant participants to participants in the study. In fact, Litwin et al. (1998) contended that the high response to their study (79.4%) suggested that men with prostate cancer were interested to address issues related to their general QOL and prostate-specific QOL. This contention could be another reason that could contribute to the high response to this study. On the other hand, Babbie (2001) thinks that interview survey usually have a high response rate. He described a response rate of 80-85% of interview survey as a “completion rate” (p. 258). Babbie added that another advantage of this method for data collection is decreasing the numbers of “don’t knows” and “no answers” (p.258).

Description of Study Measures

The study included several groups of measures such as demographic variables, general health-related variables, and variables describing the level of QOL. These are in addition to the answers for the open question related to barriers to health care. Demographic variables included age, level of education, whether the participant lives with his wife or not, and place of living. The general health-related measures included having a health insurance, having another cancer beside prostate cancer, when prostate cancer was diagnosed, whether he received treatment for prostate cancer or not, type of treatment, where he received or receiving treatment, and whether he had other comorbidities and/or health-related problems or not.

The other set of measures were used to assess QOL. One set included the 36 items (SF-36) that measure QOL related to general health. The SF-36 covers the following nine domains: physical functioning, role physical (role limitation due to physical health problems), bodily pain, general health, vitality (energy/fatigue), social functioning, role emotional (role limitation due to emotional problems), mental health (psychological distress and psychological well-being), and health transition. The other set of measures included 20 items that measure QOL specific to prostate cancer (Prostate-Cancer Index).

These items specifically measure urinary dysfunction and bother, bowel dysfunction and bother, and sexual dysfunction and bother.

Demographic Variables

Demographic variable included the following variables: age, level of education, place of living, marital status, and whether a participant had a health insurance or not.

Age

The age of participants at the time of data collection ranged between 49 and 91 years with a mean of 70.29 and a standard deviation of 8.81 (Table 4-1). The mean and standard deviation of age for the participants in this study were compatible with several studies that used the UCLA-PCI instrument which ranged between 67.7 and 72.7 years (Kakehi et al., 2002; Karakiewicz et al., 2003; Korfage et al., 2003; Ishihara et al., 2005; Namiki et al., 2006; Namiki et al., 2007; Inoue, et al.,2009). After calculating the mean and the standard deviation for the age of the participants, the age variable was categorized into the following categories: under 45, 46-50, 51-55, 56-60, 61-65, 66-70, 71-75, and over 75. As table 4-2 shows, the highest prevalence of prostate cancer was among the participants who were over the age of 75 (65 participants who represented 33.3% of the total population) while the lowest prevalence was among those who were between the ages of 45 and 49 (2 participants who represented 1% of the total sample).

Table 4-1: Descriptive Statistics for Age of Participants.

Group	Variable	Median	Mode	Mean	Std. Deviation	Minimum	Maximum	Skewness
All Participants	Current age	70.0	70.0	70.29	8.80	49	91	0.41
	Age at diagnosis	66.0	75.0	65.99	8.27	46	85	0.61
Participants receiving treatment	Current age	70.5	70.0	70.21	8.77	49	89	0.43
	Age at diagnosis	66.5	75.0	66.58	8.26	46	85	0.46
Participants receiving no treatment	Current age	70	70	70.49	8.97	55	91	1.49
	Age at diagnosis	64	68	64.41	8.17	47	83	0.44

Table 4-2: Age by Category

Age category		Participants were receiving Treatment		Participant were not receiving treatment		All Participants		Cumulative % for all participants
		Freq.	%	Freq.	%	Freq.		
45-49	Now	2	1.4	0	0	2	1.0	1.0
	At diagnosis	4	2.8	2	3.8	6	3.1	3.1
50-54	Now	4	2.8	0	0	4	2.1	3.1
	At diagnosis	5	3.5	2	3.8	7	3.6	6.7
55-59	Now	10	7.0	7	13.2	17	8.7	11.8
	At diagnosis	21	14.8	11	20.8	32	16.4	23.1
60-64	Now	20	14.1	9	17.0	29	14.9	26.7
	At diagnosis	28	19.7	14	26.4	42	21.5	44.6
65-69	Now	25	17.6	9	17.0	34	17.4	44.1
	At diagnosis	28	19.7	12	22.6	40	20.5	65.1
70-74	Now	33	23.2	11	20.8	44	22.6	66.7
	At diagnosis	29	20.4	3	5.7	32	16.4	81.5
75 or more	Now	48	33.8	17	32.1	65	33.3	100.0
	At diagnosis	27	19.0	9	17.0	36	18.5	100.0
Total		142	100.0	53	100.0	195	100.0	

Age of the participants at the time of diagnosis ranged between 46 and 85 with a mean of 65.99 years and a standard deviation of 8.27 (table 4-1). These results were relatively less than the means (68.1-69.5 years) reported in other studies (Lubeck, Litwin, Henning, and Carroll, 1997; Madalinska et al., 2001; Jayadevappa et al., 2006). The highest frequency of participants (n=42, 21.5%) were diagnosed at the age of 60-64, followed by the age category of 65-69 (n=40, 20.5%). The lowest frequency was noticed at the age younger than 50 years old as only 6 (3.1%) participants were diagnosed at that age group (Table 4-2). When examining the age at diagnosis carefully, it would be noticed that the majority of participants (n=108, 55.38%) were diagnosed with prostate cancer at the age of 65 years or older. Diagnosing prostate cancer at such age will put some clients at high risk to be treated by surgery and therefore, will eliminate the surgical option from their options' list to treat their cancer. On the other hand, such an old age at diagnosis would suggest the introduction of early screening for prostate cancer using digital rectal examination (DRE) and/or by testing for Prostate-Specific Antigen (PSA).

To compare the mean of age for the group that was receiving treatment to the group that was not receiving treatment, t test was used. The result showed that there was no statistically significant difference between the means of both groups (t= -.192, df=193, p= .848).

Level of Education

Table 4-3 depicts the level of education for participants. The table shows that 62 participants (31.8%) did not receive any education at all, 28 (14.4%) received some education but did not complete the primary (sixth grade) level, 20 (10.3%) finished primary school, 18 (9.2%) completed the preparatory (9th grade) school, 37 (19.0%) completed high school, and 30 (15.4%) had higher education.

Place of Living

Table 4-4 shows the place of living for participants. 37 participants (19%) live in the northern governorate, 82 (42.1%) live in the Gaza governorate, 29 (14.9%) live in the

Table 4-3: Level of Education of Participants.

Level of education	Participants were receiving Treatment		Participant were not receiving treatment		All Participants		Cumulative % for all participants
	Freq.	%	Freq.	%	Freq.	%	
No School	42	29.6	20	37.7	62	31.8	31.8
Some educating below Primary School	23	16.2	5	9.4	28	14.4	46.2
Finished Primary School	13	9.2	7	13.2	20	10.3	56.4
Finished Preparatory School	15	10.6	3	5.7	18	9.2	65.6
Finished High school	29	20.4	8	15.1	37	19.0	84.6
Higher Education	20	14.1	10	18.9	30	15.4	100.0
Total	142	100.0	53	100.0	195	100.0	

Mid-Zone governorate, 26 (13.3%) live in Khanyounis governorate, and 21 (10.8%) live in Rafah governorate.

As it was noticed from these results, the prevalence of prostate cancer was higher among men who lived in Gaza Governorate (42.1% of participants). When compared with the percentage of the male population who were living in Gaza governorate, which was 35.1% of all males living in Gaza Strip in the year 2007 (Palestinian Central Bureau of Statistics, 2009), it was noticed that men with prostate cancer in Gaza Governorate were over-represented (42.1% of participants live in Gaza Governorate while males represented 35.1% of male population in Gaza Strip), while men with prostate cancer were under represented in the Southern governorates (Khanyounis and Rafah

Table 4-4: Place of Living for Participants

Place of living	Participants were receiving Treatment		Participant were not receiving treatment		All Participants		Cumulative Percent for all participants
	Freq.	%	Freq.	%	Freq.	%	
Northern Governorate	27	19.0	10	18.9	37	19.0	19.0
Gaza Governorate	67	47.2	15	28.3	82	42.1	61.0
Mid zone Governorate	25	17.6	4	7.5	29	14.9	75.9
Khanyounis Governorate	13	9.2	13	24.5	26	13.3	89.2
Rafah Governorate	10	7.0	11	20.8	21	10.8	100.0
Total	142	100.0	53	100.0	195	100.0	

Governorates) (comparison presented in Table 4-5). On the other hand, the percentages of men with prostate cancer living in the Northern and Mid Zone Governorates were representative to the male population in both governorates.

Such a difference between Gaza Governorate and the southern Governorates could be related to the difference in the socioeconomic status. Gaza is the main city and the capital of Gaza Strip and has a better economical status than both Khanyounis and Rafah. Therefore, it is expected that men who lived in Gaza Governorate consume more red meat than their counterparts who lived in the Southern Governorates. Munden (2007) and Held-Warmkessel (2007) included that the incidence of prostate cancer increases with diet high in saturated fats, high-calorie diet, and high consumption of red meat. This is besides their ability to buy and smoke cigarettes as 37.28% of participants who were

Table 4-5: Comparison between Male Population and Prostate Cancer Survivors According to Their Place of Living.

Place of living	Male population in Gaza Strip 2007		Participants (men diagnosed with Prostate cancer)	
	Frequency	Percent	Frequency	Percent
Northern Governorate	137,596	19.2	37	19.0
Gaza Governorate	252,465	35.1	82	42.1
Mid zone Governorate	103,608	14.4	29	14.9
Khanyounis Governorate	137,577	19.1	26	13.3
Rafah Governorate	87,465	12.2	21	10.8
Total	718,711	100.0	195	100.0

smoking at the time of data collection or had a history of smoking lived in Gaza Governorate while men represented 35.1% of the male population in Gaza Strip. According to Held-Warmkessel (2007), a long history of tobacco smoking may increase the risk for prostate cancer.

Health Insurance Possession and Marital Status

The results of the study showed that 194 (99.5%) participants had a health insurance and only one participant (0.5%) did not have a health insurance. Results also showed that 155 participants (79.5%) were married and lived with their wives. The rest of participants (n=40, 20.5%) were either divorced, widowed, or not married (Table 4-6).

Table 4-6: Marital Status of Participants.

	Participants were receiving Treatment		Participant were not receiving treatment		All Participants		Cumulative Percent for all participants
	frequency	percent	frequency	percent	frequency	percent	
Living with wife	114	80.3	41	77.4	155	79.5	79.5
Has no wife	28	19.7	12	22.6	40	20.5	100.0
Total	142	100.0	53	100.0	195	100.0	

Prostate Cancer-Related Variables

Most of the participants (175=89.7%) had only prostate cancer and had no other cancers. Among those who had other cancers (20 participants =10.3%), in 15 cases (75%), prostate cancer was diagnosed before the other cancer, which may reflect that prostate cancer was the primary cancer and had metastasized to other organs later on. In the other 5 cases (25%), other cancers were diagnosed before prostate cancer which may indicate that prostate cancer was secondary and was metastasized from the other primary cancers. It also could be interpreted that prostate cancer was there but was not discovered until it was metastasized to the other organs as men may live and die with prostate cancer without discovering it. According to the American Cancer Society (2008), autopsy studies showed that many older men and some younger men who died due to other diseases also had prostate cancer that never caused a problem for them while they were alive.

The time elapsed after being diagnosed with prostate cancer at the time of data collection ranged between 3 months and 17 years with a mean of 48.90 months and a standard deviation of 34.14 (Table 4-7). After calculating the mean and the standard deviation for the elapsed time of diagnoses, this variable was categorized into the following categories: zero to 3 months, more than 3 moths up to 6 months, more than 6 moths up to 9 months, more than 9 moths up to 1 year, more than 1 year up to 1.5 year, more than 1.5 year up to 2 years, and more than 2 years (Table 4-8). The results showed that the majority of cases (n=122, 62.2%) were diagnosed more than 2 years ago.

When t test was done to check if there is any statistical difference between the means of time elapsed after diagnosis with prostate cancer between the group of participants who were receiving treatment at the time of data collection and the group of participants who were not receiving treatment at that time, the result showed that there was a statistically significant difference between the two means (t=-44.7, df=173, p < .001).

Table 4-7: Descriptive Statistics for Time Elapsed after Diagnosis (by month)

Group	Median	Mode	Mean	Std. Dev.	Minimum	Maximum	Skewness
All Participants	36	18	48.90	43.14	3	204	8.43
Participants receiving treatment	30	24	40.85	36.83	3	156	7.45
Participants receiving no treatment	60.0	60.0	70.49	51.12	6	204	3.41

Table 4-8: Time Elapsed after Diagnosis by Category

Time category	Participants received treatment		Participant received no treatment		All participants		Cumulative percent for all participants
	Freq.	%	Freq.	%	Freq.	%	
Zero to 3 months	5	3.5	0	0	5	2.6	2.6
More than 3 months up to 6 months	12	8.5	0	0	12	6.2	8.7
More than 6 months up to 9 months	6	4.2	0	0	6	3.1	11.8
More than 9 months up to1 year	13	9.2	1	1.9	14	7.2	19.0
More than 1 year up to 1.5 year	14	9.9	6	11.3	20	10.3	29.2
More than 1.5 year up to 2 years	13	9.2	3	5.7	16	8.2	37.4
More than 2 years	79	55.6	43	81.1	122	62.6	100.0
Total	142	100	53	100	195	100	

Of the total number of participants, 142 participants (72.8%) were receiving treatment at the time of data collection, while the rest of them (n=53, 27%) were not receiving any treatment at that time (Table 4-9).

Table 4-9: Frequency of Patients Who Were Receiving or Not Receiving Treatment

Group of participants	Frequency	Percent	Valid Percent
Receiving treatment	142	72.8	72.8
Not receiving treatment	53	27.2	27.2
Total	195	100.0	100.0

Table 4-10 shows that the most common type of treatment used by participants was hormonal therapy (n=62, 31.8%) followed by prostatectomy (n=41, 21%) and combined therapy of prostatectomy and hormonal therapy (n=35, 17.9%). The least common methods used for treatment were radiation therapy and combination of hormonal, radiation, and chemotherapy as only one participant (0.5%) used each type of these treatment options.

In spite that most of the literature (Turini et al. 2003, Heidenreich et al. 2008, and Fourcade et al. 2009) cited that prostatectomy and radiation therapy are the two most common modalities used in treating prostate cancer, the case in Gaza Strip was different. The most common method used to treat prostate cancer among participants in this study was hormonal therapy. About 31.8% of participants used hormonal therapy as a solo method of treatment compared to 21% who were treated by prostatectomy (Table 4-10). The overuse of hormonal therapy to treat prostate cancer could be due to the relatively old age of participants at the time of diagnosis of prostate cancer. The majority of participants (n=108, 55.38%) were diagnosed with prostate cancer at the age of 65 years or older. At such age, with the limited facilities available in Gaza Strip, performing the surgery will be risky and, in the absence of radiation therapy option, the use of hormonal therapy will be safer.

Although the literature showed that patients treated with radiation therapy reported higher QOL in several domains of QOL, i.e. urinary and sexual dysfunction domains, than those treated with either prostatectomy or hormonal therapy (Jonler, 1994; Nguyen, Pollack, and Zagars, 1998; Sommers and Ramsey, 1999; Potosky et al. 2004),

Table 4-10: Types of Treatment Provided to Participants.

	Participants receiving Treatment		Participant receiving no treatment		All Participants		Cumulative %t for all participants
	Freq.	%	Freq.	%	Freq.	%	
Prostatectomy	14	9.9	27	50.9	41	21.0	21.0
Hormonal therapy	60	42.3	2	3.8	62	31.8	52.8
Radiation therapy	0	0	1	1.9	1	.5	53.3
Prostatectomy & hormonal therapy	23	16.2	12	22.6	35	17.9	71.3
Prostatectomy & chemotherapy	11	7.7	7	13.2	18	9.2	80.5
Hormonal & chemotherapy	15	10.6	1	1.9	16	8.2	88.7
Prostatectomy, hormonal, & chemotherapy	6	4.2	3	5.7	9	4.6	93.3
Prostatectomy, hormonal, & radiation therapy	2	1.4	0	0	2	1.0	94.4
Hormonal & Radiation therapy	8	5.6	0	0	8	4.1	98.5
Hormonal therapy & Orchiodectomy	2	1.4	0	0	2	1.0	99.5
Prostatectomy, hormonal, radiation & chemotherapy	1	.7	0	0	1	.5	100.0
Total	142	100.0	53	100.0	195	100.0	

only one participant used radiation therapy as a solo treatment for his prostate cancer and another 11 participants (5.64%) used radiation along with other modalities for treating their prostate cancer. Such limited use of radiation therapy was due to the unavailability of this option for men living in Gaza Strip which did not have the facility to offer radiation therapy. Patients who would need to be treated with radiation therapy were usually referred to receive treatment outside Gaza Strip (mostly to Egyptian or Israeli Hospitals). With the inability to move outside Gaza Strip due to the blockade imposed against Gaza since June, 2006, a very few number of patients could travel outside Gaza Strip to receive such a treatment.

According to Table 4-11, the major center for providing treatment to prostate cancer survivors in Gaza was Shifa Hospital. The majority of participants, 118 (60.5%), received or were receiving treatment at Shifa Hospital. Forty-one participants (21%) received treatment at Gaza European Hospital, 8 participants (4.1%) received treatment abroad, 22 participants (11.2%) received treatment abroad and in one of the local medical centers and only three participant (1.5 %) were receiving or had received their treatment at Gaza European Hospital and abroad (Table 4-11).

In a total, 141 participants (72.31%) had received treatment at Shifa Hospital at some point while 44 participants (22.56%) only had received treatment at Gaza European Hospital. The rest of participants (n=10, 5.14%) had received their treatment at other facilities or abroad. Shifa Hospital serves the population of Northern, Gaza, and Mid-zone governorates which contains 68.7% of the male population in Gaza Strip (Palestinian Central Bureau of Statistics, 2010) and 76% of the participants (men diagnosed with prostate cancer) while Gaza European Hospital serves Khanyouns and Rafah Governorates which contains 31.3% of the male population in Gaza Strip and 24%

Table 4-11: Place of Treatment

Place of treatment	Frequency	Percent	Valid Percent	Cumulative Percent
Shifa Hospital	118	60.5	60.5	60.5
Gaza European Hospital	41	21.0	21.0	81.5
Received treatment abroad	8	4.1	4.1	85.6
Others	2	1.0	1.0	86.7
Shifa and others	4	2.1	2.1	88.7
Shifa and abroad	19	9.7	9.7	98.5
European and abroad	3	1.5	1.5	100.0
Total	195	100.0	100.0	

of the participants. Such results reflect that Gaza European hospital is providing services to less proportional percentage of the participants. These findings could be normal knowing that Shifa Hospital has the major oncology center at Gaza Strip and has more experienced physicians. Besides that, several participants are referred from Gaza European Hospital to Shifa Hospital.

Comorbidities and other Related Medical Conditions

Participants reported that they had several comorbidities and other related health conditions. Table 4-12 shows that a large number of participants (n=74, 37.9%) had two comorbidities, followed by 48 (24.8%) participants who had only one comorbidity, and 32 (16.4%) participants had three comorbidities or health-related issues. Only 25 participants (12.8%) had no comorbidities or health-related issues. The rest of the participants (n=16, 8.2%) had four or more comorbidities. The most common reported comorbidity/ health-related issue was current or previous cigarette smoking as 110 participants reported that they were smokers or previous smokers. The second more common comorbidity was diabetes mellitus (n=72) followed by heart attack and complaining of chest pain (n=47). The least common reported comorbidities were seizure (n=1) and major depressions (n=0) (Table 4-13).

Table 4-12: Total Number of Comorbidities and Health-Related Problems Reported by a Single Participant

Number of total comorbidities	Frequency	Percent	Valid Percent	Cumulative Percent
0	25	12.8	12.8	12.8
1	48	24.6	24.6	37.4
2	74	37.9	37.9	75.4
3	32	16.4	16.4	91.8
4	10	5.1	5.1	96.9
5	5	2.6	2.6	99.5
6	1	.5	.5	100.0
Total	195	100.0	100.0	

Table 4-13: Most Common Comorbidities and Health-Related Problems Reported by Participants.

Comorbidity	No.	Comorbidity	No.
Diabetes mallets	72	Stroke	14
Heart attack, chest pain	47	Amputation	4
Circulation problems in your legs or feet	7	Kidney disease	25
Asthma, emphysema, breathing problems	30	Major depression	0
Stomach ulcer, irritable bowel	19	Seizer	1
Current or past cigarette smoker	110	Other health problems	

Quality of Life Variables

Prostate cancer is the second most common type of cancer among males in the world (American Cancer Society, 2007a) and in Palestine (MoH, 2006). The new medical technology along with the use of screening techniques involving the use of digital rectal examination (DRE) and testing for prostate-specific antigen (PSA) had helped to diagnose those patients who did not show any signs or symptoms of prostate cancer and helped to diagnose prostate cancer at the early stages of its occurrence (Hoedemaeker et al., 2001; Hugosson et al., 2004; Makinen et al., 2004; Gorin et al., 2008). According to Tewari et al. (2004), about 57% of new prostate cancers are diagnosed while the carcinoma is localized which will help in improving the survival rate of those men and improve their prognosis especially with the presence of several treatment modalities; such as surgical removal of the prostate, radiation therapy, hormonal therapy, and watchful waiting to treat prostate cancer. The use of prostatectomy, radiation, and hormonal therapies helped to increase the survival rate of men with prostate cancer, which is the primary goal of treatment for any patient diagnosed with prostate cancer (Middleton et al., 1995). Furthermore, according to Ramos, Carvalhal, Smith, Mager, and Catalona (1999) and Martinez et al. (2000), the survival rates of the available different treatment options are usually similar. On the other hand, all of these treatment modalities will cause life-lasting side effects that mostly affect urinary, bowel, and sexual functions (Sommers and Ramsey, 1999; Wei et al., 2002; Penson and Litwin, 2003; Potosky et al., 2002; Clark et al., 2003; Turini et al., 2003; Albaugh, and Hacker, 2005). Therefore, in recent years, more attention is paid to the issues of health-related quality of life as they play a major role in the decision-making process of the treatment option that the patient and his physician will make about which method to use to treat prostate cancer. Assessing health-related QOL can provide men diagnosed with localized prostate cancer with valuable knowledge about the potential risks, benefits, and changes in their health-related QOL that they may experience after initiating treatment (Litwin, 1994, Moul, 1998; Clark, Rieker, Propert, and Talcott, 1999; Saigal, Gornbein, Reid, and Litwin, 2002; Ishihara et al., 2004; Kakehi et al., 2006; Arredondo, 2007; Inoue et al., 2009).

Several studies had assessed the level of QOL for men with prostate cancer using different tools. One of the most commonly used tools to assess QOL for men with prostate cancer is the UCLA-PCI instrument. This instrument has the advantage to assess general health QOL and prostate-specific QOL including; urinary, bowel, and sexual functions and bothers. The UCLA-PCI instrument was used in this study to measure QOL of prostate cancer survivors in Gaza Strip. To compare the result of this study with the literature, several studies that used the UCLA-PCI were reviewed. Unfortunately, none of the studies gave a total score for QOL but they reported on the scores of each individual sub-domain of the general QOL (SF36) and/or those related directly to prostate cancer. The scores of the QOL sub-domains reported in the reviewed studies are summarized in Table 4-14.

Table 4-15 depicts the scores of the quality of life for participants of this study. Quality of life was described in three categories: a) General quality of life (SF 36), b) Prostate-Specific QOL (PCI-QOL), and c) total quality of life (both general QOL and PCI-QOL).

General Quality of Life (SF 36)

The general QOL scale (SF36) includes 9 domains: physical function, role limitation due to health problems, role limitation due to emotional problems, vitality, mental health, social functioning, bodily pain, general health, and health transition (Litwin et al., 1998). The mean score of the general quality of life for all participants was 52.53. The mean of score for general quality of life (SF-36) for the participants who were receiving treatment at the time of data collection was 51.31 while the mean of the general QOL scores for the participants who were not receiving treatment at the time of data collection were 55.81 (Table 4-15). The results of t test showed that there were no statistically significant differences between the means of the general QOL scores of the two groups ($t= -1.26$, $df=193$, $p= 0.211$).

Table 4-14: Comparison between Results of Current Study and Several Studies Used the UCLA-PCI

Authors Method of treatment	Current study	Range of scores	Lubeck et al. (1997)	Albertsen et al. (1997)	Litwin et al. (1998)	Schapira et al. (2001)		Karakiewicz et al. (2003)	Korfage et al. (2003)
						RP	RT		
Country	Gaza		USA	USA	USA	USA		Canada	Germany
Physical Function	52.44	63.3-86.78		62.3	72.5	84.4	62.3	80.95	
Role Limitation – Physical	42.69	42-85.1		53.4	61.3	72.2	42	70.67	
Role Limitation-emotional	41.79	55.3-95.2		71.8	71.2	77.3	70.2	77.52	
Vitality	50.99	60.1-82.12		60.1	62.2	68.7	55.6	64.75	
Mental Health	58.23	64.2-85.4		78.9	76.7	77.1	76.4	74.15	
Social Functioning	60.38	58.9-92.9		80.4	80.0	88.0	58.9	82.13	
Bodily Pain	68.50	61.2-90.2		73.5	73.3	78.3	61.2	81.56	
General Health	53.51	56-73.5		60.8	67.0	70.9	59.2	71.31	
Health Transition	50.26	50.4-80.05							
Urinary function	62.32	62.2-94	71.2		83.8	62.2	88.6	70.86	85.0
Urinary bother	46.28	69.5-88.84	69.5		79.4	66.7	78.8	74.30	86.6
Bowel function	86.71	79.4-90.3	82.7		84.4	87.5	79.4		80.5
Bowel bother	90.26	76.6-95.8	80.5		83.1	86.3	76.6		87.0
Sexual function	22.24	19.6-45.2	21.1		38.5	19.6	25.1	21.47	
Sexual bother	53.08	32.7-78	43.5		36.3	33.4	49.9	33.68	

Table 4-14 Continued: Comparison between Results Current Study and Several Studies Used the UCLA-PCI

Authors	Gacci et al (2005)		Ishihara, et al, 2006	Jayadevappa, et al. (2006)	Arredondo et al. (2007)	Namiki et al, 2007			Shikanov et al. (2008)	Wakatsuki et al. (2008)	Inoue et al. (2009)
Type of treatment	RP	RT				RP	RT	HR			
Country	Italy		Japan	USA	USA	Japan			USA	Japan	Japan
Physical Function	86.87	86.81	85.7	69.8	80.2						
Role Limitation – Physical	72.73	85.51	71.4	69.8	67.6						
Role Limitation-emotional	55.30	66.02	70.1	95.2	80.2						
Vitality	81.94	82.12	62	74.1	62.3						
Mental Health	72.63	69.70	64.2	85.4	77.2						
Social Functioning	80.18	89.03	79.5	92.9	81.9						
Bodily Pain	86.79	90.21	74.1	86.1	79.5						
General Health	66.36	61.62	56	73.5	71.1						
Health Transition	80.05	58.01			50.4						
Urinary function	75.18	88.66	84.2	77.1	69.9	74	90	94	72.0	82.5	71.8
Urinary bother	75.44	88.84	72.9	85.7	73.4	78	88	86	79.0	79.2	80.6
Bowel function	89.80	81.22	86	92.2	84.1	90	89	87		90.3	86.0
Bowel bother	84.96	76.51	88.8	96.4	82.9	92	89	90		95.8	86.3
Sexual function	17.89	26.69	32.5	21.7	25.6	14	21	14	45.2	38.9	7.3
Sexual bother	53.32	57.96	74.2	32.7	40.8	59	78	74	50.7	72.9	58.4

Table 4-15: Descriptive Statistics of Means of Total QOL, General QOL (SF36) and PCI-QOL Domains.

	Group	Median	Mode	Mean	Std. Deviation	Minimum	Maximum	Skewness
Total Quality of Life	All	52.45	24.07	52.09	19.32	15.80	89.29	0.045
	Treatment	47.13	24.07	49.68	18.813	15.80	89.14	0.911
	No treatment	61.57	61.12	58.56	19.33	18.30	89.29	1.773
General quality of life (SF36)	All	52.22	19.86	52.53	22.33	7.64	96.53	0.201
	Treatment	50.76	19.86	51.31	22.91	7.64	96.53	0.478
	No treatment	57.78	57.36	55.82	20.56	11.67	90.28	1.287
(PCI) Prostate Specific Index	All	50.85	31.65	51.30	19.83	15.40	98.75	1.902
	Treatment	44.15	31.65	46.74	17.90	15.40	93.75	2.975
	No treatment	57.78	57.36	63.49	20.56	11.67	90.28	1.532

Tables 4-16, 4-17, and 4-18 summarizes the scores of QOL for each of the 9 domains of the general health QOL (SF-36). In general, participants who were not receiving treatment at the time of data collection reported higher scores than those who were receiving treatment at that time in all domains except the domains of social functioning, bodily pain, and health transition. The lower scores reported by participants who were receiving treatment could be related to impact of the side effects of the treatment they were receiving at that time.

To compare if there were any statistically significant differences between the means of the sub-domains of the general QOL among participants who were receiving treatment and those who were not receiving treatment at the time of data collection, t test was done. The results (Table 4-19) showed that there were statistically significant differences between the means of the participants in the two groups only in the areas of vitality (t=-2.17, df=193, p=0.033) and health transition (t=3.40, df= 193, p=0.001).

By examining the scores of the general health QOL (SF-36) reported by participants of this study and comparing them to those reported in the literature and summarized in Table 4-14, it can be noticed that the scores of QOL reported by men diagnosed with prostate cancer and living in Gaza Strip were less than those reported in the literature with the exception of three sub-domains; role limitation due to physical function, social functioning, and bodily pain. The mean of scores reported in this study for role limitation due to physical function was 42.69 while the least reported score in the literature for this sub-domain was 42 (Schapira et al., 2001) followed by a score of 53.4 (Albertsen et al., 1997) and a score of 61.3 (Litwin et al., 1998). The score of 42 reported

Table 4-16: Descriptive Statistics SF36-QOL Domains for all Participants.

	Median	Mode	Mean	Std. Deviation	Minimum	Maximum	Skewness
Physical Function	55	55	52.44	30.24538	0	100	0.66
Role Limitation-physical	50	0	42.69	34.68	0	100	0.89
Role Limitation - Emotional	41.67	0	41.79	33.99	0	100	0.97
Vitality	50	50	50.99	25.05	0	100	0.84
Mental Health	60	55	58.23	19.49	0	100	0.48
Social Functioning	62.50	100	60.38	30.19	0	100	2.07
Bodily Pain	77.5	100	68.50	30.47	0	100	4.37
General Health	60	70	53.51	28.44	0	100	2.07
Health Transition	50	50	50.25	34.71	0	100	0.03

Table 4-17: Descriptive Statistics of SF36-QOL Domains for Participants Receiving Treatment.

	Median	Mode	Mean	Std. Deviation	Minimum	Maximum	Skewness
Physical Function	50	100	50.07	31.42	0	100	.0005
Role Limitation-physical	37.5	0	40.98	35.38	0	100	1.35
Role Limitation - Emotional	37.5	0	39.90	34.93	0	100	1.63
Vitality	50	50	48.64	24.77	0	100	0.68
Mental Health	60	55	57.46	20.47	5	100	.0005
Social Functioning	62.5	100	61.44	31.42	0	100	1.79
Bodily Pain	77.5	100	70.04	29.40	0	100	4.08
General Health	57.5	75	52.54	27.02	0	100	1.41
Health Transition	50	100	55.28	34.70	0	100	0.95

Table 4-18: Descriptive Statistics of SF36-QOL Domains for Participants not Receiving Treatment

	Median	Mode	Mean	Std. Deviation	Minimum	Maximum	Skewness
Physical Function	55	55	58.77	26.07	0	100	1.04
Role Limitation-physical	50	0	47.29	32.60	0	100	0.54
Role Limitation - Emotional	50	75	46.86	41.10	0	100	0.98
Vitality	62.5	75	57.31	24.93	0	100	2.95
Mental Health	60	45	60.28	16.57	0	100	0.99
Social Functioning	62.5	75	57.55	26.67	0	100	1.47
Bodily Pain	77.5	100	64.39	33.13	0	100	2.45

Table 4-19: Independent Samples Test for the Domains of the SF36.

Domain	Group	Mean	SD	t	df	p
Physical Function	Treatment	50.07	31.42	-1.798	193	.074
	No Treatment	58.77	26.07			
Role Limitation Physical	Treatment	40.98	35.38	-1.131	193	.259
	No Treatment	47.29	32.60			
Role Limitation Emotional	Treatment	39.91	34.93	-1.272	193	.205
	No Treatment	46.86	31.10			
Vitality	Treatment	48.64	24.77	-2.172	193	.031
	No Treatment	57.31	24.93			
Mental Health	Treatment	57.46	20.47	-.898	193	.370
	No Treatment	60.28	16.57			
Social Functioning	Treatment	61.44	31.42	.801	193	.424
	No Treatment	57.55	26.67			
Bodily Pain	Treatment	70.03	29.39	1.152	193	.251
	No Treatment	64.38	33.13			
General Health	Treatment	52.54	27.019	-.785	193	.433
	No Treatment	56.13	32.06			
Health Transition	Treatment	55.28	34.70	3.398	193	.001
	No Treatment	36.79	31.24			

by Schapira et al. was for patients who were treated with radiation therapy. Knowing that only one participant of the current study was treated with radiation therapy as a monotherapy, would make it more appropriate to compare the score results of this study with those reported by Albertsen et al. (1997) for patients treated with radical prostatectomy, which was 53.4. The same thing can be said about the domain of social functioning. The reported score in this study was 60.38, which was only higher than the score of 58.9 reported by Schapira et al. for patients who were treated with radiation therapy. The second least score for the social function domain was reported by Litwin et al. (1997) which was 80 for patients who were treated with radical prostatectomy. The scores of bodily pain are of no difference. It was only the scores reported by Schapira et al. for patients who were treated with radiation therapy lower than those scores reported in this study. In general, it can be inferred that all the scores reported for the sub-domains of the SF-36 were less than those reported in the literature for patients who were treated with radical prostatectomy.

Though, one cannot infer that the scores are actually different and that this difference among scores could be merely due to chance or sample fluctuation. To examine if these differences were not due to chance or sampling errors, the t test using the following formula was calculated for all studies that reported needed information (mean, standard deviation, and number of participants) to calculate the t test (Munro, 1997):

$$t = \frac{\bar{x}_1 + \bar{x}_2}{\sqrt{\frac{S1}{n1} + \frac{S2}{n2}}}$$

The results of the comparison of t tests are presented on table 4-20. As the sample of this study was 195, the degree of freedom (df) for this study and any other study will be more than a 120, therefore, the critical value of 1.98 at an alpha of 0.05. is the value to

Table 4-20: Comparison between t Test Results of Current Study and Several Studies Used the UCLA-PCI

Authors	This study	Litwin et al. (1998)		Karakiewicz et al. (2003)		Korfage et al. (2003		Gacci et al (2005)		Namiki et al, 2007		Shikanov et al. (2008)		Wakatsuki et al. (2008)		Inoue et al. (2009)	
	$\bar{x}$	$\bar{x}$	t	$\bar{x}$	t	$\bar{x}$	t	$\bar{x}$	t	$\bar{x}$	t	$\bar{x}$	t	$\bar{x}$	t		
Physical Function	52.44	72.5	10.95	80.95	13.51			86.8	16.33								
Role Limitation – Physical	42.69	61.3	8.46	70.67	11.96			72.7	13.81								
Role Limitation-emotional	41.79	71.2	17.42	77.52	15.44			55.3	5.99								
Vitality	50.99	62.2	7.40	64.75	7.87			81.9	18.99								
Mental Health	58.23	76.7	16.51	74.15	11.86			72.63	16.12								
Social Functioning	60.38	80.0	10.44	82.13	10.30			80.18	10.09								
Bodily Pain	68.50	73.3	6.74	81.56	6.12			86.79	8.63								
General Health	53.51	67.0	7.83	71.31	8.97			66.36	7.85								
Health Transition	50.26							80.05	12.76								
Urinary function	62.32	83.8	10.75	70.86	7.88	85.0	12.02	75.18	7.36	74	7.47	72.0	5.18	86.1	2.89	71.8	10.89
Urinary bother	46.28	79.4	13.39	74.30	10.45	86.6	17.98	75.44	18.46	78	14.65	79.0	13.6	78.1	6.01	80.6	18.84
Bowel function	86.71	84.4	2.35			80.5	8.49	89.80	3.36	90	3.95			89.6	1.38	86.0	1.44
Bowel bother	90.26	83.1	6.64			87.0	3.66	84.96	4.87	92	1.67			90.6	0.01	86.3	4.68
Sexual function	22.24	38.5	9.96	21.47	0.37			17.89	2.43	14	4.88	45.2	15.3	30.7	2.10	7.3	7.10
Sexual bother	53.08	36.3	15.69	33.68	10.01			53.32	0.17	59	6.75	50.7	2.73	71.8	2.57	58.4	2.95

be used to infer the significance of the differences between the means reported in this study and the means reported in the studies reviewed in the literature. By examining the results of means for SF36 quality of life scores and t tests, it is noticed that the means reported in this study are less than all of those reported in table 4-20 and the t values were more than the critical value of 1.98 which reflect that all of these differences were statistically significant.

Such low scores can be interpreted in two different ways. First, the low scores reported in this study compared to those reported in the literature could be related to the fact that this study was conducted in a developing country, while those reviewed in the literature were conducted in developed countries including USA, Canada, Germany, Italy, and Japan. Developed countries have more facilities that will help men to discover prostate cancer earlier than their counterparts living in developing countries and they have more advanced medical technology and more experienced physicians than developing countries. Therefore, it is expected that patients living in developed countries to have a better level of QOL than those living in a developing country such as Gaza Strip.

Second, the low scores reported in this study could be related to the unique situation that surrounds Gaza Strip. Blockade and economical sanctions had been imposed against Gaza since June 2006 and were tightened on May 2007. Blockade and economical sanctions affected the medical supply incluging medications that are needed for patients living in Gaza. Furthermore, they limited the number of patients who would travel to receive treatment outside Gaza Strip (Association of International Development Agencies, 2010 and World Health Organization: West bank & Gaza, 2010). Such shortage in medical supplies and limited chances for patients to travel to receive treatment outside Gaza might attributed to the low scores reported by men participated in this study. Finally, those low scores reported in this study could be related to both blockade and living in a developing country.

Prostate-Specific QOL (Prostate-Specific Index)

The Prostate-Specific QOL variable contains 6 domains; urinary function (UF), urinary bother (UB), bowel function (BF), bowel bother (BB), sexual function (SF), and sexual bother (SB) (Litwin et al. 1998). The mean for prostate specific quality of life scores for the entire sample was 51.29. It was 46.74 for the group that were receiving treatment at the time of data collection while it was 63.49 for the group that were not receiving treatment (Table 4-15). The result of the t test showed that there was a statistically significant difference (p less than 0.001) between the means of the prostate specific QOL scores of the two groups. Such lower scores for the group of participants who were receiving treatment at the time of data collection could be attributed to the consequences and side effects of the treatment that they were receiving.

Table 4-21 summarizes the mean scores of QOL for the 6 domains included in the prostate-specific index for the total sample and for the group of participants who were receiving treatment and who were not receiving treatment at the time of data collection. The highest scores were those for BB and BF domains and the lowest scores were for the SF and UB (22.23 & 46.31 respectively). In general, participants who were not receiving treatment at the time of data collection reported higher scores than those who were

Table 4-21: Descriptive Statistics of Means of QOL for PCI-QOL Domains.

	All participants		Participants were receiving treatment		Participants were not receiving treatment	
	Mean	Std. Div	Mean	Std. Div	Mean	Std. Div
Urinary function	62.32	31.00	59.95	31.87	68.65	27.88
Urinary bother	46.28	38.44	41.55	37.29	58.96	38.94
Bowel function	86.71	16.97	86.00	16.12	88.61	19.09
Bowel bother	90.26	21.57	90.32	21.23	90.09	22.65
Sexual function	22.24	29.39	13.63	24.30	45.30	29.61
Sexual bother	53.08	29.22	50.18	29.55	60.85	27.08

receiving treatment at that time in all domains except the BB domain as the scores were almost equal.

To compare if there were any statistically significant differences between the mean scores of QOL of these six domains between both groups, t test was done and results showed (Table 4-22) that there were statistically significant differences between the mean scores of participants in the two groups in the areas of UB ($p = 0.005$), SF ($P < 0.001$), and SB ($p = 0.023$).

To the contrary of the scores reported by participants of this study for the SF-36 sub-domains, all the scores of the sub-domains of the PCI-QOL fell within the range of the reported scores in the literature with the exception of urinary bother which was much less than the least reported score in the literature (Table 4-14). The scores reported by participants for the urinary bother sub-domain were 42.8 compared to the least score of 69.5 reported in the literature by Lubeck et al. (1997).

When the t test was calculated to compare the means of PCI QOL reported by participants of this study and those reported in the literature (that reported the needed information to calculate the t tests), it was found that the scores of urinary function and urinary bother were less than the means reported in the literature(Table 4-20). The results of the t test showed that these differences were statistically significant (result of t tests exceeded the critical value of 1.98). The difference was larger in the urinary bother domain. The mean of score for urinary bother reported by participants of this study was 46.28 while the lowest score was 74.30 reported by Karakiewicz et al. (2003). This huge difference in the urinary bother scores could be related to the fact that being clean of urine and stool is one of the requirements for any Muslim for praying. When Muslims

Table 4-22: Independent Samples Test for Means of QOL for PCI-QOL Domains.

Domain	Group	Mean	SD	t	df	p
Urinary Function	Treatment	59.95	31.87	-1.750	-1.750	-1.750
	No Treatment	68.65	27.88			
Urinary Bother	Treatment	41.55	37.29	-2.866	-2.866	-2.866
	No Treatment	58.96	38.94			
Bowel Function	Treatment	86.00	16.12	-1.750	-1.750	-1.750
	No Treatment	88.61	19.09			
Bowel Bother	Treatment	90.32	21.23	-2.866	-2.866	-2.866
	No Treatment	90.09	22.65			
Sexual Function	Treatment	13.63	24.30	-1.750	-1.750	-1.750
	No Treatment	45.30	29.61			
Sexual Bother	Treatment	50.18	29.55	-2.866	-2.866	-2.866
	No Treatment	29.55	60.85			

prepare themselves for their prayers, they clean themselves from residuals of urine and stool by toilet paper and water before they proceed to purification which includes washing several body parts with water. Although the laws of Islam give a special permission for patients who cannot control their urination and/or defecation; people, especially the elderly, are very hesitant and feel inferior and stressed to use such permissions and they prefer and act to be clean as their counter partners who are not suffering from their disease conditions.

The relatively high scores for bowel function and bowel bother were due to the fact that not so many patients used radiation therapy as a monotherapy or along with other adjunct treatment modalities. Side effects that affect bowel function and leads to bowel bother are most likely due to radiation therapy. When t tests were calculated to examine the significance between the reported scores by participants of this study and the scores reported in the literature for bowel function and bowel bother, the majority of the t test values showed that there were statistically significant difference between the results (Table 4-20).

Although the scores reported by participants about sexual function was low (22.24), the scores reported about sexual bother were much higher (53.08). The same huge difference between scores of sexual function and sexual bother was noticed in the reviewed studies that were summarized in Table 4-14. Such differences could be related to the fact that these men whose mean age was 70.29 (± 8.80) had accepted changes in their sexuality and related these changes to the process of aging and not to the impact of the disease or its treatment on their sexual functioning. In fact, Gacci et al. (2005) found that there was no correlation between sexual function and sexual bother domains and suggested the each domain to be treated as a discrete construct and to be considered separately. When t tests were calculated to examine the significance between the reported scores by participants of this study and the scores reported in the literature for sexual function and sexual bother, all the t test values showed that there were statistically significant differences between the results except for the Karakiewicz et al. (2003) study for the sexual function and the Gacci et al. (2005) for the sexual bother domain as the t results did not reach to the critical value of 1.98 (Table 4-20).

Total Quality of Life

Total quality of life includes the mean of all variables related to quality of life (those related to general health QOL and to prostate-specific QOL). The total QOL for all participants was 52.09. The mean of the total QOL for participants who were receiving treatment was 49.67 while it was 58.56 for those participants who were not receiving treatment. The results of t test showed that there was a statistically significant difference between the means of the total quality of life (t=291, df=193, & p= 0.004) of the scores of participants who were receiving treatment and the scores of participants who were not receiving treatment at the time of data collection. Unfortunately, none of the studies reviewed in the literature reported on the total score for QOL but they reported on the scores of each individual sub-domain of the general QOL (SF36) and/or those related directly to prostate cancer.

Relationship between Quality of Life and Treatment Modalities

Analysis of variance (ANOVA) test was run to examine if there were any statistically significant differences in the level of general QOL, prostate specific QOL, and total QOL among participants using various treatment methods. Results (Table 4-23) showed that there were no statistically significant differences among the mean scores of general QOL (p=0.272) and total QOL (p=.090) and the use of different treatment modalities, while there was a statistically significant difference of the mean scores of prostate specific QOL (p=0.008). The statistical difference among the means of PCI QOL was due to the difference between the means of PCI QOL for patients used prostatectomy (mean=59.47)and patients who used hormonal therapy options (mean=46.22) as the p value was 0.015.

Table 4-23: Results of Analysis of Variance to Examine Impact of the Use of Different Treatment of Prostate Cancer on Total QOL, General QOL, and Prostate-Specific QOL.

		Sum of Squares	df	Mean Square	F	Sig.
General quality of life	Between Groups Within Groups Total	4276.183 88627.095 92903.279	7 183 190	610.883 484.301	1.261	.272
Prostate Specific Index QOL	Between Groups Within Groups Total	7148.938 66257.513 73406.451	7 183 190	1021.277 362.063	2.821	.008
Total QOL	Between Groups Within Groups Total	4488.961 65214.374 69703.335	7 183 190	641.280 356.363	1.800	.090

ANOVA test was repeated to examine if there were any statistical differences between the QOL of participants who used different treatment modalities in the group was receiving treatment at the time of data collection and the group which was not receiving treatment at the same time. Results showed that there were no statistical differences in QOL related to treatment modalities in both group in all three domains (total QOL, PCI QOL, and SF36QOL). The p values were ≥ 0.210 in all results. These results reflected that patients who were treated with prostatectomy (mean=59.47) enjoyed better QOL in the domains included in prostate-specific QOL (UF, UB, BF, BB, SF, and SB) than those treated with hormonal therapy (mean=46.22). The difference between the two means was found to be statistically significant (p=0.018). In fact, this was expected as usually prostatectomy is used as a curative option to treat localized prostate cancer (Turini et al., 2003) while hormonal therapy is usually used (alone or along with other treatment options) as a palliative option to treat advanced prostate cancer (Albaugh and Hacker, 2005). It can be also given for patients with localized tumor who are unfit for curative treatment (Fourcade et al., 2009).

Unfortunately, not so many studies reported about the quality of life for prostate cancer men treated with hormonal therapy. Only one study was found to compare between QOL of patients received different treatment options including the use of hormonal therapy (Namiki et al, 2007). The scores of the prostate-specific QOL reported in this study and by Namiki et al. are summarized in Table 4-24. The comparison presented in Table 4-24 shows that participants of this study had much lower scores than the scores reported by Namiki et al for Japanese men in all domains with few exception. Participants of this study treated with prostatectomy showed higher scores in the bowel

Table 4-24: Comparison of Prostate-Specific QOL Scores Reported in this Study and by Namiki et al. (2007)

PCI Domain	This study		Namiki et al. (2007)	
	Prostatectomy	Hormonal	Prostatectomy	Hormonal
Urinary Function	70.57	58.06	74	94
Urinary Bother	56.71	41.94	78	86
Bowel Function	89.66	89.08	90	87
Bowel Bother	92.07	92.74	92	90
Sexual Function	34.29	12.20	14	14
Sexual Bother	54.88	45.56	59	74

bother and sexual function domains, while those treated with hormonal therapy showed a slightly higher scores in the domains of bowel bother and bowel function than those reported by Namiki et al.

The literature reported that the use of prostatectomy don't cause bowel dysfunction as much as radiation therapy (Potosky et al., 2000) and patients treated with prostatectomy reported higher scores in the bowel dysfunction and bowel bother domains. On the other hand, compared to prostatectomy, radiation therapy causes fewer sexual side effects (D'Amico et al., 1997), but it still cause some erectile problems for men (Potosky et al., 2004) and other urinary complications such as urinary incontinence and irritation (Brandeis et al., 2000). On another study by Potosky et al. (2000), patients treated with radiation therapy reported less experience of urinary incontinence (3.5%) than those treated with radical prostatectomy (9.6%), less leakage of urine (2.3% compared to 13.8%), and less urinary frequency and bother than those treated with radical prostatectomy. Potosky's et al. (2000) study further added that impotence was less common among patients treated with radiation than with prostatectomy (61.5% compared to 79.6%) and sexual bother was less common among younger patients who were 55-59 years old (25.3% compared to 59.4%). Unfortunately, the results of this study could not provide any comparison between QOL of men treated with prostatectomy and radiation therapy as only one participant reported that he was treated with radiation as a monotherapy.

Barriers to Health Care

After examining the scripts of the participants' responses, emerging themes were identified and coded into the following major concepts: barriers due to unavailability, organizational barriers, geographical barriers, socioeconomic barriers, and barriers related directly to the blockage imposed on Gaza Strip. Under the umbrella of each concept, there were several sub-concepts that had emerged (Figure 4-1).

In general, it was noticed that the percentage of patients who reported having at least one barrier was much higher among participants who were still receiving treatment at the time of data collection than those who were not receiving any treatment at that time. In total, 119 participants (61.02) reported facing some barriers at a certain point of their treatment time. From the 142 participant who were receiving treatment, 107 participants (75.35%) reported having at least one barrier to health care. From the group was not receiving treatment (n=53), only 12 participants (22.64%) reported having some barriers to health care at a certain point. The barriers reported by participants of this study were compatible with the barriers reported in the literature with the exception of

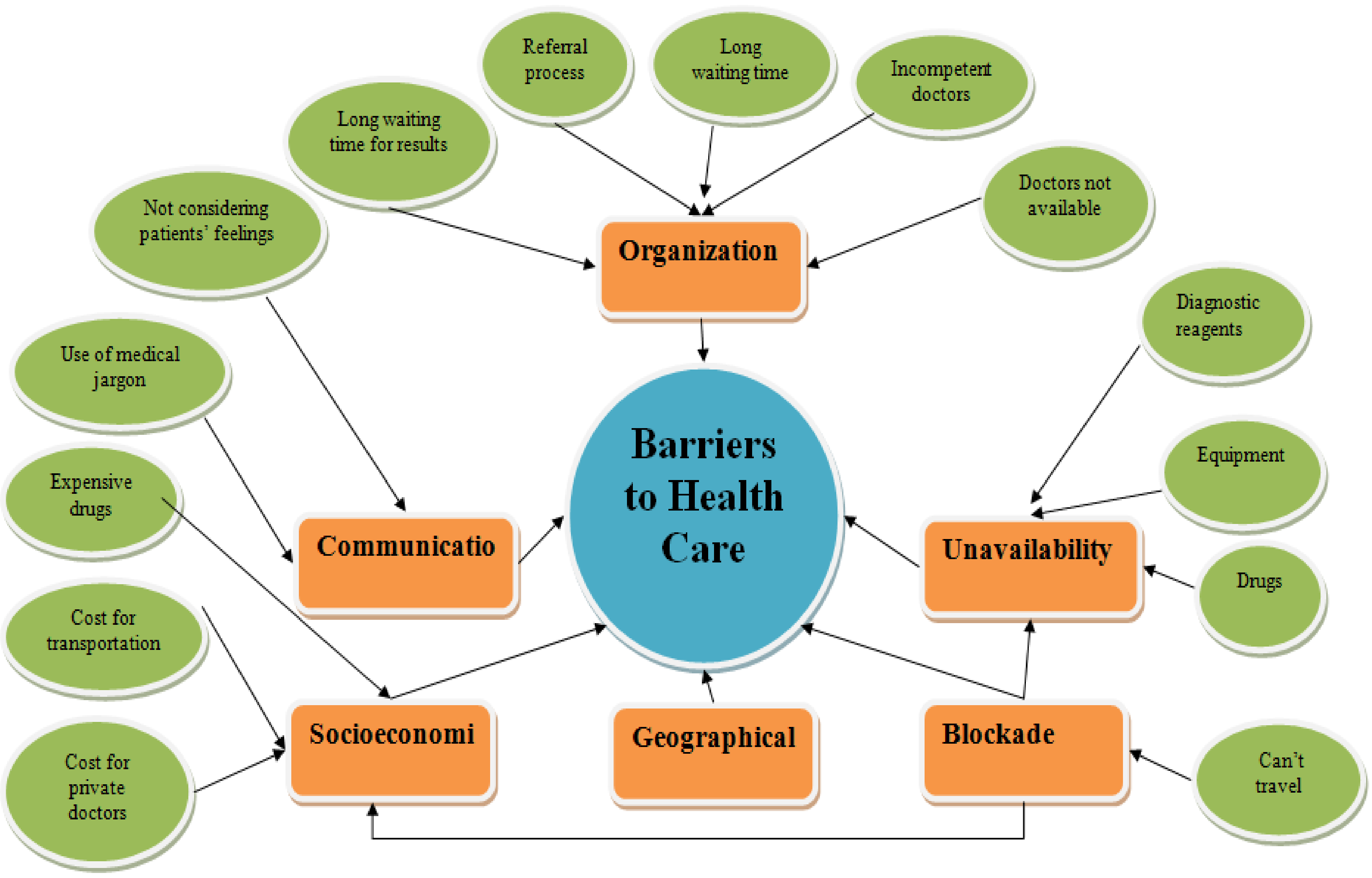


Figure 4-1: Descriptive Model of Barriers to Health Care.

those barriers related directly to the impact of the blockade imposed against Gaza Strip (McKinlay, 1972; McCullock-Melnyk, 1988; Estrada et al., 1990, Trevino, and Ray 1990; Margolis, et al., 1995; Battista, Williams, and MacFarlane, 1996; Weinick et al., 1997; Demark-Wahnefried, 1995; Bennett, 1999; Beckman, et al. 2000; Weinrich, Reynolds, Tingen, and Starr 2000; Chin, et al., 2001; Rutten, Nelson, and Meissner, 2004; the American Medical Student Association, 2009).

Barriers Related to Unavailability

Participants reported that several items and services were not available at the health care system in Gaza. These items included drugs, equipments, reagents for some diagnostic procedures, and the absence of the radiation therapy option. The most commonly reported missing item was drugs. Many participant (n= 86) reported that drugs were not available at some point at the governmental health system during their treatment time. In case needed drugs were available at the drug stores outside the governmental health system, those who could afford to buy them had to pay for it from their own money. And in case drugs would not be available at other drug stores or if participants could not afford to buy them, they would stay without their drugs until they would become available at the pharmacies of the medical centers at the governmental health care system. In response to lack of certain drugs, doctors had to prescribe other available drugs that were not as effective as the needed drugs. One participant mentioned:

> Drugs are not available at most of the times; therefore, the doctors had to change me to another drug. The problem was that the first drug was very expensive as I need about 2000 New Israel Shekel (NIS) each month, which I can’t afford.

For this participant, he could not afford to buy his medication because it would cost him too much to get his monthly supply of the drug as he needed about 2,000 NIS (1$= 3.8 NIS). This amount of money is more than the monthly income for a new graduate nurse. Even for those participants who could afford to buy the drug from private drug stores, they, sometimes, faced the same problem that the drug was not available. Twenty seven participants mentioned that when they looked for the drugs at the private drug stores, they were not available. Therefore some participants had to find their own way to get their drug supply. For some participants, as one mentioned, they asked friends or relatives in Egypt to buy the drug for them and pass it to Gaza from one the tunnels used to smuggle goods and food from Egypt to Gaza:

> The drugs are not available at the government pharmacies. They are not available at outside drug stores too. Therefore, we have to call our friends and relatives who live in Egypt and ask them to buy these drugs and we smuggle them from the tunnels under the border between Egypt and Gaza Strip.

Others who had some friends or relatives living in West Bank or in Israel, they asked them to buy the drugs for them and they had to wait until any person would pass into Gaza and send the drug with him/her. For those who couldn't manage to get their drugs from Egypt or any other place and those who could not afford to buy their drug supply from private drug stores, they had to spend the time without taking their drugs until it becomes available again at the governmental health system. This could take several weeks or several months, and it would affect their level of health and their QOL. One participant summarized his suffering as follow:

> Drugs were not available sometimes at the hospital pharmacy. I used to take my drug (from the pharmacy at the governmental health care system) every 15 days. Sometimes I come to the hospital to get my drug and it was not available. I looked

> at the outside drug stores; it was not available there too. What shall I do? I had to spend the time without treatment until the drug becomes available at the hospital.

To overcome the problem of unavailability of their drugs in neither the governmental health care system or at the private drug stores, some participants mentioned that they sometimes had to buy drugs that had passed its expiration date by several months, as expressed by one participant:

> One time, the drug I used to take, was not available neither at the hospital nor at the outside drug stores. I and my children looked for it in all the drug stores that we know until we found it at one store, but it was expired for about 6 moths. I decided to buy it and to take it. I thought it was better than staying without taking any drug.

Other participants expressed that the lack of drugs had affected negatively their health status and this was reflected on the level of their Prostate-Specific Antigen (PSA) results.

> After I had a bone scanning done to me in Egypt, the treating physician prescribed to me a hormonal therapy called 'Cadex,' or its substitute. The doctor wrote a report about this issue and gave it to me. But when I came back to Gaza, I gave the report to the doctors at the hospital. The doctors told me that neither the drug nor its substitute was available at the pharmacy at the governmental hospital at that time. I spent several weeks without the drug. This resulted in the elevation of my tests levels (means the PSA level), which negatively affected my health.

Other items that were reported as "unavailable" by other participants were the lack of some equipments and chemical reagents for some diagnostic procedure. Nine patients mentioned that at some point some equipment were not available for either their treatment or their diagnoses. The result then would be waiting for the equipment to become available or waiting for a referral to be treated outside Gaza Strip then waiting again for either a permission to pass Israel to receive treatment either in West Bank or in an Israeli hospital or waiting for the border to open so that they can travel to Egypt to receive treatment. One participant summarized his concerns:

> The machine needed for bone scanning is not available in Gaza, therefore, we have to wait until we get a referral either to Egypt or to Ramallah (in West Bank) to do this. Only Allah (God) knows if we will get the referral and if will be able to travel.

Other participants (n=13) expressed their frustration about the lack of the diagnostic equipments and some chemical reagents that needed for diagnostic procedures. Such lack would delay the diagnoses for their cases which will result in physical and emotional distress. One of them mentioned:

> The lack of the diagnostic equipments is one of the big barriers. It’s true that they took a biopsy from me, but they sent it to outside laboratories (laboratories outside the governmental health care system) and the result took so much time to appear. You can imagine how my emotional and psychological conditions were at that time while I was waiting for the result.

Besides the direct impact of restricting patients to travel outside Gaza Strip to receive treatment, the blockade affected several domains of quality of life of people living in Gaza Strip. The impact of the blockade on quality of life in general and on health-related quality of life in particular was well recognized by international organizations including the United Nations (UN) and the World Health Organization (WHO). For example, on the 20th of January 2010, Max Gaylard, the Resident Humanitarian Coordinator for the occupied Palestinian territories (oPt), said:

> The continuing closure of the Gaza Strip is undermining the functioning of the health care system and putting at risk the health of 1.4 million people in Gaza. It is causing on-going deterioration in the social, economic and environmental determinants of health. It is hampering the provision of medical supplies and the training of health staff and it is preventing patients with serious medical

> conditions getting timely specialised treatment outside Gaza (Association of International Development Agencies, 2010, p. 1).

Many participants of this study reported that so many items were not available at the health care system in Gaza including drugs, equipment, chemical reagents needed for diagnostic procedures and the lack of the radiation treatment option. Lack of drugs at some point was reported by participants as the most missing item from the health care system in Gaza. Usually, drugs, equipments, and other medical supplies are provided to Gaza from Rammallah stores in the West Bank or could be provided directly to Gaza when some humanitarian organizations succeed to challenge the siege and enter Gaza through the Mediterranean Sea or from the Egyptian borders. At either case, the importation of the supplies is contingent on the permission of the Israelis to let the supplies provided from Rammallah to enter into Gaza and the permission of the Egyptians to open the borders between Gaza and Egypt which used to be opened for limited hours per day for two to three days every one to three months.

According to the reports of the Association of International Development Agencies (2010) and the World Health Organization: West bank & Gaza (2010), disposables and drug supplies were generally allowed into Gaza, but there were usually a shortage of some items on the ground. For example Table 4-25 shows that between March and December, 2009, shortage in drug supplies ranged between 14-30% while shortage of medical disposables ranged between 10-20%. The list for essential drug supply includes 480 drugs while the list for essential medical disposables includes 700 items (World Health Organization: West bank & Gaza, 2010).

Table 4-25: Percentages of missing drugs and medical disposables in the stores of ministry of health in Gaza Strip. Source: World Health Organization: West bank & Gaza (2010).

Store	Mar.	Apr.	May	Jun.	Jul.	Aug.	Sept.	Oct.	Nov.	Dec.
Drugs	30%	14%	17%	15%	16%	22%	29%	16%	26%	
Disposables	10%	13%	14%	16%	20%	15%	14%	17%	17%	18%

At the same time, both reports recognized that certain types of medical equipments including those needed for x-ray and other electronic devices were very difficult to be brought into Gaza. Furthermore, the reports added that in many times, provided equipments were either broken or out of date and spare parts were not available (Association of International Development Agencies, 2010 and World Health Organization: West bank & Gaza, 2010). For example, the computerized tomography scanning (CT scan) machine at Gaza European Hospital, which is one of the two medical centers that provide oncology care in Gaza Strip, was broken for more than a year. Parts were not allowed, so far, to be supplied to MoH to repair it. Such lack of equipment and drug supply will hamper the quality of provided health care to patients living in Gaza Strip and therefore their QOL.

The issue of lacking some medical supplies or drugs was not mentioned extensively in the literature. A few studies had reported about this issue. For example, based upon the data from the Medical Expenditure Panel Survey Household Component, Weinick et al., (1997) found that inability to afford health care services was reported by about 60% of families as the major barrier for family members to receive the needed health care. Other literature (McKinlay (1972, McCullock-Melnyk, 1988) reported about the refusal of health insurance to cover the expenses of the services or the cost of the drugs not on the lack of the services or drugs themselves.

Gaza Strip has a unique situation due to the pertaining political situation that prevails in the area. Such a situation contributed to the lack of several drugs, equipments and supplies to be available at the medical centers that provide oncology care. Besides that, Abed (2007) included that there is a lack of several services at the MoH and he attributed this lack to the inability of the MoH to finance such services which depends on donating countries which covers about 50% of the budget of the MoH. Such constraints on the health care system can impede the delivery of care for beneficiaries (Mandelblatt, Yabroff, and Kerner, 1999) and alter the quality of care that is provided to people living in Gaza Strip.

Not so much literature addressed the availability of drugs, equipments, and offering other services in the health care system. For example Battista, Williams, and MacFarlane (1996) reported that the lack of radiation therapy was one of the barriers to health care reported by adult cancer patients. Weinick et al. (1997) reported that lack of appropriate equipments was a barrier for health care utilization and Estrada et al. (1990) reported that care was not available when needed.

Organizational Barriers

Several barriers were reported under the concept of organizational barriers. The sub-concepts emerged under the organizational barriers included: long waiting time, incompetent physicians, physicians are not available at their offices, complicated referral process for treatment abroad, and long time to hear about the results of their diagnosis.

The oncology outpatient clinics opens between 8:00 am to 1:00 pm. Usually, patients do not have exact appointments for follow up. Therefore, they are served on the basis of "first comes, first served." After the patient is seen by the treating physician, he will go to the pharmacy to collect his medication. If he needs a drug, such as an injection or a chemotherapeutic agent, he will go to the oncology nurse to receive his treatment then he will go home. Depending on how much busy is the clinic at that day, the process may take between 30 minutes and up to more than four hours. Usually, the clinic gets busy at the beginning of the month, the time the drugs are delivered to the pharmacy.

Fifty one patients had expressed their feelings that the waiting time was too long to them. The reported waiting time varied between two and four hours. One participant reflected his frustration about the long waiting time by saying:

> Waiting time is too long. It is really long. Sometimes it takes me about 4 hours to wait in order to be seen by the doctor. It is very boring. I have to bring my wife with me each time I come to the clinic so that I can find someone to talk to.

Some times the rule of "who comes first served first" is violated by health care personnel who sometimes allow their family members, friends, and acquaintances to be seen by the doctors without following the order they came to the clinic. This usually leads to prolonging the waiting time for other patients and occasionally leads to verbal or physical violence among waiting patients and personnel. One participant expressed his feelings:

> Employees in the health care system do not follow the order for seeing the patients. Some patients come late, but because they know someone in the hospital,

> they will be seen by the doctor before the patients who have been waiting for hours. Some doctors too allow the patients who come to their private clinics to be seen before us who were waiting for hours outside.

The process even becomes more complicated and the waiting time becomes even longer, according to some participants, as some physicians leave their offices for long periods of time which leads to frustration among the waiting patients. Physicians are employed by the MoH and they are supposed to stay in their offices during the working hours to see their patients. But because the system doesn’t enforce a disciplinary action policy, some physicians leave their offices to chat with other colleagues or go home early.

Seven participants expressed lack of confidence in their physicians and described them as being incompetent. This is in fact a general feeling in Gaza Strip about the competency of physicians, especially about young physicians who graduated from the former Soviet Union counties and Romania. The reputation of graduates from these countries is not good as people heard so many stories about how these graduates pass their exams by paying money or buying presents to their professors. One participant described his concerns as:

> The doctors here (in Gaza Strip) are not good. They don’t understand anything in medicine. For example, one doctor told me that my treatment is by passing a tube into my urethra and take small chips of the prostate (Trans-Urethral Resection of Prostate). Another doctor told me that the prostate should be removed by a surgical operation. A third one treated me for urinary tract infection. The issue is that there are no doctors who are competent in the area of urology. When I went to Palestine Hospital in Cairo, the doctor there asked to do some tests for prostate cancer, but here, none of the doctors; I went to, asked for this test.

Fifteen participants expressed that the process of getting a referral to be treated abroad (outside Gaza Strip) was very complicated. Usually the process is time consuming and has to be signed by several doctors and other personnel from the Ministry of Health. With the presence of blockade, the process even became more complicated. This is related to the blockade itself, therefore, the MoH work to limit the number of the referred patients to the lowest possible number, so that when the borders open, it will be much easier to manage the process for a smaller number of patients.

Five more participants reported that the results for the diagnostic tests and procedures took too much time and that such a long time of waiting for them is very difficult. One participant expressed his feelings as:

> The result of the diagnostic tests takes so much time. One time, the result of the PSA took about a month and a half as the material (reagent) was not available because of the blockade. You can’t imagine how my condition was while I was waiting to hear about the results. I was living in sever distress for that period of time.

Organizational barriers reported by participants of this study are not unique. The reported barriers are consistent with what had been reported in the literature. For example, Weinrich, et al. (2000) mentioned that participants in their study reported that doctors’ hours were not convenient. The long waiting time, in spite of having a previous appointment, was reported as a barrier to heath care by McCullock-Melnyk (1988), Estrada et al. (1990), Weinick et al. (1997), Bennett, 1999, Beckman et al. (2000), Chin et al. (2001), and the American Medical Student Association (2009). Long waiting time was not the only time-related barrier reported in the literature. Some studies also reported that participants complained about waiting too long to get an appointment or that there was a long time between appointments themselves (Estrada et al., 1990; Weinick et al., 1997; Chin et al., 2001; the American Medical Student Association, 2009).

Because sometimes some physicians were not available at their offices, patients had to wait for them until they come back or in some instances, they would see another physician. Seeing a different physician may lead to interruption and inconsistency in the treatment plan. Demark-Wahnefried (1995) reported that not having a regular physician was reported by both blacks and whites as a barrier for prostate cancer screening. Margolis et al. (1995) identified limited availability of health care providers as a barrier to health care while Rutten, Nelson, and Meissner (2004) reported that having ‘no physician’ was a barrier for pap smear and mammography which are used to screen for cervix and breast cancers.

The participants of this study were not unique in mistrusting their physicians. Others had reported that mistrust of health care recipients in their physicians was one of the barriers that impeded the utilization of health care services (Powell, Gelfland, Parzuchowski, Heilbrun, and Franklin, 1995; Robinson, Ashley, and Haynes, 1996). Although barriers to referring patients to be treated in a different country was not reported in the literature, but participants in the Weinick et al., (1997) study reported that in some instances, referrals required by the insurance companies were not obtainable. Other organizational barriers that were reported in the literature included the lack of support personnel (Drass et al., 1998).

Communication Barriers

Some of the participants (n=24) complained that the treating physicians and other health care professionals were not considering their emotional status when they talked to them and felt that they were humiliated by the way the physicians talked to them. They thought that they need and deserve special treatment and communication methods when they communicate with them as they felt that being diagnosed with cancer is a big issue. One participant described the way his doctor talked to him:

> Some of the doctors don't think that we are human beings. We are like them, flesh and blood and have feelings like they have. Some of them (the doctors) are inconsiderate to what we feel. It is enough to be diagnosed with cancer. They should put this into their consideration and know how to deal with us."

Another participant confirmed:

> I don't know how these doctors deal with us. They think that we are less than animals and have no feelings. For example, one of the physicians told me that whether I take the medication or not, the disease (cancer) will spread all over my body. Even if this is a true, he should give me more information about my condition and instruct me about what to do to prevent or limit the spread of cancer to other parts of my body.

Six participants complained about the medical jargon that some doctors used when they communicated with them. They expressed that sometimes they were nodding their heads to convey to those doctors that they understood what they were saying while they did not understand anything. They even complained that if they (the participants) will go to the private clinic of the same doctor, they will be treated much better and that the doctor will spend more time to explain for them about their health condition and to discuss with them what to do and what not to do.

The reported communication barriers by participants are consistent with the literature. For example, the participants in Estrada's et al. (1990) study reported that health care staff was disrespectful. Weinick et al. (1996) and Chin et al. (2001) added that communication problems were one of the most common reported barriers to health care. Furthermore, Mandelblatt et al. (1999) mentioned that health care providers are usually not prepared well to communicate with patients diagnosed with cancer especially when communicating the complexities related to cancer care, treatment, and its complications to their clients. On the other hand, the Center for Universal Design and The North Carolina Office on Disability and Health (2009) added that communication skills and the pattern of communication between providers and clients, especially those who are disabled, is a major barrier to health care that could lead to frustration among that vulnerable group of clients.

McCullock-Melnyk, 1988; Mandelblatt et al. (1999); and Chin et al. (2001) reported that some of the major barriers to health care and health education were related to language and cultural differences among health care providers and health care recipients. Such differences in language and culture may alter the process of communication between providers and recipients of health care services. The good thing about Gaza Strip is that all people are speaking the same language and have the same cultural backgrounds; therefore, neither culture nor language by itself were reported as barrier to health care.

Socioeconomic Barriers

Under the socioeconomic barriers, several sub-concepts emerged. These sub-concepts related to the high cost of drugs, diagnostic procedures, and private doctor visits. Many participants reported that they could not afford to buy these expensive drugs or to go to the private clinics of their physicians. A few number of participants reported that they even could not afford to pay for their transportation to go to the medical centers.

Since the siege was imposed on Gaza Strip on June 2006, living in Gaza became very hard. A large number of people who used to work in Israel lost their jobs and therefore, their income. Besides that, the expenses of living became very high as the quantity of so many goods became limited in the market because of the blockade. As a consequence, poverty level increased among Gaza inhabitants and several families became unable to afford providing their basic physical needs. Such hardship affected prostate cancer survivors and several participants reported that when the drugs became unavailable at the governmental health care system and in case it was available at private drug stores, they could not afford to buy these drugs and they had to wait without drugs for several days, weeks, or months until the drug becomes available at the governmental health care system. 35 participants complained that the cost of the drugs were very expensive. One participant expressed his concerns:

> When the drug becomes unavailable at the hospital, my children look for it at the private drug stores. If they found it, it is usually very expensive. In one time, I bought 50 capsules of my drug. The cost was very, very expensive as it was 5,000 NIS (About $1300). I could afford to buy the drug this time, but if it becomes unavailable one more time, I will not be able to buy it. Where shall I get the money to buy it? It is very expensive as you see. For me I could buy the drug at

> that time, but most of other patients are not able to buy the drug at such an expensive cost. What shall they do? Shall they wait and die slowly?

For this participant, he could manage to buy his drug, but many other participants reported that they could not afford to buy theirs. One participant concluded:

> Sometimes my drug is not available. It is very expensive to buy from outside drug stores. I can't afford to buy it. Therefore, I have to wait without medication until the drug becomes available again at the hospital. I need to come back to the cancer clinic every few days to ask if the drug became available. What shall I do? Life became very difficult in this country after the blockade. This is our fate and we have no other choice.

Inability to afford to cover the cost of drug supply was not the only socioeconomic barriers. Few participants complained that they could not afford to cover for the cost of transportation to the medical health centers to see their doctors and obtain their drug supply.

Because doctors show more interest and spend more time with patients when they go to visit them in their private clinics, some patients prefer to be seen at the private clinics of their doctors and they will come only to the governmental health centers to collect their drug supply. But not all participants can afford to cover the expenses to see their doctors at their private clinics. Some of them expressed their concerns about the high cost of seeing their doctors at their private clinics (visit cost between $10-15 for specialized physicians).

The high cost of services also applied to some diagnostic procedures. As mentioned previously, sometimes some diagnostic procedures or some chemical reagents are not available at the health care system; therefore, patients needed to do these procedures or tests at clinics or laboratories outside the health care system and cover for their cost from their pocket money. Usually, the expenses for such procedures and tests are expensive and several participants expressed that they were not able to cover for their costs. One participant put it straight forward and said:

> The cost of treatment at the outside clinics (private clinics) and the outside diagnostic centers is very expensive. I can't afford to pay for seeing the doctors at their clinics or to do exams outside (means outside the health care system). I hardly can cover the cost of the basic issues for me and my family to live.
> Since the siege was imposed on Gaza Strip on June 2006, living in Gaza became very hard and the cost of living increased so high to become intolerable for many people.

A large number of people who used to work in Israel lost their jobs and therefore their income. According to the Palestinian Central Bureau of Statistics (2009), over than 140,000 citizens (constituting 41.5% of work force in Gaza) living in Gaza were unemployed in the first quarter of 2009. As a result, poverty level increased. According to a household survey conducted by ICRC (2009) in May 2008, over than 70% of Gaza families had less than one US dollar per day per person with about 40% of surveyed families were living on income of less than 0.5 US dollar per person per day.

Besides that, the expenses of living became very high as the quantity of so many goods became limited or unavailable in the market because of the blockade. As a consequence, poverty level increased among Gaza inhabitants and several families became unable to afford providing their basic physical needs. Such hardship affected quality of life of most people living in Gaza including prostate cancer survivors. Due to their inability to afford buying their drug supplies, several participants reported that when the drugs were not available at the governmental health care system they could not afford to buy these drugs and they had to wait with no drugs for several days, weeks, or months until the drug became available at the governmental health care system. Such a delay of drug would affect the health-related QOL of these patients.

The literature had reported about issues related to cost and inability of patients to afford the expenses of health care. Weinrich et al. (2000) reported that participants with total family income of less than $59,000 per year were less likely to perform screening for prostate cancer than men who had higher family income. Chin et al. (2001) reported that diabetic patients and health care providers reported inability to afford buying devices to monitor their blood glucose at home as one of the major barriers to health care. Based upon the data from the Medical Expenditure Panel Survey Household Component, Weinick et al. (1997) found that inability to afford health care services was reported by about 60% of families as the major barrier for family members to receive the needed health care.

On the other hand, Blazer, Landerman, Fillenbaum, and Homer (1995) reported that cost was a major reason for patients to delay seeking health care especially for those living in rural counties. Many others had also reported that the cost of health services, cost of transportation, and other financial issues were major barriers to health care (Estrada et al., 1990, McCullock-Melnyk, 1988, Weinick et al., 1996, Bennett, 1999, Mandelblatt. et al., 1999, Beckman et al, 2000, American Medical Student Association, 2009, and Choice Regional Health Network, 2009).

Other sociodemographic barriers reported in the literature such as barriers related to gender, social class, culture, race, and ethnicity were not reported by participant in this study. This could be due to the fact that all participants were males and all of their doctors were males too. This is besides that people living in Gaza Strip had the same racial and cultural backgrounds and speak the same language.

Geographical Barriers

Geographical barriers reported by the participants of this study included few sub-concepts; distance, physical accessibility, and availability of public transportation. Physical accessibility was a very major barrier to health care utilization before September 2005 (the time the Israelis pulled out from Gaza Strip). At that time, Israelis used to have checkpoints at the main roads between the major cities in Gaza Strip. One could spend a few minutes or several hours to pass from these check points. Sometimes, the Israelis used to block the major roads between cities up to several days that could extend to more than a week in rare occasions. As a result, several participants could not physically access either one of the two medical centers that provide oncology care at that time. In fact, most of the participants who mentioned physical accessibility as a barrier were from participants who had been diagnosed with prostate cancer before September 2005 and most of them had finished their treatment. After September 2005, physical accessibility became not a major concern as only a few number of participants reported that distance and availability of public transportation were a major barrier to health care at the current time. This is because the two oncology centers are located in strategic geographical positions to be accessible by patients (Figure 4-2). For example, Shifa Hospital is located at Gaza city which located in the middle of Gaza governorate and between the Northern Governorate and the Mid-zone Governorate. It serves participants from these three

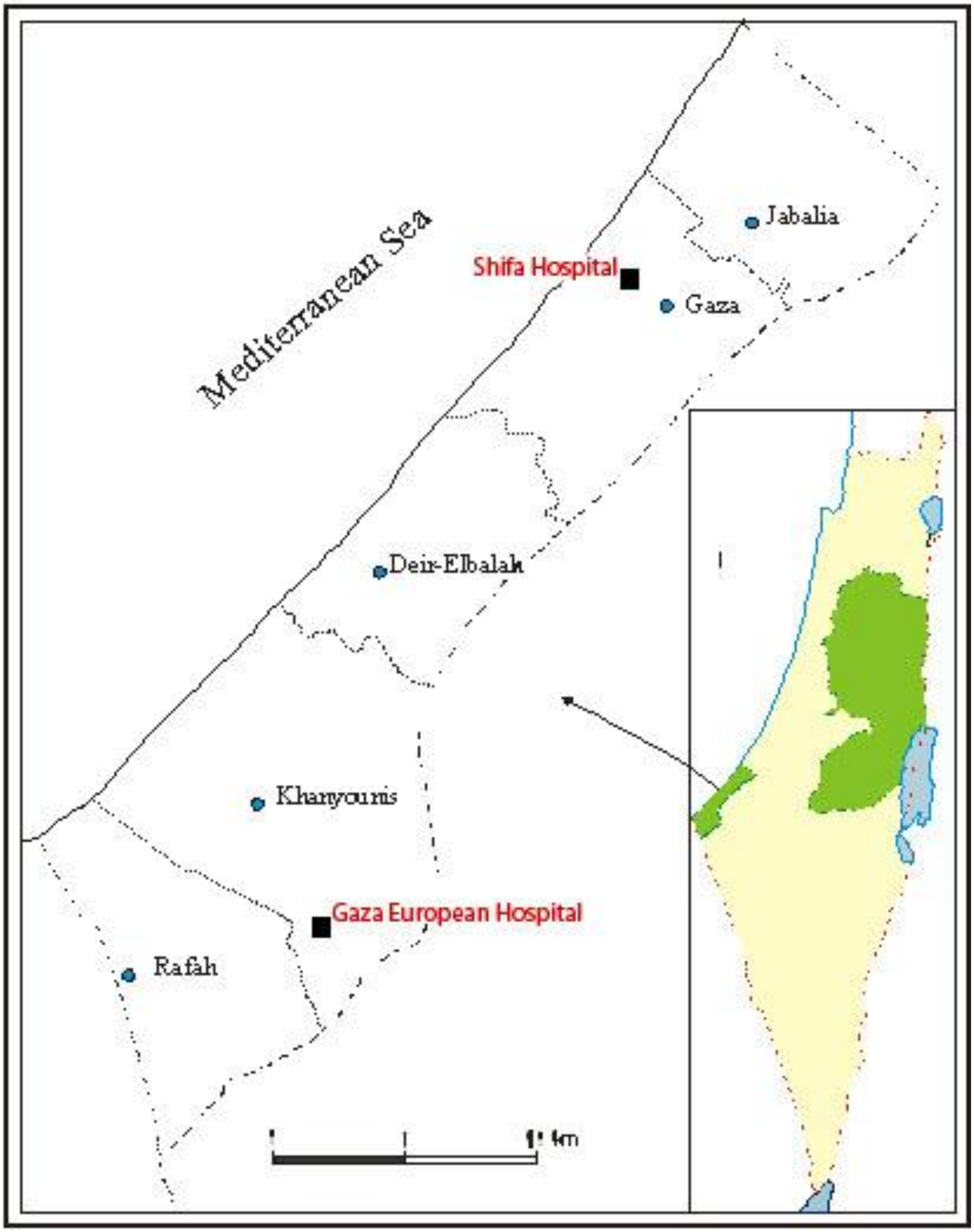


Figure 4-2: Geographical Location of Shifa Hospital and Gaza European Hospital.

governorates. On the other hand, Gaza European Hospital is located between Rafah and Khanyounis Governorates and it is easily accessible by participants who live there. In general, the location of the two hospitals was accessible by most of the participants and public transportation was usually available and relatively the cost was not expensive. Only a few number of patients who lived away from major roads had reported geographical-related barriers.

Geographical and transportation-related barriers were reported in many studies. For example, Guidry, Aday, Zhang, and Winn (1997) reported that transportation was one of the major barriers for African Americans to cancer treatment. In another study, Blazer, et al. (1995) reported that transportation was a barrier to access health care services for those who live in the rural areas. McCullock-Melnyk, 1988; Weinick, et al. (1996); Guidry, et al., (1997) reported that physical proximity and distance between place of living and health care facilities was a barrier to health care. Other related barriers that were reported in the literature included not having transportation (Estrada et al., 1990), not having a car, inability to drive, lack of public transportation (Weinick, et al., 1996), lack of access to automobile and unavailability of someone to drive patients to health care facilities (Guidry et al., 1997).

Blockade

Blockade as a barrier is related directly to the barriers labeled under the titles of “unavailability” and “socioeconomic barriers.” In fact, most of the items that were not available within the health care system and the low socioeconomic status were due to blockade. Usually, drug supplies, equipments, diagnostic reagents, and other stocks are supplied to Gaza either from the major stores located in Ramallah in the West Bank, or donated directly from donor countries or organizations to the health care system in Gaza.

After the election which took place in Palestine in January 2006, Hamas, an Islamic political party that is not accepted by Israel and the Western countries, won the election and formed the government in April 2006. Sanctions were imposed against Gaza Strip started at that time and were tightened after imprisoning an Israeli soldier by Palestinian military groups in Gaza Strip in June, 2006. Since that time, Israel limited the number and quantity of items that enter Gaza including food, fuel, and medical supplies. Besides that, Israel restricted the movement of people living in Gaza to leave Gaza Strip. As a result, the majority of patients who can’t find treatment in Gaza Strip and used to be referred for treatment in hospitals in West bank, Egypt, Jordan, and Israel were prohibited to travel. The most affected categories of patients affected by the blockade were those who had cardiology and oncology problems (Association of International Development Agencies, 2010 and World Health Organization: West bank & Gaza, 2010).

The process to travel outside Gaza for medical purposes is very complicated. After the patient gets a referral from the governmental health system (which is a complicated process as mentioned earlier), if they want to travel to West Bank or to Israel, they need to apply to the Israelis to get a permission to travel through the Gaza-Israeli border. Israelis give a little number of permissions to patients. According to the fact sheet issues by World Health Organization: West bank & Gaza (2010), many patients were denied permission to cross Israeli borders to receive treatment. For example, in December 2009, 1103 patients applied to get a permission to cross the borders to travel for treatment in an Israeli hospital or a Palestinian hospital at the West Bank. Out of them, 21% were denied these permissions or the permissions were delayed so patients had lost their appointment and had to start over to set a new appointment and start a new process to get a new permission to cross the Israeli borders (Figure 4-3 depicts the number of patients who were issued or denied a permission to cross the borders). Several patients died while waiting to get permission or because they were denied permissions to travel to receive treatment outside Gaza Strip. Figure 4-4 depicts the number of people from Gaza Strip who died while waiting for a permit to cross the Israel border to receive

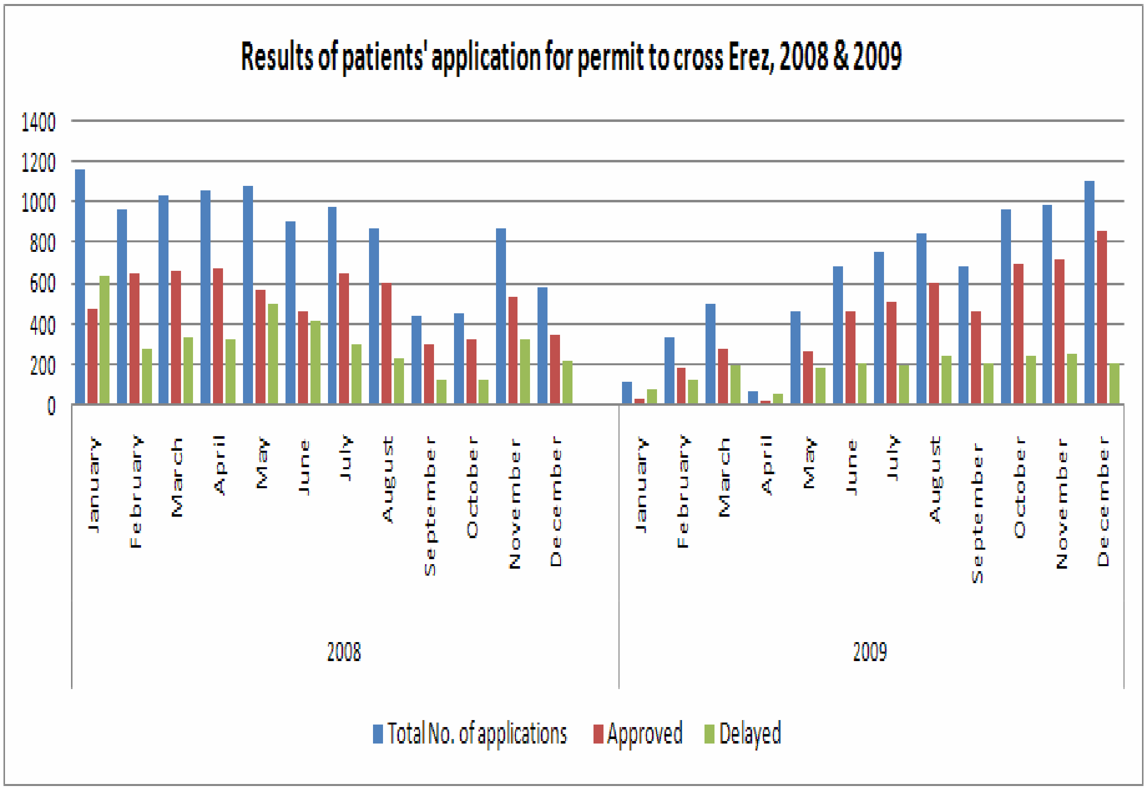


Figure 4-3: Result of Patients Application for Permit to Cross Israeli Borders. Source: World Health Organization: West bank & Gaza (2010, p.2).

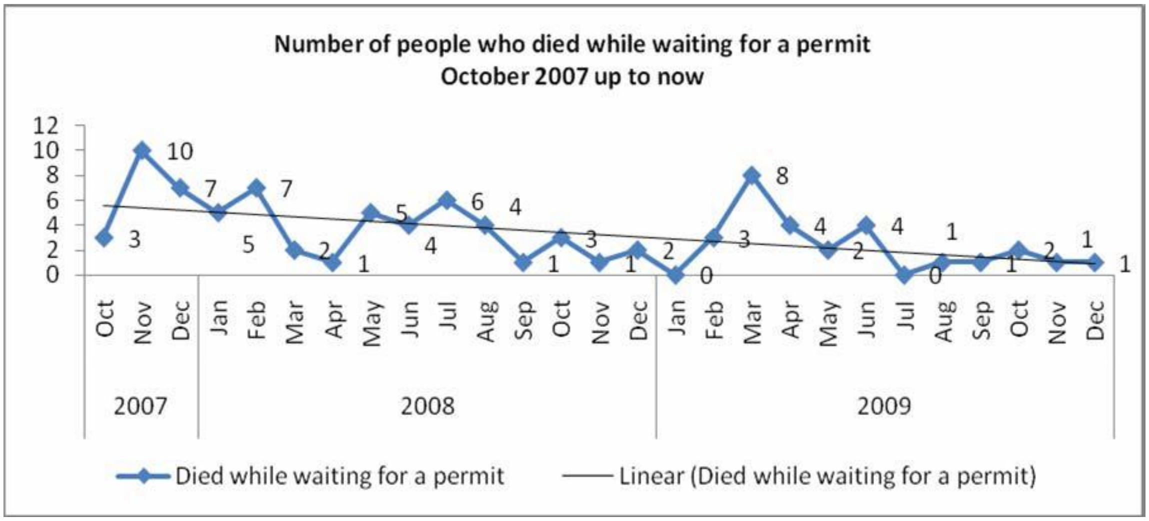


Figure 4-4: Number of People Who Died While Waiting for a Permit to Cross the Israel Border to Receive Treatment between October 2007 up to December 2009. Source: World Health Organization: West bank & Gaza (2010.p.2).

treatment between October, 2007 up to December, 2009 (World Health Organization: West bank & Gaza, 2010). According to the ministry of health (2010), up to March, 9th, 368 patients from Gaza strip died because of the blockade.

Indeed, many patients were denied such permissions under the excuse of “security reasons” which may apply to any person live in Gaza who himself or one of his immediate or extended family members were in prison, were injured, or killed due to the Israeli Palestinian conflict. On the other hand, patients who are referred to receive treatment in Egypt need to wait until the borders open and they will be lucky to pass at the first attempt as a few hundreds of travelers are allowed to pass at each occasion when the border opens. One participant summarized his agony about his inability to travel freely to Egypt by saying:

> My treatment is in Egypt. The biggest barrier to me is the blockade. When I traveled to Egypt last time, I had to wait for three months in order to be able to get to Egypt. Now, I am scheduled for a follow up visit in Egypt and I am very worry that the borders will not be open in the near future and I will not be able to go to Egypt for my follow up appointment.

Summary

The results of this study reflected that prostate cancer survivors living in Gaza Strip had reported lower scores of general quality of life than those reported in the literature for patients treated with prostatectomy and radiation therapy and used the UCLA-PCI instrument. Prostate-specific quality of life scores reported by participants of this study were congruent with those reported in the literature with the exception of the scores reported for urinary bother which were lower than those reported in the literature. Participants who were treated with prostatectomy reported higher PCI QOL scores than those treated with hormonal therapy. In general, scores of quality of life reported by participants who were not receiving treatment at the time of data collection were higher than those who were receiving treatment at that time which could reflect the impact of treatment on quality of life.

Results revealed that participants had faced many barriers to health care. These barriers were categorized into five major concepts: barriers due to unavailability, organizational barriers, geographical barriers, socioeconomic barriers, and barriers related directly to the blockage imposed on Gaza Strip. Under each concept, several sub-concepts were identified. It was found that participants who were receiving treatment had reported more barriers to health care than those who were not receiving treatment at that time. Lack of drug at the governmental health care facilities was the most reported missing item from the system. So many participants could not afford to buy these drugs when they were not available which had a negative impact on their health.

CHAPTER V

CONCLUSIONS AND FUTURE DIRECTIONS

This chapter summarizes the results of the study findings. Where appropriate, conclusions are derived. Then, implications and recommendations for the practice of health policy are discussed. In addition, recommendations for future areas of study are also outlined. Finally, limitation are discussed.

Summary of Study

Prostate cancer is one of the most common cancers among male population and it was the second most common cancer and the second cancer-related leading cause of death among Palestinian males (Ministry of Health, 2006). The incidence of diagnosing new prostate cancer cases is increasing as the Palestinian population is aging. In developed countries, the incidence of diagnosing new prostate cancer is increasing due to the use of digital rectal examination and prostate-specific antigen in screening for new cases (American Cancer Society, 2007a). The rate of cure of localized prostate cancer is very high (Turini et al., 2003). The use of different treatment modalities such as prostatectomy, radiation therapy, and hormonal therapy helped many prostate cancer survivors to live for longer periods of time than they used to live few decades ago.

Managing cancer itself and the consequences of its treatment became of paramount importance recently as patients now live longer and have to bear with the burdens of cancer itself and the consequences of its treatment (American Cancer Society, 2007b). Such problems, if not taken into consideration, will result in longer or incomplete recovery, higher stress, and long-term impact on QOL (Gotay & Muraoka, 1998; Green et al. 2000). Because the use of prostatectomy and radiation in treating localized prostate cancer provide similar curative results, issues related to QOL that accompany each treatment option become more important in the decision making about which treatment option to use (Turini et al., 2003). The use of radiation therapy produces bowel dysfunction and bowel bother while prostatectomy doesn’t. Both options result in urinary dysfunction and bother and sexual dysfunction and bother. Though, radiation therapy produces less urinary and sexual symptoms (Potosky et al, 2000).

As explained in chapter one nearly all of the studies related to QOL of prostate cancer survivors were conducted in developed countries and none was found to be conducted in a developing country. Further, no study addressed barriers to health care as perceived by prostate cancer survivors. For example, Lubeck et al. (1997); Albertsen et al. (1997); Litwin et al. (1998); Potosky et al. (1999); Stanford et al. (2000); Potosky et al. (2000); Schapira et al. (2001); Penson et al. (2003); Reis et al. (2004); Jayadevappa et al. (2006); Arredondo et al. (2007); and Shikanov et al. (2008) examined QOL of prostate cancer survivors in the USA .Karakiewicz et al. (2003) examined QOL of prostate cancer survivors in Canada. Korfage et al. (2003) examined QOL of prostate cancer survivors in Germany. Gacci et al. (2005) examined QOL of prostate cancer survivors in Italy. Chapple and Ziebland (2002) examined QOL of prostate cancer survivors in United

Kingdom. Hedesting et al. (2005) examined QOL of prostate cancer survivors in Sweden. Ishihara et al. (2006); Namiki et al. (2007); and Wakatsuki et al. (2008) examined QOL of prostate cancer survivors in Japan. Oliffe (2005) examined QOL of prostate cancer survivors in Australia. Navon and Morag (2003) examined QOL of prostate cancer survivors in Israel. Further, no study addressed barriers to health care as perceived by prostate cancer survivors. The purpose for this study was to evaluate the level of QOL and to assess the barriers to health care as perceived by prostate cancer survivors who live in Gaza Strip in an attempt to fill part of the gap in the literature related to QOL of prostate cancer survivors and barriers to health care in the developing countries.

In order to evaluate the level of QOL, the UCLA-PCI including the RAND 36-Item Health Survey v2 (SF-36 v2) Health-Related Quality of life was used to evaluate the level of QOL for prostate cancer men living in Gaza Strip. Barriers to health care were assessed by using a semi-structured interview. The design for the study used both qualitative and quantitative approaches in data collection. 199 patients were recruited from the two medical centers that provide oncology care in Gaza Strip. 195 patients agreed to participate in the study with a response rate of 97.98%.

The findings of this study revealed that the mean age of participants was 72 years (± 8.81) and the mean of their age at time of diagnosis was 65.99 years (± 8.27). More than 55% of prostate cancer cases were diagnosed after the age of 65 years. Gaza governorate had a relatively higher percentage of men diagnosed with prostate cancer than the percentage of its male population. The majority of participants (72.8%) were receiving treatment at the time of data collection and most of them (60.5%) were treated at Shifa Hospital which has the major oncology center in Gaza Strip. The most common method of treatment used as a monotherapy was hormonal therapy (31.8% of participants) followed by prostatectomy (21.0% of participants). Only one patient used radiation therapy as a monotherapy. The rest of participants used a combination of the different treatment options including chemotherapy. Most of the participants (87.2%) had, at least, one comorbidity with a current or a past history of smoking being the most common comorbidity followed by diabetes mellitus.

The findings of this study revealed that the scores of the general quality of life (SF-36 QOL) of prostate cancer men living in Gaza Strip was less than those reported in the literature in all domains of SF-36 with the exclusion of the scores reported by Schapira et al., (2001) for patients who used radiation therapy. The scores of all domains of Prostate-Specific Index fell within the range of scores reported in the literature with the exception of the scores of urinary bother. Participants' score for urinary bother was 42.8 while the least score reported in the literature was 69.5 (Lubeck et al., (1997). This big difference in the urinary bother score could be related to the fact that being clean of urine and stool is one of the conditions any Muslim should have before praying. Further, participants who were treated with prostatectomy (59.47) had reported higher scores of PCI QOL than those treated with hormonal therapy (46.22). This difference was proved to be statistically significant (p=0.018).

Participants had reported several barriers to health care. These barriers were categorized under five major categories. These categories included barriers due to unavailability, organizational barriers, geographical barriers, socioeconomic barriers, and barriers related directly to the blockage imposed on Gaza Strip. Under the umbrella of each category, there were several subcategories that had emerged (figure 4-1). In general, most of the barriers reported by participants were compatible with barriers reported in the literature with the exception of those barriers related directly to the impact of the blockade imposed against Gaza Strip.

Answers to Research Questions

It was noticed that the available literature about quality of life of prostate cancer survivors addressed this topic in developed countries. None of the available studies addressed QOL of prostate cancer survivors in any of the developing countries. The topic of barriers to health care was addressed in general in the literature, but no studies addressed the topic of barriers to health care as perceived by prostate cancer survivors. This study was designed to evaluate the level of quality of life of prostate cancer survivors and to assess barriers to health care for prostate cancer survivors living in Gaza Strip.

Research Question #1: What is the Level of the Perceived Quality of Life of Prostate Cancer Survivors Who Live in Gaza Strip?

Quality of life of prostate cancer survivors living in Gaza Strip was described in three categories: a) General quality of life (SF-36), b) Prostate-Specific QOL (PCI-QOL), and c) total quality of life (both general QOL and PCI-QOL). The UCLA-PCI including the RAND 36-Item Health Survey v2 (SF-36 v2) Health-Related Quality of life was used to assess QOL of prostate men survivors in Gaza.

General Health Quality of Life

The general QOL scale (SF36) includes 9 domains: physical function, role limitation due to health problems, role limitation due to emotional problems, vitality, mental health, social functioning, bodily pain, general health, and health transition (Litwin et al., 1998). The mean score of the general quality of life for participants was 52.53. Scores for each domain of the general health QOL was presented in Table 4-15. In general, participants who were not receiving treatment at the time of data collection reported higher scores than those who were receiving treatment at that time in all domains except the domains of social functioning, bodily pain, and health transition.

The general health QOL scores reported by participants of this study were less than those reported in the literature with the exception of three sub-domains; role limitation due to physical function, social functioning, and bodily pain. In fact those lower scores were reported by Schapira et al. (2001) for patients who were treated with radiation therapy. Since only one participant of this study used radiation therapy as a monotherapy, scores of participants would be less than other scores reported in the literature for patients treated with prostatectomy or hormonal therapy.

Prostate-Specific QOL (Prostate-Specific Index)

The Prostate-Specific QOL variable contains 6 domains; urinary function, urinary bother, bowel function, bowel bother, sexual function, and sexual bother (Litwin et al., 1998). The mean score for prostate specific quality of life scores reported by participants was 51.29. The highest scores reported by participants were those for bowel function and bowel bother domains and the lowest scores were for the sexual function and urinary bother domains (22.23 & 46.31 respectively). The results (Table 4-15) showed that participants who were not receiving treatment at the time of data collection reported higher scores (mean score = 63.49) than participants who were receiving treatment at that time (mean score = 46.74). This difference was found to be statistically significant (p less than 0.001).

To the contrary of the scores reported by participants of this study for the general health sub-domains, all the scores of the sub-domains of the PCI-QOL fell within the range of the reported scores in the literature with the exception of urinary bother which was much less than the least reported score in the literature. The scores reported by participants for the urinary bother sub-domain was 42.8 compared to the least score of 69.5 reported in the literature by Lubeck et al. (1997). This big difference in the urinary bother score could be related to the fact that being clean of urine and stool is one of the conditions any Muslim should have before praying. Such inability to control their urinary function could have a negative impact on participants' feelings. In spite that the laws of Islam give a special permission for patients who cannot control their urination, usually, elderly Palestinian people are very hesitant and feel inferior and stressed to use such permission and they prefer and act to be clean as their counter partners who are not suffering from their disease conditions.

The relatively high scores for bowel function and bowel bother reported in this study are due to the fact that only a few number of patients used radiation therapy as a monotherapy or along with other adjunct treatment modalities. Side effects that affect bowel function and leads to bowel bother are most likely due to radiation therapy.

Although the scores reported by participants about sexual function were low (22.24), the scores reported about sexual bother were much higher (53.08). The same relatively huge difference between scores of sexual function and sexual bother was noticed in the reviewed studies that were summarized in Table 4-14. Such differences could be related to the fact that participants had accepted changes in their sexuality and related these changes in their sexuality to the process of aging and not to the impact of the disease or treatment on their sexual functioning.

Total Quality of Life

Total quality of life variable includes the mean of all variables related to quality of life (those related to general health QOL and to prostate-specific QOL). The total score of QOL for participants was 52.09. The mean of the total QOL for participants who were not receiving treatment (58.56) was higher than those were not (49.67). The difference between the two scores was found to be statistically significant (p= .004). Unfortunately, none of the studies reported in the literature reported on the total scores of QOL, rather they reported on the scores of each individual sub-domain of the general QOL (SF36) and/or those related directly to prostate cancer.

Impact of Treatment Options on Quality of Life

The results of this study showed that the use of different treatment options had no effect on the level of general quality of life while it had a significant impact on the prostate-specific QOL (p=0.008). Participants who were treated with prostatectomy had reported higher mean scores (59.47) than those who were treated with hormonal therapy (46.22). The difference between the two means was found to be statistically significant (p= 0.015). Such differences in QOL scores are expected. Usually prostatectomy is used as a curative option to treat localized prostate cancer (Turini et al., 2003) while hormonal therapy is usually used (alone or along with other treatment options) as a palliative option to treat advanced prostate cancer (Albaugh & Hacker, 2005). It can be also given for patients with localized tumor and unfit for curative treatment (Fourcade et al., 2009).

Research Question #2: Are there any Differences of the Perceived Quality of Life Issues Reported by Prostate Cancer Survivors Who Live in Gaza Strip and Currently Receiving Treatment and Those who Had Finished their Treatment?

Quality of life of prostate cancer survivors living in Gaza Strip was described in three main categories: a) General quality of life (SF-36), b) Prostate-Specific QOL (PCI-QOL), and c) Total quality of life (both general QOL and PCI-QOL). The UCLA-PCI including the RAND 36-Item Health Survey v2 (SF-36 v2) Health-Related Quality of life was used to assess QOL for prostate cancer survivors in Gaza Strip. After evaluating the level of QOL in the three main categories of QOL mentioned earlier, a comparison between levels of QOL between the group of participants who were receiving treatment at the time of data collection and the group of participants who were not receiving treatment at that time was performed.

The score of the general quality of life (SF36) for the participants who were receiving treatment was 51.30 while it was 55.81 for participants who were not receiving treatment (Table 4-19). The result of the t test (Table 4-20) showed that there was no statistically significant difference (p=0 .211) between the scores reported by participants of each group. The SF36 consists of nine sub-domains. The mean scores of the sub-domains of the general quality of life (SF36) for participants of each group were presented in table 4-21. Results showed that participants who were receiving treatment at the time of data collection had lower scores in all sub-domains of the general QOL than participants who were not receiving treatment at that time with the exception of the domains of social functioning, bodily pain, and health transition as they reported higher scores. To compare if there were any statistically significant differences between the means of the sub-domains of the general QOL among participants of both groups, t test was done. The results showed (Table 4-22) that there were statistically significant differences between the means of the participants in the two groups only in the areas of vitality (p=.033) and health transition (p=.001).

The score for prostate specific index (PCI) quality of life for the entire sample was 51.29. It was 46.74 for participants who were receiving treatment at the time of data collection while it was 63.49 for participants who were not receiving treatment at that time (Table 4-19). The result of the t test showed that there was a statistically significant difference (p less than 0.001) between the reported scores of the two groups. Such lower scores for the group of participants who were receiving treatment at the time so data collection could be attributed to the sequel and side effects of the treatment that they were receiving.

Table 4-23 summarizes the scores of QOL for the six sub-domains included in the PCI for the total sample and for participants who were receiving treatment and participants who were not receiving treatment at the time of data collection. The highest scores reported by participants were those for bowel bother and bowel function sub-domains and the lowest scores were for the sexual function and urinary bother (22.23 & 46.31 respectively). In general, participants who were not receiving treatment at the time of data collection reported higher scores than those who were receiving treatment at that time in all domains except the bowel bother domain as the scores were almost equal. Although scores of sexual function were the lowest scores in both groups, but it is noticed that there was a relatively huge difference between the scores reported by participants in each group (score of sexual function reported by participants who were receiving treatment was 13.62 compared to 45.29 for participants who were not receiving treatment). The results of the t test (Table 4-24) showed that there were a statistically significant differences between the mean scores of participants in the two groups in the areas of urinary bother ($p = 0.005$), sexual function ($P < 0.001$), and sexual bother ($p = 0.023$).

Total quality of life includes the scores of all variables related to quality of life (all the sub-domains of the SF36 and the PCI scores). The score of the total QOL for participants who were receiving treatment was 49.67 while it was 58.56 for those participants who were not receiving treatment (Table 4-19). The result of t test showed that there was a statistically significant difference between the means of the total quality of life (p= 0.004) between the scores reported by participants of the two groups.

Research Question # 3: What are the Barriers to Health Care Faced by Prostate Cancer Survivors Living in Gaza Strip during their Treatment Period?

Many barriers to health care were reported by the participants of this study. 119 participants (61.02%) reported facing at least one barrier to health care at a certain point of their treatment time. In general, it was noticed that barriers to health care were reported by more participants who were receiving treatment at the time of data collection (n=107) than those who were not receiving any treatment at that time (N=12).

After examining the scripts of the participants' responses, emerging themes were identified and coded into the following major concepts: barriers due to unavailability, organizational barriers, geographical barriers, socioeconomic barriers, and barriers related directly to the blockage imposed on Gaza. Under the umbrella of each concept, there were several sub-concepts that had emerged (figure 4-1).

Barriers related to Unavailability

Participants reported that several items or services were not available at the health care system in Gaza. These items included drugs, equipments, reagents for some diagnostic procedures, and the absence of the radiation therapy option. The most commonly reported missing item was drugs as many participants (N= 86) reported that drugs were not available at some point at the governmental health system during their treatment time. Some participants could afford to buy drugs from other drug stores in case they were available, but many others could not. For those who could not afford purchasing drugs from outside drug stores or if the drugs were not also available at outside drug stores, participants had to wait without drugs until these drugs were delivered to the pharmacy of the governmental health care centers, which could negatively impact the status of their health and quality of life.

Usually, drugs, equipments, and other medical supplies are provided to Gaza from Rammallah stores in the West Bank or by some humanitarian organizations that succeed to challenge the siege and enter Gaza through the Mediterranean Sea or from the Egyptian borders. Therefore, the importation of the supplies is contingent on the permission of the Israelis to let the supplies provided from Rammallah to enter into Gaza and the permission of the Egyptians to open the borders between Gaza and Egypt which used to be opened for limited hours per day for two to three days every one to three months. In general, reports from World Health Organization: West bank & Gaza (2010) and the Association of International Development Agencies (2010) showed that between March and December, 2009, shortage in drug supplies ranged between 14-30% while shortage in medical disposables ranged between 10-20% and that certain types of medical equipments including those needed for x-ray and other electronic devices were very difficult to get them into Gaza. Furthermore, the reports added that in many times, provided equipments were either broken or out of date and spare parts were not available. Such lack of equipment and drug supply will hamper the quality of provided health care to patients living in Gaza Strip and therefore their QOL.

The issue of lacking some medical supplies or drugs was not mentioned extensively in the literature. A few studies had reported about this issue. For example, Weinick et al., (1997) found that inability to afford health care services was reported by about 60% of families as the major barrier for family members to receive the needed health care.

Organizational Barriers

Several barriers were reported under the concept of organizational barriers. The sub-concepts emerged under the organizational barriers included: long waiting time, incompetent physicians, physicians are not available at their offices, complicated referral process for treatment abroad, and long time to hear about the results of their diagnoses. These barriers were congruent with what was reported in the literature. Some examples reported in the literature included inconvenient doctors' hours (Weinrich et al., 2000), long waiting time in spite of having a previous appointment (McCullock-Melnyk, 1988; Estrada et al., 1990; Weinick et al., 1997; Bennett, 1999; Beckman et al., 2000; Chin et al., 2001), waiting too long to get an appointment or long time between appointments themselves (Estrada et al., 1990; Weinick et al., 1997; Chin et al., 2001), limited availability of health care providers (Margolis et al., 1995), having no physicians (Rutten et al., 2004), and mistrust in physicians (Powell, et al., 1995; Robinson et al., 1996).

Communication Barriers

Some of the participants (N=24) complained that the treating physicians and other health care professionals were not considering their emotional status when they talked to them and felt that they were humiliated by the way the physicians talked to them. Complaining participants thought that they needed special treatment and communication methods when they communicate with them as they felt that being diagnosed with cancer is a big issue that should be considered. Other participant reported that the use of some medical terminologies by their physicians impeded the process of communication and they did not understand the instructions or the explanations made by their physicians.

Several studies reported that communication problems were one of the reported barriers to health care (Weinick et al., 1996; Chin et al., 2001). Further, participants in Estrada's et al., (1990) study reported that staff being disrespectful as one of the barriers to health care. According to Mandelblatt et al., (1999), health care providers are usually not prepared well to communicate with patients diagnosed with cancer especially when communicating the complexities related to cancer care, treatment, and complication to their clients.

Socioeconomic Barriers

Under the socioeconomic barriers, sub-concepts related to the high cost of drugs, diagnostic procedures, and doctor visits emerged. Many participants reported that they could not afford to buy these expensive drugs or to go to the private clinics of their physicians. A small number of participants reported that they even could not afford to pay for their transportation to go to the medical centers.

After the blockade was imposed against Gaza Strip, the level of unemployment reached 41.5% (Palestinian Central Bureau of Statistics, 2009) and poverty markedly increased (ICRC, 2009). The cost of living in Gaza also increased as several basic goods became unavailable in the market or smuggled from Egypt through the tunnels. Such hardship affected prostate cancer survivors and several participants reported that when drugs were unavailable at the governmental health care system, they could not afford to buy them and they had to wait without drugs for several days, weeks, or months until the drug became available at the governmental health care system which may have negative impact of their health and QOL.

Cost and inability of clients to afford the expenses of health care or the cost of transportation loomed as a major barrier to health care in several studies (Estrada et al., 1990; Landerman et al, 1995; McCullock-Melnyk, 1988; Weinick et al., 1996; Bennett, 1999; Mandelblatt. et al., 1999; Beckman et al, 2000; Weinrich et al., 2000; Chin et al., 2001).

Geographical Barriers

Geographical barriers reported by the participants of this study included few sub-concepts; distance, physical accessibility, and availability of public transportation. Physical accessibility was a very major barrier before September 2005 before the Israelis pulled out from Gaza Strip. At that time, Israelis used to have checkpoints at the main roads between the major cities in Gaza which impeded or prevented physical accessibility to health care facilities. After September 2005, physical accessibility became not a major concern since the two oncology centers are located in geographical locations that allows easy accessibility without traveling for long distances (Figure 4-2) and have public transportation that are relatively not expensive to reach them. Geographical and transportation-related issues were reported as barriers to health care in several studies (Estrada et al., 1990; McCullock-Melnyk, 1988; Blazer, et al., 1995; Weinick, et al., 1996; Guidry, et al., 1997).

Blockade

Beside that blockade was associates with the absence of many items at the health care system and inability of participants to cover the cost of needed drugs and other health care services, it was also involved as a barrier of inability of participants to travel to receive treatment outside Gaza Strip. After the elections took place in 2006, sanctions were imposed against Gaza Strip. Sanctions included the prohibition of people, including patients, to leave Gaza Strip. Since that time, the process to travel outside Gaza for medical purposes became very complicated as patients need to get special permissions from the Israelis to leave Gaza for treatment in West bank or in an Israeli hospital or to wait for the borders between Gaza and Egypt which opens occasionally for few day and relatively, a very few number of people is allowed to pass.

Israelis deny issuing permissions to many patients to cross Israeli borders to receive treatment. For example, in December 2009, 1103 patients applied to get permissions to cross the borders to travel for treatment in an Israeli hospital or a Palestinian hospital at the West Bank (World Health Organization: West bank & Gaza (2010). Out of them, 21% were denied these permissions or the permissions were delayed so patients had lost their appointments and had to start over to set a new appointment and start a new process to get a new permission to cross the Israeli borders (figure 4-3). In fact, several patients died while waiting to get permissions or because they were denied permissions to travel to receive treatment outside Gaza Strip (Figure 4-4). Inability of people to travel freely in and out of Gaza deprived several prostate cancer patients to receive radiation therapy which could be necessary if the patient was diagnosed with localized prostate cancer and was not fit for surgery.

Implications for Health Policy Change

Prostate cancer is one of the most common cancers that affect men. It was the second most common type of cancer and the second leading cancer-related cause of death among Palestinian males (Ministry of Health, 2006). The incidence of prostate cancer and the probability of developing invasive cancer increase with age (American Cancer Society, 2007b; Held-Warmkessel; 2007; Munden, 2007). In spite of that, when discovered while localized, prostate cancer is curable (Tewari et al., 2004) and the survival rate had improved a lot in recent years. The five-year relative survival rates for prostate cancer in the United States (the chance of living 5 years after being diagnosed with prostate cancer) was 99.9% at all stages of cancer and 100% if the cancer was local between 1996 and 2002 (American Cancer Society, 2007b). The five-year survival rate decreases to 94% for patients diagnosed with regional prostate cancer and to 31% for patients with distant metastasis (Parker, Tong, Bolden, and Wingo, 1997). Tewari et al., (2004) added that about 57% of prostate cancers are diagnosed while still localized with a ten-year survival rate of 93% and a crude survival rate of 67%.

With the high incidence of prostate cancer, high survival rates, and with the several potential morbidities associated with the different treatment methods, more focus on quality of life issues was observed in the relevant literature (Sommers, and Ramsey, 1999; Kakehi et al, 2002; Gacci et al, 2005; Ishihara et al, 2006; Inoue et al, 2009). Secchi and Strepparava (2001) added that QOL is now considered one of the most important parameters in evaluating clinical trials. Furthermore, the American Cancer Association (2007b) added that managing the consequences of cancer itself and treatment-related consequences become more important because patients live longer with the burdens of treatment consequences. Not understanding or not considering these issues can contribute to poorer recovery, higher level of stress, and disturbances in their QOL (Gotay & Muraoka, 1998; Green et al., 2000). Therefore, this group of patients deserves more attention from health policy decision-makers to improve the quality of their lives and to eliminate barriers to health care which would improve the quality of provided care which might be reflected on their QOL. Several implications for policy health policy came out from this study. The suggested health policy areas include requesting physicians to inform patients about the pros and cons of the different treatment modalities, set a plan to introduce a prostate cancer screening policy, reconsider the referral policy to increase radiation therapy, and set polices designated to eliminate barriers to health care.

Requesting Physicians to Inform Patients about the Pros and Cons of the Different Treatment Modalities

There are several treatment options available for prostate cancer that include prostatectomy, radiation therapy, hormonal therapy, and watchful waiting (Albaugh, & Hacker, 2005; Turini, Redaelli, Gramegna, & Radice, 2003). For localized prostate cancer, treatment is usually curative. Prostatectomy and radiation therapy, either external beam radiation or internal radiation, are the most commonly options used to treat localized prostate cancer and they usually provide prolonged survival rate (Turini et al., 2003). Since both options may result in several long-term complications, some men prefer the watchful approach (Turini et al., 2003). In Europe, radical prostatectomy is recommended for younger patients with ≥ 10 years of life-expectancy who are willing to accept its complications (Heidenreich et al., 2008). Radiation therapy is used for patients who are expected to live for a long time or who are unfit for surgical procedure and willing to accept treatment-related complications (Fourcade et al., 2009).

While hormonal therapy is not curative but it is usually used as a palliative option in advanced prostate cancer, where cancer have spread to involve lymph nodes and other organs such as bone. It is used to suppress testosterone production which will diminish the growth rate of the hormone-dependent tumor and to limit the complications resulting from this growth (Albaugh & Hacker, 2005). It can be also given for patients with localized tumor and unfit for curative treatment (Fourcade et al., 2009). Other combination modalities such as prostatectomy, radiation, or chemotherapy could be used along with hormonal therapy to limit disease complications and relieve symptoms (Turini et al., 2003; Fourcade et al., 2009). On the other hand, according to Van Erps, van den Weyngaert, and Denis (1998), the best treatment option for localized prostate cancer still controversial as there is no proven evidence about the superiority of one over the others. But Fleming et al. (1993) concluded from the results of decision analysis study that younger patients were the ones who clearly benefited from prostatectomy and radiation therapy. Turini et al (2003) added that prostatectomy is usually the treatment of choice used in the United States but in case of presence of concurrent medical conditions, radiation therapy is used.

Each of the available treatment modalities has several long-lasting complications that may negatively impact the quality of life (Albaugh & Hacker, 2005). For example, radical prostatectomy may lead to several urinary problems such as incontinence, nocturia (frequent urination during the night time), dribbling, and incomplete bladder emptying; sexual dysfunction including impotence, lack of ejaculation, changes in orgasm, and penile shortening; psychological concerns, and rarely death (Woolf, 1995; Clark et al., 2003; Turini et al., 2003; Albaugh & Hacker, 2005). Sommers and Ramsey (1999) reviewed the literature about post-prostatectomy complications and reported that the incidence of some degree of urinary incontinence reported in the literature they reviewed ranged between 4 to 74%, between 6 to 34% reported significant bother related to incontinence, and between 85 to 100% experienced some degree of sexual dysfunction. Sexual problems that lasted for 2-4 years affected 69-89% of patients in the literature reviewed by Sommers and Ramsey.

Radiation therapy has its own complications that include changes in bowel function, urinary function, and sexual function (Clark et al., 2003). The urinary dysfunction is usually related to bladder irritation, incontinence, and obstructive symptoms that include urgency, frequency, burning pain during voiding, and incomplete emptying of the bladder (Wei et al., 2002; Albaugh & Hacker, 2005). In their extensive review of the literature, Sommers and Ramsey (1999) found that 21 to 36% of patients used radiation therapy reported that they had experienced moderate to major changes in their bowel function. Bowel dysfunction includes frequency, urgency, diarrhea, fecal incontinence, pain during bowel movement, proctatitis, and blood in stool. This is besides other complications such as erectile dysfunction, lymphadema, and feeling tired during the treatment course (Sommers & Ramsey, 1999; Albaugh & Hacker, 2005).

Hormonal therapy commonly leads to sexual problems such as impotence, decreased libido, and erectile dysfunction; gynacomastia (increase breast size in men); weight gain, hot flashes, sleep disturbances, fatigue, altered mood and depression; and osteoporosis (Sommers & Ramsey, 1999; Potosky et al., 2002; Penson & Litwin, 2003; Turini et al., 2003; Albaugh & Hacker, 2005). Melmed, Kwan, Reid, and Litwin (2002) further added that hormonal therapy is associated with diminished QOL because of subsequent deterioration in physical function and pain domains in the SF-36 health assessment tool.

One more option for treating prostate cancer is watchful waiting. It involves carefully monitoring the prognosis of the disease which includes regular PSA testing and periodical prostate biopsy to determine the need and/or time of introducing treatment. Usually, this approach is used with elderly men or with those who have limited life span due to other comorbidities as they might not be good candidates for surgical intervention or might not be able to tolerate the complications of the other available treatment options

(Albaugh & Hacker, 2005). In spite of introducing no treatment, watchful waiting has its own psychological consequences. These consequences include stress, anxiety, and fear of the unknown (Chodak & Warren, 2006). On the other hand, men who choose watchful waiting may report some bladder problems such as frequency, urgency, and incomplete bladder emptying as the growing tumor will lead to obstruction of bladder neck. Others may complain of severe bone pain and fractures if the cancer is metastasized to bone, which will negatively impact their QOL (Chodak & Warren, 2006; Albaugh & Hacker, 2005).

As it had been noticed by Van Erps et al., (1998), the best treatment option for localized prostate cancer is still controversial because there is no proven evidence about the superiority of one option over the others. It will be a hard decision to be made by the patients and the treating physicians about which treatment option to choose. In general, younger patients usually get more benefits from prostatectomy and radiation therapy (Fleming et al, 1993). Although patients treated with prostatectomy reported higher (87%) confidence than patient treated with radiation therapy (73%) that prostate cancer was eliminated (Fowler et al., 1996), there is no evidence that prostatectomy has a better survival rate than the use of radiation (Turini et al., 2003). On the other hand, patients treated with radiation therapy reported high level of satisfaction (81-97%) about their treatment (Jonler, 1994; Nguyen, Pollack, Zagars, 1998).

With all of the reported complications and side effects of each treatment option and their impact on quality of life, Litwin et al. (1998) noticed that patients diagnosed with prostate cancer rated QOL in a different manner than their treating physicians. In another study, Crawford et al., (1997) found that the goals of patients with prostate cancer are completely different from the goals of their treating physician. The most important goal for patients was preserving QOL (45%) followed by extending life (29%) while the goals of their physicians were related to treatment efficacy (86%), followed by side effect (43%) and cost (29%). Albaugh, and Hacker, (2005) suggested that the potential cure from prostate cancer must be weighed with the predicted impact of different treatment options on quality of life. Since each individual is a unique, that individual is the best person to report about his own level of QOL. Therefore, a clear policy should be made that physicians should inform their patients and fully discus with them about all available treatment options, their physical and psychological consequences, and their impact on quality of life. Patients with prostate cancer should be fully aware of potential outcomes of their treatment option and should feel confident about their decision (Albaugh, and Hacker, 2005).

Prostate Cancer Screening Policy

As the Palestinian male population is aging, prevalence of prostate cancer is expected to increase and its cost will have a significant burden on the health care system in the next few decades. In the developed countries, the increased incidence of prostate cancer was linked to the policy of early screening for prostate cancer (American Cancer Society, 2007b and Kvåle et al., 2007). Therefore, Palestinian health policy decision makers need to give attention to early detection of prostate cancer in Palestine.

Early detection through screening for several cancers such as breast and colorectal cancers showed to reduce cancer-related mortality among elderly 65 years and older

(Gorin, Gauthier, Hay, Miles, & Wardle, 2008). As cancer will be diagnosed at earlier stages, survival rates will be improved and morbidity will decrease (Rutten et al., 2004; Albaugh & Hacker, 2005). Rutten et al. (2004) added that screening for many types of cancer may reduce their devastating effects and the complications associated with cancer treatment.

Although there are controversial opinions about prostate cancer screening, several organizations recommend for screening. For example, The American Urological Association, the American Cancer Society, the American College of Radiology, and German Urology Association recommend yearly prostate cancer screening for men over 50 years and have a ten year life expectancy. On the other hand, the Swedish Council on Technology Assessment in Health Care and the National Cancer Institute don't recommend screening as scientific support for large-scale screening is not available (Holmberg, Carlsson, Löfman, & Varenhorst, 1998). The controversy about prostate cancer stems because prostate cancer has a relatively low biological risk and it is difficult to predict whether a newly diagnosed cancer will remain latent and localized or will progress into more advanced stages (Turini et al, 2003). Fourcade et al. (2009) added that the link between PSA screening and improvement in survival rate is less clear than that between prostate cancer incidence and PSA screening and some hypothesized that the increase in survival rate was related to the availability of radiation and hormonal therapies. Nevertheless, Schröder (2008) thinks that introducing a screening policy for prostate cancer in the health care is desirable as it will be effective in decreasing mortality and morbidity related to prostate cancer at an acceptable price in terms of cost and quality of life.

While several authors think that the results of Prostate, Lung, Colorectal and Ovary (PLCO) Cancer Screening Trial in the USA and the European Randomized Screening for Prostate Cancer (ERSPC) trial will provide more information about the impact of PSA screening on mortality and morbidity of prostate cancer (Sommers and Scott, 1999; Gorin et al., 2008), the good news is that some evidence about the efficacy of prostate cancer screening is emerging (Gorin et al., 2008). For example, several studies reported an important reduction of grade and stage of prostate cancer between first and second rounds of screening in several ERSPC centers (Hoedemaeker et al., 2001; Hugosson et al., 2004; Makinen et al., 2004). In a study that involved a control group, Holmberg et al. (1998) reported that the screening group generated more than twice the number of localized prostate cancer than in the non-screening group. The cancers detected in the control group were usually more advanced. Identified cases in the screening group with the potential cure were triple those in the non-screening group. Holmberg et al. concluded that the chance is higher for cure in the screening group and that screening can “be performed at a reasonable cost per detected localized cancer and probably at an acceptable cost per curative treated cancer” (p.146).

To prove their economical conclusion regarding cost effectiveness of prostate cancer screening, Holmberg et al. (1998) had estimated that the total accumulated cost (from time of diagnosis to death) for treating advanced prostate cancer was 294.100 Swedish Koruna, compared with 203.400 for treating localized cases. In a similar study, Senfalt, Sandblom, Carlsson, and Varenhorst (2004) contended that screening for prostate cancer would be probably cost effective if patients with curable cancers gained at least a survival of one year. In another study, Wilson et al. (2007) found that it was costly to treat elderly patients diagnosed with advanced stages of prostate cancer as they would usually need a combination of treatment options including hormonal therapy which was found to be much more expensive than other treatment options. This conclusion enhances the view point that supports screening as it will help to discover prostate cancer before it becomes advanced and therefore, its treatment will be less costly and produce better QOL.

Based upon the previous discussion, adoption of a prostate cancer screening policy is recommended. While the available policy options include the options to screen or not to screen, the option ‘to screen’ is recommended because of the following reasons. First, there are several emerging evidences that screening for prostate cancer helps to discover prostate cancer at early stages which will provide a higher chance for cure and the cost for treating prostate cancer while it is localized will be much cheaper than its cost when it becomes advanced. Unfortunately, there is no data about the number of prostate cancer cases diagnosed at early stages (localized) and at late stages (advanced) in Palestine. But one can read from the treatment modalities presented by Najjar et al. (2002) that many cases were diagnosed with prostate cancer at an advanced stage since 28.6% of prostate cancer patients living in Gaza received chemotherapy and 66.7% received hormonal therapy. The high percentage of using hormonal therapy (either as a monotherapy or adjuvant therapy) and relatively high percentage of using chemotherapy reveals that there were a high percentage of men diagnosed with prostate cancer at advanced stages which are usually non-curable. This is besides the economic burden comes from using such expensive drugs since the yearly cost for hormonal therapy were reported to be the most expensive method for prostate treatment (Wilson et al., (2007).

This recommendation of screening for prostate cancer is not expected to be costly to the ministry of health. The population pyramid in Palestine has a flat bottom and a very narrow top (Figure 5-1). According to the Palestinian Central Bureau of Statistics (2010), the male population falls within the target population for screening (between the ages 50 and 69 years) is expected to be 42,232 men in the year 2010. The cost of screening this relatively small number of male population will be relatively small if compared with the cost burden related to diagnosing several prostate cancer cases in the advanced stages if screening policy is not performed as the use of hormonal therapy which is used along with other treatment options including chemotherapy for advanced prostate cancer is proved to be very expensive. This is besides that if the ministry of health adopts a screening policy, it would be expected that if they require from the donating countries to finance such a program, that the donating courtiers, which show lots of interest in measures targeting health promotion and preventive measure to cover the cost of this program.

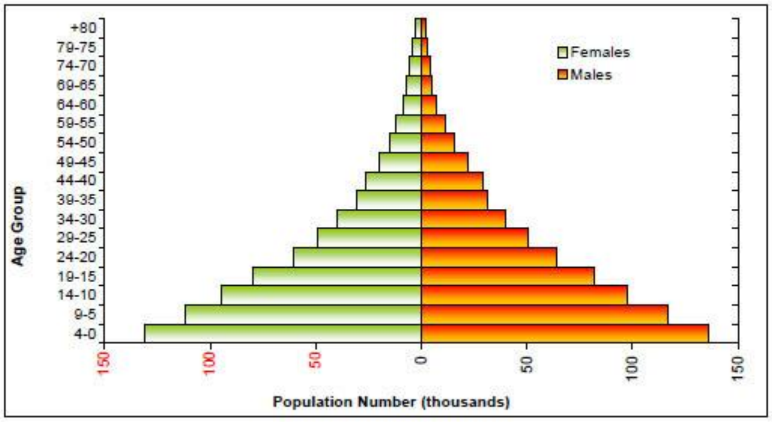


Figure 5-1: Population Pyramid in Gaza. Source, Palestinian Central Bureau of Statistics (2010)

Referral Policy to Increase Radiation Therapy

Although prostatectomy and radiation therapy are the main curative methods used to treat prostate cancer (Turini et al., 2003), the use of radiation therapy to treat men with prostate cancer in Gaza is very rare. According to Najjar et al., (2002), prostatectomy was the most common method used for treating prostate cancer in Gaza Strip. About 62.5% of total prostate cancer patients were treated surgically, 28.6% received chemotherapy, and 66.7% received hormonal therapy. The use of radiation therapy was not included as one of the methods used in treating prostate cancer patients in Gaza Strip. The results of this study support the report of Najjar et al. Only one participant was treated with radiation therapy as a monotherapy. Another 11 participants were treated with radiation therapy as adjuvant therapy. The minimal use of radiation therapy in Gaza is related to the fact that radiation therapy is not available in Gaza Strip and in sometimes, patients are referred to be treated abroad (in Egypt, Israel, or Jordan) to get radiation therapy.

Radiation therapy is used to treat localized prostate cancer and it can be used with other treatment modalities to treat advanced cases. It is used for patients who are expected to live for a long time or who are unfit for surgical procedure and willing to accept treatment-related complications (Fourcade et al., 2009). Although there is no evidence about the superiority of using radiation therapy or prostatectomy to treat localized prostate cancer (Van Erps et al., 1998), patients treated with radiation therapy reported high level of satisfaction (81-97%) about their treatment (Jonler, 1994 and Nguyen, Pollack,and Zagars, 1998). While prostatectomy don’t cause bowel dysfunction as much as radiation (Potosky et al., 2000), Sommers and Ramsey (1999) found that 21 to

36% of patients used radiation therapy reported that they had experienced moderate to major changes in their bowel function. On the other hand, compared to prostatectomy, radiation therapy causes fewer sexual side effects (D'Amico et al., 1997), but it still causes some erectile problems for men (Potosky et al., 2004) and other urinary complications such as urinary incontinence and irritation (Brandeis et al., 2000). On another study by Potosky et al., (2000), patients treated with radiation reported less experience of urinary incontinence (3.5%) than those treated with radical prostatectomy (9.6%), less leakage of urine (2.3% compared to 13.8%), and had less urinary frequency and bother than those treated with radical prostatectomy. Potosky's et al. (2000) study further added that impotence was less common among patients treated with radiation than with prostatectomy (61.5% compared to 79.6%) and sexual bother was less common among younger patients who were 55-59 years old (25.3% compared to 59.4%).

Based upon that, it is recommended that health policy decision makers to reconsider the referral policy for treatment abroad and provide more referrals for prostate cancer patients to be treated with radiation therapy especially for younger patients who would be more concerned about their sexuality and those diagnosed with prostate cancer and unfit for surgery. At the long run, it is recommended to establish a radiation therapy center in Gaza Strip. Such a center will provide radiation treatment not only for prostate cancer patients, but also for patients diagnosed with other cancers. Having such a center will help in decreasing the cost of referring cancer patients to receive radiation therapy abroad as the total cost of treatment abroad consumed about 45.9% of the actual health expenditure in 2004 (Ministry of Health, 2005).

Eliminating Barriers to Health Care

Several barriers to health care were reported in this study by men diagnosed with prostate cancer that were categorized into five major categories; barriers due to unavailability, organizational barriers, geographical barriers, socioeconomic barriers, and barriers related directly to the blockade imposed on Gaza Strip. Under the umbrella of each category, there were several subcategories that had emerged (Figure 4-1). Such barriers may influence negatively the quality of provided care and limit the utilization of health care services by recipients. According to the Health Promotion Model, “situational influences in the external environment can increase or decrease commitment to or participation in health-promoting behavior” (Pender et al., 2002, p. 63-64). Therefore, eliminating barriers to health care in Gaza is expected to increase utilization of health care services which will be reflected on the health-promoting behaviors.

The health policy makers then are required to eliminate these barriers by taking some actions to “control the system, to help solve problems within it or caused by it, or to help obtain benefits from it” (Walker (2000, p. 13). Of course not all reported barriers are removable as there are many barriers that are not directly related to the system but they were imposed on the system. Barriers related directly or indirectly to the effect of blockade are almost non-removable. On the other hand, almost all barriers reported under the concepts of organizational and communication barriers could be eliminated.

For example, workshops can be arranged to train health professionals about how to communicate with patients in general and how to communicate with patients with sensitive diagnosis such as prostate cancer. Especially the literature reported that health care providers are usually not prepared well to communicate with patients diagnosed with cancer especially when communicating the complexities related to cancer care, treatment, and complications to their clients (Mandelblatt et al., 1999). Such workshops also may address the importance of communication and stress the avoidance of using medical jargon while communicating with patients and stress the use of simple terms that are understandable by their clients. Improving health professionals' communication skills is expected to help them to achieve the goals and benefits of communicating with their patients.

Establishing and enforcing a disciplinary policy for those professionals who leave their offices for hours is recommended so that they can abide to their working hours. Long waiting times could be solved by establishing an appointment system so that a certain number of patients will be given appointments for certain dates. Such policy may reduce waiting time and crowdedness at the outpatient oncology clinics.

To resolve the barriers related to unavailability of drugs, equipments, and some diagnostic reagents, MoH is encouraged to be opportunistic and ask for extra supply when the Israelis will allow the entrance of medical supply from the main stores in the West Bank and request donating countries and organizations to supply them with the needed equipment and provide them with a list of needed drugs to bring with when the crossing borders with Egypt will open. Finally, it might be wise at this time that the government exercises its regulatory role and observe and control the prices of drugs and other services provided outside the governmental system.

Findings and the Health Promotion Model

The Health Promotion Model (Pender, et al., 2002) was used as the conceptual framework for this study. The model involves explaining the complex biopsychosocial process and how it motivates humans to practice activities that are directed toward enhancing their health and well-being. According to the revised Health Promotion Model (HPM), there are many factors that are involved in the patient's decision making process about treatment options for prostate cancer which include psychological, socio-cultural, biological factors, environmental factors, other's experience, barriers to health care, as well as prior related behavior that will make the patients think about and evaluate the benefits, obstacles, and complications of the different treatment options which will influence their decisions about making the right choice of the available treatment options.

The results of this study showed that patients who were treated with surgical intervention to treat prostate cancer (prostatectomy) reported higher scores of QOL than those who were treated with hormonal therapy. The experience of others (in this case, the participants of this study), can serve as an impetus for newly diagnosed patients to prefer the surgical intervention (Pender, et al., 2002). Therefore, establishing a health policy that requires treating physicians to fully inform newly diagnosed patients about the advantages and disadvantages of each treatment option is very important in providing these patients with the necessary information before making the decision about the treatment option.

Such information will help newly diagnosed patients to assess the perceived benefits, perceived barriers, and the perceived-self efficacy of each treatment option and how it will affect their quality of life. Keeping in mind that one of the assumptions of the HPM is that “health professionals constitute a part of the interpersonal environment, which exerts influence on persons throughout their lifespan” (p. 63) and that “health care providers are important sources of interpersonal influence that can increase or decrease commitment to and engagement in health-promoting behavior” (p. 64) is a very important aspect that will help in the decision making process. Because the treating physicians know more about the available treatment options, their opinions will be highly appreciated and mostly will be considered by patients in the decision making process.

Other factors that may intervene in their decision making include interpersonal influences and situational influences. In this case, interpersonal influences include the effect of other men who received different treatment modalities and health care professionals. Situational influences include the ability to pursue the chosen treatment modality especially that such a decision is contingent and depends completely on the political situation in the area. For example, if a patient chooses to receive radiation therapy, which is not available in Gaza Strip, and needs a referral to be treated outside Gaza Strip, he may not be able to have such a treatment for several months because of the limited number of referrals made for treatment abroad and the Israeli closure for the borders of Gaza Strip. Even other choices for treatment will be affected by the closure imposed on Gaza Strip since it affects the availability of hormonal and chemotherapy choices and affects the availability of instruments and anesthetic agents that are required for the surgical choice and equipments and chemical reagents that are necessary for the diagnosis of prostate cancer.

Because some patients will not be fit for surgical intervention, it may be wise to manipulate the referral policy to allow those patients to be treated abroad outside Gaza Strip. The referral policy and inability to travel outside Gaza were some of the reported barriers by men in Gaza who have prostate cancer. According to the HPM (Pender, et al., 2006), barriers can constrain commitment to an action plan and will discourage individuals to participate in health promoting activities which in this case may have a negative impact on their QOL. Here comes the importance of the proposed policy focusing on eliminating barriers to health care reported by participants of this study.

Barriers to health care may negatively influence the quality of care provided to men in Gaza Strip diagnosed with prostate cancer and limit their utilization of the available health care services. According to the Health Promotion Model, "situational influences in the external environment can increase or decrease commitment to or participation in health-promoting behavior" (Pender et al., 2002, p. 63-64). Therefore, eliminating barriers to health care in Gaza is expected to increase the utilization of the available health care services which will be reflected on the health-promoting behaviors and the level of QOL.

Since the Health Promotion Model depicts that health promotion involves activities directed toward developing means that enhance or maintain an individual's well-being, individual will adopt behaviors that promote their health (Pender, et al, 2002). Further, the HPM assumes that "persons commit to engaging in behaviors from which they anticipate deriving personally valued benefits (p. 63). Based on that, the proposed policy related to prostate cancer screening will serve to meet the needs of the male population in Gaza Strip to promote their health. Screening is considered one of the primary prevention tools for prostate cancer (Harris & Lohr, 2002) and early detection of cancer through screening was described by Brawer (1995) as the only feasible possibility to reduce cancer-related mortality. Early detection of prostate cancer will help in identify men who are asymptomatic. When the disease is detected at the early stages, treatment will be more effective and complications will be less (Harris & Lohr, 2002; Frankel, Smith, Donovan, & Neal, 2003; American Urological Association, 2009). Rutten et al. (2004) added that screening for many types of cancer may reduce their devastating effects and the complications associated with their treatment. Therefore, these patients are expected to have better diagnosis and better levels of their QOL.

Limitations

Like all other studies, this study has its own limitations. These limitations are discussed in the following paragraphs.

Many studies had addressed the issue of quality of life for cancer patients including quality of life for prostate cancer survivors. As discussed earlier, all of these studies were conducted in developed courtiers and none was found addressing the quality of life for prostate cancer survivors in any developing country including Palestine. Although barriers to health were addressed in several studies, most of these studies had addressed barriers to health care in general. Some had addressed barriers related to socioeconomic status, language, immigrants, and for some categories of patients such as prenatal care, mentally ill, and so. Some studies had addressed barriers to prostate cancer screening, but none had addressed barriers to health care faced by prostate cancer patients. Because Gaza Strip has a unique situation as there is a blockade imposed against it since June 2006, which possibly had affected the results of the study. Therefore, results can't be generalized to patients diagnosed with prostate cancer who live in the West bank, the other part of Palestine, nor to other patients with prostate cancer living in other developing countries.

One of the limitations was that all new prostate cancer cases that were diagnosed after the year of 2007 were not registered by the Palestinian Cancer Registry due to the political chaos that prevails in the region. To identify patients diagnosed with prostate cancer at Shifa Hospital, all medical records available at the oncology department at Shifa Hospital were examined manually to identify those patients. The process was much easier at Gaza European Hospital which has a computerized system that helped in identifying patients diagnosed with prostate cancer in a short time. Such thing took too much time and efforts from the researcher and it could be possible that some prostate cancer patients who were receiving treatment at Shifa Hospital had been missed and were not included in the study.

One of the expected limitations and experienced limitations for this study was identifying participants contact information. Some of the participants had incomplete or no contact information on their medical record. Telephone directory was used in an attempt to find contact information for those participants. For a few patients, it was not possible to find any contact information and therefore they were not included in the study. Even after identifying some participants' addresses, because most of the streets in Gaza Strip has no names and houses have no numbers, so much time and efforts were spent to reach to these participants.

Another limitation of this study was that there was only one participant who used radiation as monotherapy and another 11 participants used radiation therapy along with other treatment modalities. The lack of representation of patients who received radiation therapy did not allow the researcher to compare between QOL of patients receiving different treatment options especially that the literature usually reported more commonly about the QOL of prostate cancer patients receiving radiation therapy and prostatectomy and to a less extent, patients receiving hormonal therapy. Therefore, the results of this study can’t be generalized to patients treated with radiation as a monotherapy.

Finally, the high level of bureaucracy that prevails in the governmental health care system was a major limitation. As a result of that bureaucracy, it was not possible to get information about prostate cancer patients from the Palestinian Cancer Registry, especially those who were diagnosed with prostate cancer before the year of 2007. As a result, the number of participants who were diagnosed with prostate cancer and were not receiving treatment at the time of data collection was under represented. Having an access to a higher number of these patients would definitely add to the quality of the findings produced by this study.

General Recommendations

Several recommendations came from this study. The recommendations made pertain to the following areas: hospital administration, practice, public health policy, and public administration.

Implication for Hospital Administration

The process of identifying patients diagnosed with prostate cancer was much easier at Gaza European Hospital than at Shifa Hospital as they had a computerized system that helped to identify prostate cancer patients by punching the diagnosis of prostate cancer into the system. Within a few seconds, a list of all patients who were treated for prostate cancer was displayed. On the contrary, at Shifa Hospital, they don’t have such a system. To identify patients diagnosed with prostate cancer at Shifa Hospital, all patients’ records that were available at the oncology clinic were examined manually to identify patients who had prostate cancer, which took a lot of time and efforts. Therefore, it is recommended that a computerized system to be established at Shifa Hospital similar to the one available at Gaza European Hospital. Such a system will help in providing appointments for oncology patients which will help in resolving one of the barriers reported by the participants of this study. On the other hand, it will help in future researches as it will help future researchers to identify their clients and will save their times in looking for their contact information. Such thing will encourage researchers to conduct more research in the area of oncology which hopefully will contribute to improving and promoting the health of people living in Gaza Strip and their QOL.

Further, it is recommended that patients to be questioned if they mind to release their names for possible research in the future or not. Providing such information, either in a computerized system or on the current paper work files, will help researchers in identifying their clients who are willing to participate in their studies and relieve any ethical dilemmas of looking at their files without their permissions.

Several participants in this study reported that in several cases it took a long time for them to hear about the results of their diagnoses. Because the diagnosis of cancer leads to feelings of anxiety and fear of the unknown, it will be good that some measures to be taken into consideration by the hospital management to work on decreasing the time between taking the sample from the patient and disclosing the results. This will help to decrease the amount of anxiety experienced by the patient and his family while waiting to hear about the results of the diagnosis.

Implications for Practice

Usually, the diagnosis of cancer leads to stress, anxiety, and feelings of fear of death and fear of the unknown. When a man is diagnosed with prostate cancer, he may experience additional fears and stress about becoming impotent and/or infertile. When a health care provider will tell a patient about his diagnosis, he needs to consider the patient's feelings while communicating with him. He needs to use his communication skills to introduce the diagnosis for the patient and accept the reaction of the patient to the diagnosis. It might be wise to communicate the diagnosis and related treatment to the patient on a step-wise progression. Crightom suggested the following steps when communicating the diagnosis of cancer to the clients (p. 124):

> provide the diagnosis with compassion, allow time for patients to process the meaning, listen to their interpretation of the diagnosis, provide patient-friendly information, give them additional information resources, provide a list of questions they should ask, and instill in them that they are part of the health care team.

To help health care providers to improve their communication skills, it is recommended that some workshops to be organized where some experts in communication guide health care providers involved in the oncology care to improve their communication skills.

Several participants of this study reported that the treating physicians were not competent. This is a general feeling among people in Gaza Strip especially toward young physicians who graduated from Romania and former Soviet Union countries. Therefore, it is recommended that the MoH in Gaza Strip to arrange for continual education programs and provide seminar sessions for these doctors to improve their competency. It is also highly recommended to supply the libraries in the hospitals with recent books and periodicals that pertain to prostate cancer and providing an access to some related electronic data base.

Implications for Public Health Policy

In this research endeavor, the researcher faced many obstacles related to high bureaucracy that prevails in the governmental health care system. An example was inability to get information about prostate cancer patients from the Palestinian Cancer Registry. Presence of high bureaucracy within the system may discourage and impede future research. Therefore, it is recommended that a new approach to be adopted to allow access for researchers to public information. Hopefully, in the near future such data will be available on the internet for public use. Easy accessibility for information or having it available on line will encourage researchers to conduct more studies that meet their interests and the needs of their clients.

The Palestinian Cancer Registry is a health information system that is designated to register all cancer cases in Palestine. There is a branch in Gaza Strip and another branch in West Bank. New cancer cases that were diagnosed after 2007 were not entered into the system. This is due to the political chaos that prevails in the region after the fighting between Hamas and Fateh in May 2007 since the employees who receive their salaries from West Bank were asked not to work in all governmental systems administered by Hamas. It would be highly appreciated if both parties work for the good of the nation and keep their political conflicts away from public organizations. But at the time being, it would be highly recommended to employ new staff by Gaza government so that they can work on entering cases that were discovered earlier and not entered into the system along with new cancer cases that will be discovered in the coming future.

Prostate cancer is one of the most common cancers that affect men. If diagnosed early while at the localized stage, the cure rate is very high. Therefore, it is recommended that health education programs to be established. The target of these programs is to be directed about prevention of prostate cancer and the importance of screening for prostate. This could be accomplished through teaching people about the risk factors for prostate cancers that were addressed in the literature review chapter and how to avoid them. Teaching men living in Gaza Strip about the importance of screening for prostate cancer will encourage men to participate in prostate cancer screening programs.

Diagnosis of cancer by itself leads to several feelings of anxiety and fear of death and the unknown. The diagnosis of prostate cancer adds the fears of becoming impotent or infertile. Therefore, it is recommended that a health club for patients diagnosed with prostate cancer to be established. Usually, patients who had the same diagnosis will provide newly diagnosed patients with the best emotional support. Meeting with other men who had suffered the same diagnosis, treated with same treatment, and suffered from the consequences of treatment options will help those patients to mutually provide support to each other and alleviate their anxiety.

One of the major criticism to the health care system in Palestine mentioned in the literature review chapter was the fragmentation of the health policy process between Gaza Strip and West Bank, and between the governmental health care system, the NGO's, UNRWA, and the private sector. It is highly recommended to unify the health policy process and policy making between Gaza Strip and West Bank and among the four health care providers. Workshops that include the different stakeholders could be arranged to discuss health policy issues and different health polices then can be made that meet the interests of all or most of the interests of the stakeholders.

Implications for Public Administration

One of the challenges for this study was identifying participants' locations. Some of the participants had incomplete or no contact information on their medical record. Therefore, the telephone directory was used to find contact information for those participants. After identifying some participants' addresses, because most of the streets in Gaza Strip have no names and houses have no numbers, the researcher spent so much time and effort to reach to these participants. Therefore, it is recommended for the municipalities of Gaza Strip to give all or at least the major streets names and give numbers to the houses. This will make it easy for future researchers and for the public to identify the needed address and reach it without wasting so much time looking for that address.

When the data collected for this research study, it was collected via personal interview and questionnaires were not mailed to participants at their mailing addresses. Though sending questionnaires to participants through mail could save time, efforts, and money, it was impossible to do so because, as mentioned earlier, most of the streets in Gaza Strip have no names and houses have no numbers. This is besides that there are no postal code areas or postal zip codes. Therefore, it is highly recommended that the municipalities and the post office in Gaza Strip to establish a post code or zip code system. Such a system will benefit all people living in Gaza Strip in mail delivery and will save their time, efforts, and money.

Future Research

This dissertation study was meant to shed further light on barriers to health care and the level of quality of life of prostate cancer men living in Gaza Strip in an attempt to manipulate health policies to improve the quality of provided care to prostate cancer patients and to improve their quality of life. Conducting more related studies would add to the depth of this study. Therefore, the following recommendations were made for future research:

To have more information about barriers to health care and QOL of prostate cancer survivors in Palestine, it is recommended that a new study that involves participants from Gaza Strip and West Bank to be conducted to assess barriers to health care and evaluate QOL. Conducting such a study will provide information to compare barriers to health care and level of QOL reported by participants living in Gaza and participants living in West Bank and it may help to detect if the low scores concerning general QOL (SF-36) reported by participants of this study would be repeated by participants from West Bank, or there were some other factors, such as the impact of the blockade imposed against Gaza Strip since June 2006, that contributed to these low scores. Reported results in both parts of the country will contribute to motivate both health policy makers in Gaza Strip and West Bank to work together on elaborating on new health policies to improve quality of provided care, eliminate barriers to health care, and improve quality of life of prostate cancer survivors.

The design for this study was a cross-sectional design that evaluated quality of life of prostate cancer survivors living in Gaza Strip at a certain point of time (August to December, 2009). Therefore, an important recommendation for future research is to conduct a longitudinal study that evaluates QOL at different time intervals, i.e. before treatment, at 3, 6, 12, and 24 months intervals. Because treatment options will have several long-lasting consequences that will affect quality of life, conducting such a study will provide more in depth information about QOL at different points of time before and after the initiation of treatment and will provide patients with an idea about the lengths of different treatment options, the complications of each option, and their impact on QOL at different time intervals. Having such information will help physicians and patients in their decision making process regarding what type of treatment to choose for their prostate cancer.

Participants in this study had reported several barriers to health care and low scores for the general health QOL domain (SF-36). To explore if these barriers and low scores of SF-36 QOL were unique to prostate cancer survivors living in Gaza Strip, it is recommended to conduct several studies in Gaza and West Bank that involve participants who have other types of cancers. Further, it would be recommended to use the same instrument (SF-36 v2) that was used in this study to evaluate the level of general quality of life.

To build a body of literature about quality of life and barriers to health care for prostate cancer survivors in the developing countries, it is recommended that similar studies to be conducted in other developing countries. Conducting such studies will help to bridge the gap in the literature and hopefully will contribute to improving the QOL of prostate cancer survivors in the developing world.

This research endeavor examined quality of life of prostate cancer survivors using the quantitative approach. It can be noticed from the provided definitions in the literature review section that the concept of QOL has a subjective nature since it reflects one’s individual own feelings toward his/her own life depending upon the unique experiences of each individual (Ferrans, l996). Such a way to look at QOL is definitely applies to survivors of prostate cancer as the whole experience of cancer is very personal. Therefore, it is recommended that quality of life for prostate cancer survivors living in Gaza Strip to be repeated using a qualitative approach. Using a qualitative research method to evaluate QOL of prostate cancer survivors will provide more richness and texture to the findings because its inductive approach emphasizes developing insights out of the data collected (Neuman, 2006).

Summary

Prostate cancer is the second most common cancer among Palestinian males and the second leading cause of cancer-related deaths in Palestine. The incidence of diagnosing new prostate cancer cases is expected to increase as the Palestinian population is aging. The rate of cure of localized prostate cancer is very high. The use of different treatment modalities such as prostatectomy, radiation therapy, and hormonal therapy helped many prostate cancer survivors to live for longer periods of times than they used to live a few decades ago. Managing cancer itself and the consequences of its treatment became of a paramount importance as patients now live longer and have to bear with the burdens of cancer itself and the consequences of its treatment (American Cancer Society, 2007b). Because the use of prostatectomy and radiation in treating localized prostate cancer provide similar curative results, issues related to QOL that accompany each treatment option became more important in the decision making about which treatment option to use.

All available studies in the literature evaluated QOL of prostate cancer survivors were conducted in developed countries and none was conducted in a developing country. Further, no study addressed barriers to health care as perceived by prostate cancer survivors. The purpose for this study was to evaluate the level of QOL and to assess the barriers to health care as perceived by prostate cancer survivors who live in Gaza Strip in an attempt to fill part of the gap in the literature related to QOL of prostate cancer survivors and barriers to health care in the developing countries.

The UCLA-PCI including the RAND 36-Item Health Survey v2 (SF-36 v2) Health-Related Quality of life was used to evaluate the level of QOL for prostate cancer men living in Gaza Strip. Barriers to health care were assessed by using a semi-structured interview. The design for the study used both qualitative and quantitative approaches in data collection. 199 patients were recruited from the two medical centers that provide oncology care in Gaza Strip. 195 agreed to participate in the study with a response rate of 97.98%.

The findings of this study revealed that the scores of the general quality of life (Sf-36 QOL) of prostate cancer men living in Gaza Strip were less than those reported in the literature in all domains of SF-36 for patients treated with prostatectomy and hormonal therapy. The scores of all domains of Prostate-Specific Index fell within the range of scores reported in the literature with the exception of the scores of urinary bother, which was much less than those reported in the literature. Further, participants who were treated with prostatectomy had reported higher scores of PCI QOL (59.47) than who were treated with hormonal therapy (46.22). This difference was proved to be statistically significant (p=0.018). The use of hormonal therapy and prostatectomy were reported to be the most common treatment modalities used for treatment of prostate cancer in Gaza. Although radiation therapy is one of the most common methods used to treat prostate cancer, only one participant reported to be treated by radiation therapy as a monotherapy and 11 participants used radiation as adjuvant therapy.

Participants had reported several barriers to health care. These barriers were categorized under five major categories. These categories included barriers due to unavailability, organizational barriers, geographical barriers, socioeconomic barriers, and barriers related directly to the blockage imposed on Gaza. Under the umbrella of each category, there were several subcategories that had emerged. While lack of continuous drug supply was reported as the most important barrier to health care, most of the reported barriers were directly or indirectly linked to the impact of the blockade imposed against Gaza Strip since June, 2006. In general, most of the barriers reported by participants were compatible with barriers reported in the literature with the exception of those barriers related directly to the impact of the blockade imposed against Gaza Strip.

Because managing the consequences of cancer by itself and treatment-related consequences became more important since patients live longer with the burden of treatment consequences, not understanding or not considering these issues can contribute to poorer recovery, higher level of stress, and disturbances in their QOL. Therefore, this group of patients deserves more attention from health policy decision-makers to improve the quality of their lives and to eliminate barriers to health care which would improve the quality of provided care which might be reflected on their QOL. The suggested health policy areas include:

1. Requesting physicians to inform patients about the pros and cons of different treatment modalities. Since most of treatment options available for localized prostate cancer yield similar results, discussing the pros and cons of each treatment option with prostate cancer patients will help them to choose the option that they think it will give them a better quality of life.

2. Set a plan to introduce a prostate cancer screening policy. Cancer screening contributed to the high incidence reported in the last few decades in the Western Countries. Some emerging evidence shows that discovering prostate cancer at early stages, where it will be curable, will be cost effective and improve QOL.
3. Reconsider the referral policy to increase radiation therapy. Although the use of prostatectomy and radiation therapy is controversial, radiation therapy produces more bowel-related symptoms while producing less urinary and sexual dysfunction symptoms. Increasing the number of referrals for younger patients will preserve their sexual functioning and it will help in treating patients who have localized cancer but are unfit for surgical interventions.
4. Set policies designated to eliminate barriers to health care. Eliminating removable barriers from the health care system will improve the quality of provided care for prostate cancer patients and will contribute to improving their quality of life.

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APPENDICES

APPENDIX A

A PREVIEW ABOUT GAZA STRIP

The territories of the Palestinian National Authority (PNA) (Figure A-1) are comprised of two geographically separated areas known as the West Bank and Gaza Strip. The Gaza Strip is a narrow strip of land that lies along the southeastern coast of the Mediterranean Sea. It is about 41 KM (about 25 miles) long and 6 to 12 KM (4-7.5 miles) in width. The geographical area of the Gaza Strip is estimated at 360 square kilometers (about 139 square miles) (Ministry of Health, 2004) and it consists of 5 governorates: Northern Governorate, Gaza Governorate, Middle Governorate, Khanyounis Governorate, and Rafah Governorate (Figure A-2).

According to the1993 census, the Palestinian population was about 3.7 millions, 36.7 % (1.4 million) of whom lived in about 60% of the Gaza strip (Palestinian Central Bureau of Statistics, 2003). In 2007, the total population of Palestine was 3,761,646. About 37.7% (1,416,539) of them live in Gaza Strip with an average household of 6.5 people per house (Palestinian Central Bureau of Statistics, 2008). In July, 2008, the population of Gaza was estimated to be 1,500,202 (Central Intelligence Agency, 2009).

Figure A-1: Map of West Bank and Gaza Strip.

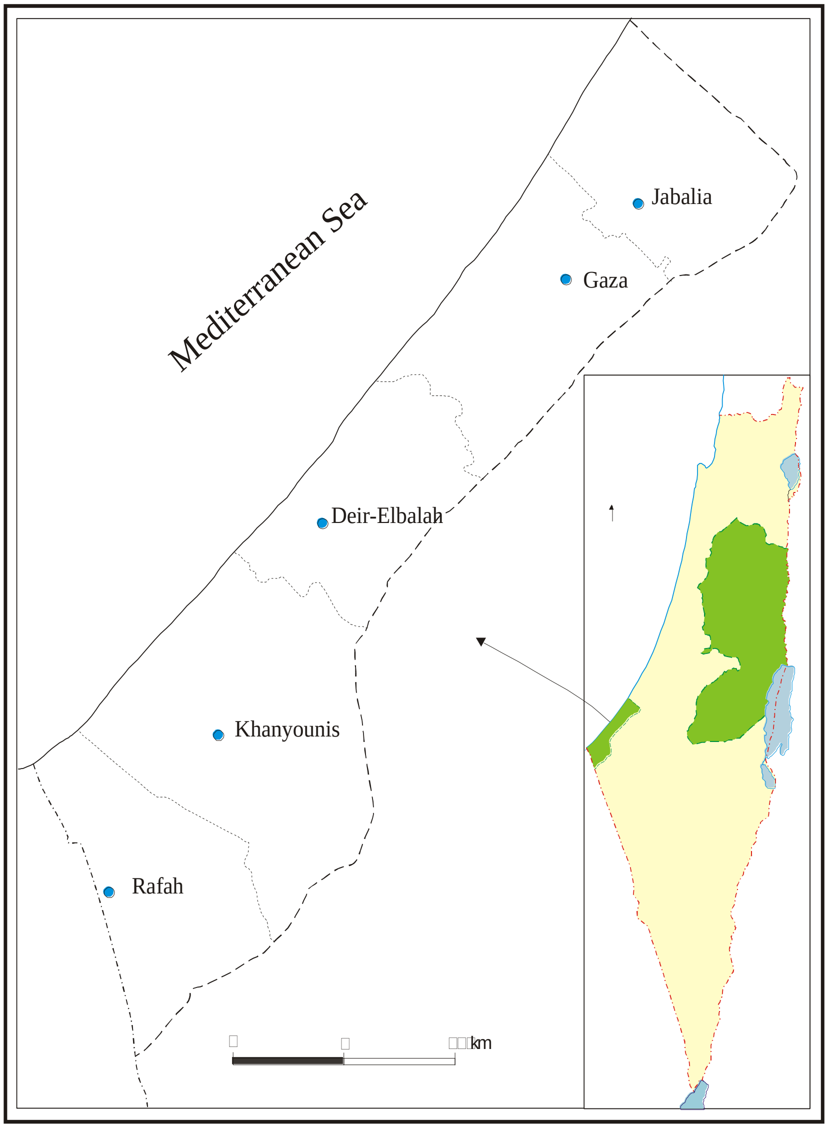


Figure A-2: Map of Governorates of Gaza Strip

Historical Palestine was ruled by Ottoman Turks for about 400 years. After the First World War, the British colonized and administered Palestine. In 1912, the British government issued the Belfour Declaration that promised to establish a homeland for the Jews in Palestine. In 1947, Britain decided to leave Palestine. In November, 1947, the United Nations (UN) adopted a plan calling for partition of Palestine into two states, Israel and Palestine. The Arab states protested that plan as it gave the majority of the Palestinian land to the Jews who were a small minority in Palestine at that time. In 1948, the Jews won the war against the Arab countries and occupied most of Palestinian land (with the exception of West Bank and Gaza Strip) and declared the State of Israel (Palestine History, 2009). In 1967 Israel occupied Gaza Strip and West Bank. Between 1948 and 1967, the West Bank was administered by Jordan, while the Gaza Strip was administered by Egypt. In 1987, the Palestinians demonstrated their rejection for the Israeli occupation for Gaza Strip and West Bank through a series of uprisings (Palestine History, 2009). Between September 1993 and September 1999, Israel with the Palestinian Liberation Organization (PLO) signed several agreements that resulted in interim self-government for Palestinians in Gaza and West Bank populated areas. Israel kept control of most of the Land between the Palestinian cities. The Palestinian National Authority (PNA) became responsible for administering civilian issues such as education, health, and municipality in the Palestinian-populated areas of the West Bank and Gaza (Central Intelligence Agency, 2009). In 2000, President Clinton hosted negotiation between the Palestinian President, Yasser Arafat, and the Israeli Prime Minister, Eyhude Barak, in an attempt to solve the Palestinian- Israeli conflict. After a failure of negotiations and postponement of the proposed date for a permanent status, a second Intifada erupted in September, 2000 and Israel reoccupied most of the Palestinian-controlled areas (Central Intelligence Agency, 2009).

In September 2005, Israel decided to withdraw its military soldiers and settlers from Gaza Strip, but continuing to control over the borders of Gaza Strip. This allowed it to control the entrance of all goods to Gaza including medical supplies. The only way

Palestinians could leave Gaza Strip is through the borders with Egypt which was administered by Palestinians and monitored by Europeans. After the 2006 elections which resulted in the win of the Islamic Resistant Movement (HAMAS) of the Palestinian legislative Council, the international community, led by Israel and the United States, refused to deal with a government lead by HAMAS and economic sanctions and a blockade were imposed against Gaza Strip including the port between Gaza and Egypt. Sanctions and blockage were tightened in June 2006. In June 2007, clashes between HAMAS and FATAH, the other major political group in Palestine, ended with HAMAS taking over all government and military institutions in Gaza (Central Intelligence Agency, 2009).

After that, the Palestinians have two governments, one headed by HAMAS and resided in Gaza, and the other government was appointed by President Abbas and resided in Ramallah at West Bank. As a result, sanctions and blockade against Gaza were severely tightened until Israel started to prevent fuel and electricity to get to Gaza. The port between Gaza and Egypt now is completely blocked. As a result of this blockade, 273 Palestinian died (up to February24th, 2010, 368 patients) because they could not travel abroad for treatment (Ministry of Health, 2009a).

APPENDIX B

QUESTIONNAIRE USED IN THE STUDY (ARABIC VERSION)

جودة الحياة والمعيقات للحصول على الخدمات الصحية لمرضى سرطان البروستاتا في قطاع غزة

السنة	الشهر	اليوم

والدي العزيز/ السلام عليكم و رحمة الله

إن هذا الاستبيان يهدف إلى:
1. التعرف على جودة الحياة لدى مرضى سرطان البروستاتا بشكل عام, و بشكل خاص كيف يؤثر سرطان البروستاتا أو علاجه على جودة حياتهم.
2. تحديد العوائق التي يوجها مرضى سرطان البروستاتا في الحصول على الخدمات الصحية أثناء فترة العلاج.

الرجاء قراءة كل سؤال في هذا الاستبيان بعناية قبل الإجابة عليه. إذا لم تكن متأكدا من الإجابة على أي سؤال, الرجاء اختيار الإجابة التي تعتقد أنها الأقرب لما تشعر به. تذكر انه لا يوجد جواب صحيح أو جواب خاطئ. الرجاء إذا شعرت بأنك تحتاج إلى توضيح أكثر عن أي سؤال, الرجاء سؤال الباحث و بدون تردد.

الباحث من جهته يعد بأن يحافظ على سرية المعلومات التي سوف تدلي بها و ألا يكشف عنها لأي شخص آخر و أنه سيقوم باستخدام هذه المعلومات فقط لغرض البحث. المعومات التي ستعطيها للباحث سيتم إضافتها إلى المعلومات التي سيحصل عليها الباحث من مرضى آخرين, مثل حضرتك, و لن يتم ذكرك بالاسم أنت أو أي شخص آخر مشارك في هذا البحث عند كتابة التقرير النهائي عن نتائج هذا البحث.

بيانات عامة

1. كم تبلغ من العمر اليوم ____________ سنة.

2. ما هو أعلى مستوى بلغته في التعليم؟
1. لم أذهب إلى مدارس   2. دون الابتدائي
3. المرحلة الابتدائية   4. المرحلة الإعدادية

5. المرحلة الثانوية   6. التعليم الجامعي

3. هل تعيش مع زوجتك؟
1. نعم   2. لا

4. أين تسكن؟
1. محافظة الشمال   2. محافظة غزة
3. محافظة الوسطى   4. محافظة خانيونس
5. محافظة رفح

5. هل يوجد عندك تأمين صحي؟
1. نعم   2. لا

6. هل يوجد عندك سرطان آخر بجانب سرطان البروستاتا؟
1. نعم   2. لا

7. إذا كانت إجابة السؤال السابق نعم, أي سرطان تم تشخيصه أولا؟
1. تم تشخيص سرطان البروستاتا أولا.   2. تم تشخيص السرطان الآخر أولا.

8. متى تم تشخيص مرض سرطان البروستاتا عندك؟

9. هل تتلقى أي علاج لسرطان البروستاتا في الوقت الحالي؟
1. نعم   2. لا

10. ما هي وسيلة العلاج التي تلقيتها أو تتلقاها حالياً؟
1. لم يكن هناك أي وسيلة علاج.   2. جراحة لاستئصال البروستاتا.
3. العلاج بالهرمونات   4. العلاج بالإشعاع الذري.
5. العلاج بالكيماوي   6. وسيلة أخرى. الرجاء ذكرها

11. أين تتلقى أو تلقيت العلاج لسرطان البوستاتا؟
1. مستشفى الشفاء   2. المستشفي الأوروبي   3. في الخارج

12. هل تعاني حاليا أو كنت تعاني في أي وقت سابق من أي من الحالات التالية؟

الرجاء اختيار نعم أو لا لكل حالة من الحالات التالية	**نعم**	**لا**
أ. مرض السكري	1	2
ب. ذبحة صدرية أو آلام في الصدر	1	2
ج. جلطة دماغية	1	2
د. بتر أحد الأطراف	1	2
ه. مشاكل في الدورة الدموية في الأرجل أو الأقدام	1	2
و. ربو, امفازيما, أو مشاكل في التنفس	1	2
ز. قرحة في العدة أو اضطرابات في الأمعاء.	1	2
ح. مرض في الكلى	1	2
ط. اكتئاب نفسي	1	2
ي. صرع أو نوبات من التشنج	1	2
ك. تدخن حاليا أو كنت تخن في السابق	1	2

13. الرجاء ان كنت تعاني من أي مرض أو حالة صحية تعتقد أنها تؤثر على جودة حياتك, الرجاء ذكره في الفراغات التالية:

____________________ ____________________

____________________ ____________________

SF-36 استبيان عن الصحّة

الأسئلة التالية تبحث في مدى متابعتك لجودة الصحة و وضعك الصحي بشكل عام:

14. بشكل عام، يمكنك أن تقول أن صحتك :

ممتازة ------------------------ 1 (اختر جواباً واحداً)
جيدة جداً ---------------------- 2
جيدة---------------------------- 3
وسط-------------------------- 4
سيئة -------------------------- 5

15. بالمقارنة مع السنة الماضية ، كيف تُقيِّم صحتك بشكل عام الآن؟
(اختر جواباً واحداً)
الآن، أفضل بكثير من السنة الماضية -----------1
الآن، أفضل إلى حد ما، من السنة الماضية ------ 2
الآن، تقريباً مثل السنة الماضية-------------------3
الآن أسوأ إلى حد ما، من السنة الماضية -------- 4
الآن، أسوأ بكثير من السنة الماضية ------------ 5

16. تُعتبر النشاطات التالية من النشاطات الاعتيادية التي يمكنك القيام بها يوميا . هل تشعر بان صحتك تعيقك عن القيام ببعض هذه النشاطات ؟ في حال نعم، إلى أي مدى ؟ (ضع دائرة حول الرقم المناسب من كل سطر)

النشاطات	**نعم تعيقني كثيراً**	نعم تعيقني قليلاً	لم تعقني أبداً
أ. **نشاطات عنيفة** كالركض، رفع أشياء ثقيلة (حقيبة التي تتطلب جهداً كبيراً. مثلاً)، الرياضة	1	2	3
ب. **نشاطات متوسطة** كتحريك طاولة، دفع مكنسة كهربائية، العمل في الحديقة....	1	2	3
ج. رفع أو حمل كيس الخضار أو البقالة.	1	2	3
د. صعود الدرج : **لعدة طوابق**.	1	2	3
ه. صعود الدرج : **طابق واحد**.	1	2	3
و. الانحناء والركوع.	1	2	3
ز. السير **لمسافة طويلة** (ألف متر فما فوق) .	1	2	3
ح. السير **لمسافة متوسطة** (أقل من ألف متر) .	1	2	3
ط. السير **لمسافة قصيرة** (مائة متر أو أقل) .	1	2	3
ي.الاستحمام أو لبس الثياب.	1	2	3

17. خلال الأسابيع الأربعة الماضية ، هل واجهتك إحدى المشاكل التالية في عملك أو نشاطاتك اليومية كنتيجة لصحتك الجسدية؟

(ضع دائرة حول الرقم المناسب من كل سطر)

المشاكل	**كل الوقت**	**معظم الوقت**	**جزءاً كبيراً من الوقت**	**بعض الوقت**	**قليلاً من الوقت**
أ. أنقصتَ من **كمية الوقت** الذي أمضيته في العمل أو النشاطات الأخرى.	1	2	3	4	5
ب. أنهيتَ **أقل مما كنت تود** أن تنهيه.	1	2	3	4	5
ج. كنتَ **مقيداً من حيث نوع العمل** أو النشاطات الأخرى.	1	2	3	4	5
د. واجهتَ **صعوبة في القيام بالعمل** أو النشاطات الأخرى (بذلت جهداً إضافياً مثلاً).	1	2	3	4	5

18. خلال الأسابيع الأربعة الماضية ، هل واجهتك إحدى المشاكل التالية في عملك أو نشاطاتك اليومية كنتيجة لحالتك النفسية (كالشعور بالإحباط أو القلق) ؟

(ضع دائرة حول الرقم المناسب من كل سطر)

المشاكل	**كل الوقت**	**معظم الوقت**	**جزءاً كبيراً من الوقت**	**بعض الوقت**	**قليلاً من الوقت**
أ. أنقصتَ من **كمية الوقت** الذي أمضيته في العمل أو النشاطات الأخرى.	1	2	3	4	5
ب. أنهيتَ **أقل مما كنت تود** أن تنهيه.	1	2	3	4	5
ج. **أهملتَ** في إنجاز بعض الأعمال أو النشاطات الأخرى.	1	2	3	4	5

19. خلال الأسابيع الأربعة الماضية، إلى أي مدى أثرت حالتك الصحية والنفسية على علاقاتك الاجتماعية تجاه عائلتك، أصدقائك، جيرانك أو الجماعات الأخرى ؟

أبداً ------------------------------ 1 (اختر جواباً واحداً)
قليلاً ------------------------------ 2
باعتدال ---------------------------- 3
كثيراً ------------------------------- 4
كثيراً جداً -------------------------- 5

20. ما هو مقدار الألم الجسدي الذي عانيت منه خلال الأسابيع الأربعة الماضية؟

لا شيء ------------------------- 1 (اختر جواباً واحداً)
قليل جداً ------------------------- 2
قليل ----------------------------- 3
وسط ------------------------------ 4
حاد --------------------------------5
حاد جداً ---------------------------- 6

21. خلال الأسابيع الأربعة الماضية ،إلى أي مدى
تعارضت آلامك الجسدية مع طبيعة عملك اليومي (المهني أو المنزلي) ؟

أبداً ---------------------------- 1 (اختر جواباً واحداً)
قليلاً -------------------------- 2
بشكل معتدل -------------------- 3
كثيراً --------------------------- 4
كثيراً جداً ----------------------- 5

22. الأسئلة التالية تدور حول طبيعة شعورك خلال الأسابيع الأربعة الأخيرة. الرجاء إعطاء الجواب الأقرب لما شعرت به . كم من الوقت خلال الأسابيع الأربعة الماضية:

(ضع دائرة حول الرقم المناسب من كل سطر)

	كل الوقت	**معظم الوقت**	**جزءاً كبيراً من الوقت**	**بعض الوقت**	**قليلاً من الوقت**	**أبداً**
أ. شعرتَ أنك **مليء بالحيوية**؟.	1	2	3	4	5	6
ب. كنتَ شخصاً **عصبياً** جداً؟ .	1	2	3	4	5	6
ج. شعرتَ بالكآبة لدرجة أن لا شيء يمكن أن يفرحك؟.	1	2	3	4	5	6
د. كنتَ **هادئاً وصبوراً**؟ .	1	2	3	4	5	6
ه. كنتَ **نشيطاً**؟ .	1	2	3	4	5	6
و. شعرتَ أنك **حزين**؟.	1	2	3	4	5	6
ز . شعرتَ أنك **مرهق**؟.	1	2	3	4	5	6
ح . شعرتَ أنك **سعيد**؟.	1	2	3	4	5	6
ط . شعرتَ أنك **متعب**؟.	1	2	3	4	5	6

23. خلال الأسابيع الأربعة الماضية، كم من الوقت تعارضت حالتك الصحية أو النفسية مع نشاطاتك الاجتماعية (زيارة الأهل، الأصدقاء، الجيران أو الجماعات الأخرى)؟

(اختر جواباً واحداً)

كل الوقت -------------------------------- 1
معظم الوقت ------------------------------2
بعض الوقت ------------------------------ 3
قليلاً من الوقت ---------------------------- 4
أبداً ------------------------------------5

24. إلى أي مدى تُعتبر الجمل التالية صحيحة أو خاطئة بالنسبة إليك؟

(ضع دائرة حول الرقم المناسب من كل سطر)

	صحيحة بالتأكيد	**صحيحة غالبـاً**	**لا أعلم**	**خاطئة غالبـاً**	**خاطئة بالتأكيد**
أ. يظهر أني أمرض بسهولة أكثر من الناس الآخرين .	1	2	3	4	5
ب. أنا سليم كأي شخص أعرفه .	1	2	3	4	5
ج. أتوقع أن تسوء حالتي الصحية .	1	2	3	4	5
د. صحتي ممتازة .	1	2	3	4	5

عمل الجهاز البولي و التحكم في عملية التبول

هذا الجزء يتعلق بالجهاز البولي و قدرتك في التحكم بعملية التبول. الرجاء أن تضع في اعتبارك وضعك في الأربع أسابيع الأخيرة عند الإجابة على الأسئلة التالية:

25. في الأربع أسابيع الأخيرة, كان البول يرشح إلى ملابسك الداخلية تقريباً

بشكل يومي .... 1 (الرجاء اختار إجابة واحدة فقط)
حوالي مرة واحدة في الأسبوع 2
أقل من مرة واحدة في الأسبوع 3
لا يرشح مني البول أبداً 4

26. أي من العبارات التالية تصف بشكل أفضل قدرتك على التحكم في عملية التبول في الأسابيع الأربع الأخيرة؟

لا أستطيع التحكم بعملية التبول إطلاقا............ 1 (الرجاء اختار إجابة واحدة فقط)
يوجد تنقيط للبول بشكل متكرر 2
يوجد تنقيط للبول بشكل بسيط 3
أتحكم بعملية التبول بشكل تام 4

27. في الأسابيع الأربع الأخيرة, كم عدد الفوَط (قطع قماش أو مناديل ورقية) التي تستخدمها يومياً لتحافظ علي نظافة ملبسك من البول الذي يرشح منك؟

أستخدم 3 فوَط أو أكثر يومياً ....1 (الرجاء اختار إجابة واحدة فقط)
أستخدم فوَطة واحة أو اثنتين يوميا 2
لا أستخدم فوَط أبداً 3

28. إلى أي مدى تشكل لك كل من المسائل التالي ذكرها مشكلة؟

(الرجاء اختار إجابة واحدة فقط من كل سطر)	لا تشكل أي مشكلة	مشكلة بسيطة جداً	مشكلة بسيطة	مشكلة متوسطة	مشكلة كبيرة
أ. تنقيط البول أو بلل ملابسك؟	**0**	**1**	**2**	**3**	**4**
ب. رشح أو تنقيط البول يؤثر على حياتيك الجنسية؟	**0**	**1**	**2**	**3**	**4**

29. بشكل عام, إلى أي مدي شكلت عملية عدم التحكم في التبول مشكلة بالنسبة لك في الأربع أسابيع الماضية؟

(الرجاء اختار إجابة واحدة فقط)

لا تمثل أي مشكلة 1
مشكلة بسيطة جداً.............................2
مشكلة بسيطة 3
مشكلة متوسطة 4
مشكلة كبيرة 5

القدرة على التحكم في عملية التبرز

هذا الجزء يتعلق بعملية التبرز وآلام البطن. الرجاء أن تضع في اعتبارك وضعك في الأربع أسابيع الأخيرة عند الإجابة على الأسئلة التالية:

30. في الأسابيع الأربع الأخيرة, كم مرة غالبا شعرت بالحاجة الشديدة للتبرز و لكنك لا تستطيع التبرز عند ذهابك إلى الحمام؟

(الرجاء اختار إجابة واحدة فقط)

أكثر من مرة واحدة في اليوم 1
حوالي مرة واحدة في اليوم 2
أكثر من مرة واحدة في الأسبوع 3
حوالي مرة واحدة في الأسبوع 4
نادراً أو لم يحصل أبداً 5

31. في الأسابيع الأربع الأخيرة, كم مرة أخرجت برازاً على شكل إسهال؟

(الرجاء اختار إجابة واحدة فقط)

أبداً 1
نادراً 2
تقريباً في حوالي نصف عدد المرات 3
في معظم الأوقات 4
دائما 5

32. ما هو مدى التعب النفسي (المعاناة النفسية) الذي سببته لك عملية التبرز على مدى الأسابيع الأربع الأخيرة؟

معاناة شديدة ....1 (الرجاء اختار إجابة واحدة فقط)
معاناة متوسطة 2
معاناة قليلة 4
لم يسبب أي معاناة 5

33. كم مرة أصابك مغص أو ألم في البطن أو منطقة الحوض في الأسابيع الأربع الأخيرة؟

عدة مرات في اليوم الواحد............................1
حوالي مرة واحدة في اليوم 2
عدة مرات في الأسبوع................................3
حوالي مرة واحدة في الأسبوع 4
حوالي مرة واحدة في الشهر 5
نادراً أو لم يحدث أبداً 6

34. بشكل عام, إلى أي مدي مثل عدم التحكم في عملية التبرز مشكلة بالنسبة لك في الأربع أسابيع الماضية؟

مشكلة كبيرة.................................. 1 (الرجاء اختار إجابة واحدة فقط)
مشكلة متوسطة................................2
مشكلة بسيطة 3
مشكلة بسيطة جداً.............................4
لم تمثل أي مشكلة............................. 5

القدرة على الممارسة الجنسية (المعاشرة الزوجية)

35. في الأسابيع الأربع الأخيرة, كيف تقيم كل من المسائل التالية؟

(الرجاء اختار إجابة واحدة فقط من كل سطر)	ضعيف جداً	ضعيف	متوسط	جيد	جيد جداً
أ. الرغبة عندك لممارسة الجنس (الجماع/المعاشرة الزوجية)	**1**	**2**	**3**	**4**	**5**
ب. قدرة عضوك الذكري على الانتصاب؟	**1**	**2**	**3**	**4**	**5**
ج. القدرة عندك للوصول إلى ذروة النشوى الجنسية و القذف؟	**1**	**2**	**3**	**4**	**5**

36. كيف يمكنك أن تصف جودة انتصاب عضوك الذكري؟

لا يوجد انتصاب أبدا ....1 (الرجاء اختار إجابة واحدة فقط)
انتصاب خفيف و لكن لا يجدي للقيام بممارسة الجنس 2
انتصاب جيد و لكن غير كافي للقيام بممارسة الجنس 3
انتصاب جيد و كافي للقيام بممارسة الجنس 4

37. كيف يمكنك أن تصف عدد المرات التي ينتصب بها عضوك الذكري؟

لا تتم عملية الانتصاب أبداً عندما أريد ذلك؟ ....1 (الرجاء اختار إجابة واحدة فقط)
تتم عملية الانتصاب بمعدل أقل من النصف عندما أريد ذلك 2
تتم عملية الانتصاب بمعدل النصف عندما أريد ذلك 3
تتم عملية الانتصاب بمعدل أكثر من النصف عندما أريد ذلك 4
تتم عملية الانتصاب في أي وقت أريد ذلك 5

38. هل يحدث و أن تستيقظ في الصباح أو أثناء النوم و يكون عضوك الذكري في حالة انتصاب؟

لا يحدث ذلك أبداً ....1 (الرجاء اختار إجابة واحدة فقط)
يحدث و لكن بشكل نادر (أقل من 25% من الوقت) 2
يحدث و لكن بشكل متوسط (أقل من نصف الوقت) 3
يحدث و بشكل متكرر(أكثر من نصف الوقت) 4
يحدث و بشكل دائم (أكثر من 75% من الوقت) 5

39. في الأسابيع الأربع الأخيرة, هل (قمت بالمعاشرة الزوجية) مارست الجنس؟

لا ....1 (الرجاء اختار إجابة واحدة فقط)
نعم, و لكن لمرة واحدة فقط 2
نعم, و لأكثر من مرة...........................3

40. في الأسابيع الأربع الأخيرة, كيف تقيم مقدرتك على ممارسة الجنس (الجماع/المعاشرة الزوجية)

ضعيفة جداً ....1 (الرجاء اختار إجابة واحدة فقط)
ضعيفة 2
متوسطة 3
جيدة 4
جيدة جداً 5

41. بشكل عام, إلى أي مدي يمثل لك موضوع القدرة على الممارسة الجنسية (الجماع/المعاشرة الزوجية) مشكلة في الأسابيع الأربع الأخيرة؟

(الرجاء اختار إجابة واحدة فقط)

لا يمثل أي مشكلة 1
يمثل مشكلة بسيطة جداً 2
يمثل مشكلة بسيطة 3
يمثل مشكلة متوسطة 4
يمثل مشكلة كبيرة 5

العوائق في طريق الحصول على خدمات صحية

42. بعد تشخيص مرضك, ما هي العوائق التي واجهتها في الحصول على الخدمات الصحية؟

. أرجوك أخبرني عن الحواجز على الرعاية الصحية التي تواجه لكم بعد تشخيص سرطان البروستاتا

ملاحظات

شكرا جزيلا لتعاونكم و بارك الله فيكم

APPENDIX C

QUESTIONNAIRE USED IN THE STUDY (ENGLISH VERSION)

UCLA PROSTATE CANCER INDEX
(UCLA-PCI),
including the
RAND 36-Item Health Survey v2
(SF-36 v2)

Today's Date: ☐ ☐ ☐

Month Day Year

The purpose of this questionnaire is to find out about your health in general and about how your prostate cancer and any treatment you received for it affects your quality of life.

Please read each question carefully before answering. If you are unsure about how to answer a question, please give the best answer you can. Remember that there are no right or wrong answers. If you have any questions or if you needed further clarifications, please feel free to ask the interviewer.

Your answers to this questionnaire will be kept confidential and will be used only for research purposes. The information you give will be combined with the responses of other patients completing this questionnaire, and you will not be identifiable in any way.

General information

I. Demographic Data:

1. **What is your age today? ________________** Years.

2. **What is your highest level of education?**
   1. No education 2. Some education below primary school
   3. Primary school 4. Secondary school
   5. High school 6. Higher education

3. **Do you live with your wife?**
   1. Yes 2. No

4. **Where do you live?**
   1. Northern Governorate 2. Gaza Governorate
   2. Mid-zone Governorate 4. Khanyounis Governorate
   5. Rafah Governorate

5. **Do you have a health insurance?**
   1. Yes 2. No

6. **Do you have other cancers beside prostate cancer?**
   1. Yes 2. No

7. **If the answer for the previous question was yes, which cancer was diagnosed first?**
   1. Prostate cancer 2. The other cancer.

8. **When your prostate cancer was diagnosed?**

   ____

9. **Do you receive any treatment for your prostate cancer at the current time?**
   1. Yes 2. No
   2.

10. **Which treatment you are receiving now or had received in the past for your prostate cancer?**
    1. I received no treatment. 2. Prostatectomy.
    3. Hormonal therapy. 4. Radiation therapy.
    5. Chemotherapy. 6. Others, describe ______________.

11. **Where do/did receive your treatment?**
    1. Shifa Hospital 2. Gaza European Hospital
    3. Abroad 4. Others _______________.

II. Health-Related data:

12. Have you ever had any of the following medical conditions?

	Please circle YES or NO for each item	YES	NO
a)	Diabetes	**1**	**2**
b)	Heart attack, chest pain	**1**	**2**
c)	Stroke	**1**	**2**
d)	Amputation	**1**	**2**
e)	Circulation problems in your legs or feet	**1**	**2**
f)	Asthma, emphysema, breathing problems	**1**	**2**
g)	Stomach ulcer, irritable bowel	**1**	**2**
h)	Kidney disease	**1**	**2**
i)	Major depression	**1**	**2**
j)	Seizer	**1**	**2**
k)	Current or past cigarette smoker	**1**	**2**

13. Please, if you have any other chronic diseases or health condition that you think it affect your quality of life, list them bellow:

__________________________ __________________________

__________________________ __________________________

General Quality of Life (SF-36 v2)

These first questions are about your health in general, BOTH RELATED and UNRELATED to your prostate cancer. Please give the best answer you can and remember there are no right or wrong answers.

14. In general, would you say your health is:

Excellent ....1 (Circle one number.)
Very Good..2
Good...3
Fair...4
Poor 5

15. COMPARED TO ONE YEAR AGO, how would you rate your health in general now?

Much better now than one year ago ....1 (Circle one number.)
Somewhat better now than one year ago 2
About the same as one year ago 3
Somewhat worse now than one year ago.....................4
Much worse now than one year ago.............................5

16. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities?

(Circle 1, 2, or 3 on each line.)	**Yes, limited a lot**	**Yes, limited a little**	**No, not limited at all**
a. **Vigorous activities**, such as running, lifting heavy objects, participating in strenuous sports……..	**1**	**2**	**3**
b. **Moderate activities**, such as moving a table, pushing a vacuum cleaner, gardening……………...	**1**	**2**	**3**
c. Lifting or carrying groceries………………………..	**1**	**2**	**3**
d. Climbing **several** flights of stairs……………………	**1**	**2**	**3**
e. Climbing **one** flight of stairs………………………...	**1**	**2**	**3**
f. Bending, kneeling, or stooping……………………...	**1**	**2**	**3**
g. Walking for long distance (**more than a Kilometer)**	**1**	**2**	**3**
h. Walking for **several hundred meters**……………..	**1**	**2**	**3**
i. Walking **one hundred meters**……………………..	**1**	**2**	**3**
j. Bathing or dressing yourself………………………...	**1**	**2**	**3**

17. During the PAST FOUR WEEKS, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

(Circle one number on each line.)	**All of the time**	**Most of the time**	**Some of the time**	**A little of the time**	**None of the time**
a. Cut down on the **amount of time** you spent on work or other activities	**1**	**2**	**3**	**4**	**5**
b. **Accomplished less** than you would like	**1**	**2**	**3**	**4**	**5**
c. Were limited in the **kind** of work or other activities	**1**	**2**	**3**	**4**	**5**
d. Had **difficulty** performing the work or other activities (for example, it took extra effort)	**1**	**2**	**3**	**4**	**5**

18. During the PAST FOUR WEEKS, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

(Circle one number on each line.)	**All of the time**	**Most of the time**	**Some of the time**	**A little of the time**	**None of the time**
a. Cut down on the **amount of time** you spent on work or other activities	**1**	**2**	**3**	**4**	**5**
b. **Accomplished less** than you would like	**1**	**2**	**3**	**4**	**5**
c. Did work or other activities **less carefully than usual**	**1**	**2**	**3**	**4**	**5**

19. During the PAST FOUR WEEKS, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

Not at all..1 (circle one number.)
Slightly 2
Moderately...3
Quite a bit...4
Extremely...5

20. How much BODILY pain have you had during the PAST FOUR WEEKS?

None ....1 (circle one number.)
Very mild...2
Mild 3
Moderate 4
Severe 5
Very severe 6

21. During the PAST FOUR WEEKS, how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all..1 (Circle one number.)
A little bit 2
Moderately..3
Quite a bit..4
Extremely..5

22. These questions are about how you feel and how things have been with you during the PAST FOUR WEEKS. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the PAST FOUR WEEKS...

(Circle one number on each line.)	**All of the time**	**Most of the time**	**Some of the time**	**A little of the time**	**None of the time**
a. Did you feel full of life?	**1**	**2**	**3**	**4**	**5**
b. Have you been very nervous?	**1**	**2**	**3**	**4**	**5**
c. Have you felt so down in the dumps that nothing could cheer you up?	**1**	**2**	**3**	**4**	**5**
d. Have you felt calm and peaceful?	**1**	**2**	**3**	**4**	**5**
e. Did you have a lot of energy?	**1**	**2**	**3**	**4**	**5**
f. Have you felt downhearted and depressed?	**1**	**2**	**3**	**4**	**5**
g. Did you feel worn out?	**1**	**2**	**3**	**4**	**5**
h. Have you been happy?	**1**	**2**	**3**	**4**	**5**
i. Did you feel tired?	**1**	**2**	**3**	**4**	**5**

23. During the PAST FOUR WEEKS, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

All of the time...1 (Circle one number.)
Most of the time 2
Some of the time 3
A little of the time 4
None of the time.....................................5

24. How TRUE or FALSE is each of the following statements for you?

(Circle one number on each line.)	**Definitely true**	**Mostly true**	**Don’t know**	**Mostly false**	**Definitely false**
a. I seem to get sick a little easier than other people	**1**	**2**	**3**	**4**	**5**
b. I am as healthy as anyone I know	**1**	**2**	**3**	**4**	**5**
c. I expect my health to get worse	**1**	**2**	**3**	**4**	**5**
d. My health is excellent	**1**	**2**	**3**	**4**	**5**

Please continue on next page.

URINARY FUNCTION

This section is about your urinary habits. Please consider ONLY THE LAST 4 WEEKS.

25. Over the LAST 4 WEEKS, how often have you leaked urine?

Every day..	1	(Circle one number.)
About once a week...........................	2	
Less than once a week.....................	3	
Not at all..	4	

26. Which of the following best describes your urinary control during the LAST 4 WEEKS?

No control whatsoever....................	1	(Circle one number.)
Frequent dribbling	2	
Occasional dribbling	3	
Total control	4	

27. How many pads or adult diapers per day did you usually use to control leakage during the LAST 4 WEEKS?

3 or more pads per day....................	1	(Circle one number.)
1-2 pads per day...............................	2	
No pads...	3	

28. How big a problem, if any, has each of the following been for you?

(Circle one number on each line.)	No Problem	Very small problem	Small Problem	Moderate Problem	Big Problem
a. Dripping urine or wetting your pants?	**0**	**1**	**2**	**3**	**4**
b. Urine leakage interfering with your sexual activity?	**0**	**1**	**2**	**3**	**4**

29. Overall, how big a problem has your urinary function been for you during the LAST 4 WEEKS?

No problem...................................... 1 (Circle one number.)
Very small problem......................... 2
Small problem.................................. 3
Moderate problem............................ 4
Big problem 5

BOWEL ELIMINATION

This section is about your bowel habits and abdominal pain. Please consider ONLY THE LAST 4 WEEKS.

30. How often have you had rectal urgency (felt like you had to pass stool, but did not) during the LAST 4 WEEKS?

More than once a day .... 1 (Circle one number.)
About once a day.............................. 2
More than once a week 3
About once a week........................... 4
Rarely or never 5

31. How often have you had stools (bowel movements) that were loose or liquid (no form, watery, mushy) during the LAST 4 WEEKS?

Never .... 1 (Circle one number.)
Rarely 2
About half the time 3
Usually.. 4
Always 5

32. How much distress have your bowel movements caused you during the LAST 4 WEEKS?

Severe distress................................. 1 (Circle one number.)
Moderate distress............................ 2
A little distress 3
No distress 4

33. How often have you had crampy pain in your abdomen or pelvis during the LAST 4 WEEKS?

Several times a day .... 1 (Circle one number.)
About once a day.............................. 2
Several times a week....................... 3
About once a week........................... 4
About once this month.................... 5
Rarely or never 6

34. Overall, how big a problem have your bowel habits been for you during the

Big problem .... 1 (Circle one number.)
Moderate problem........................... 2
Small problem.................................. 3
Very small problem......................... 4
No problem...................................... 5

Please continue to next page

SEXTUAL FUNCTION

35. How would you rate each of the following during the LAST 4 WEEKS?

(Circle one number on each line.)	Very Poor	Poor	Fair	Good	Very Good
a. Your level of sexual desire?	**1**	**2**	**3**	**4**	**5**
b. Your ability to have an erection?	**1**	**2**	**3**	**4**	**5**
c. Your ability to reach orgasm (climax)?	**1**	**2**	**3**	**4**	**5**

36. How would you describe the usual QUALITY of your erections?

None at all.. 1 (Circle one number.)
Not firm enough for any sexual activity.................. 2
Firm enough but can’t have intercourse ……......... 3
Firm enough for intercourse..................................... 4

37. How would you describe the FREQUENCY of your erections?

I NEVER had an erection when I wanted one..........................1(Circle one number)
I had an erection LESS THAN HALF the time I wanted one...2
I had an erection ABOUT HALF the time I wanted one............3
I had an erection MORE THAN HALF the time I wanted one ..4
I had an erection WHENEVER I wanted one...............................5

38. How often have you awakened in the morning or night with an erection?

Never... 1 (Circle one umber.)
Seldom (less than 25% of the time).................................... 2
Not often (less than half the time) 3
Often (more than half the time)... 4
Very often (more than 75% of the time) 5

39. During the LAST 4 WEEKS did you have a sextual intercourse?

No ....1 (Circle one number.)
Yes, once..2
Yes, more than once..........................3

40. Overall, how would you rate your ability to function sexually during the LAST 4 WEEKS?

Very poor.. 1 (Circle one number.)
Poor.. 2
Fair 3
Good... 4
Very good 5

41. Overall, how big a problem has your sexual function been for you during the LAST 4 WEEKS?

No problem....................................... 1 (Circle one number.)
Very small problem 2
Small problem................................... 3
Moderate problem 4
Big problem...................................... 5

Barriers to Health Care

42. Please tell me about the barriers to health care you faced after being diagnosed with prostate cancer.

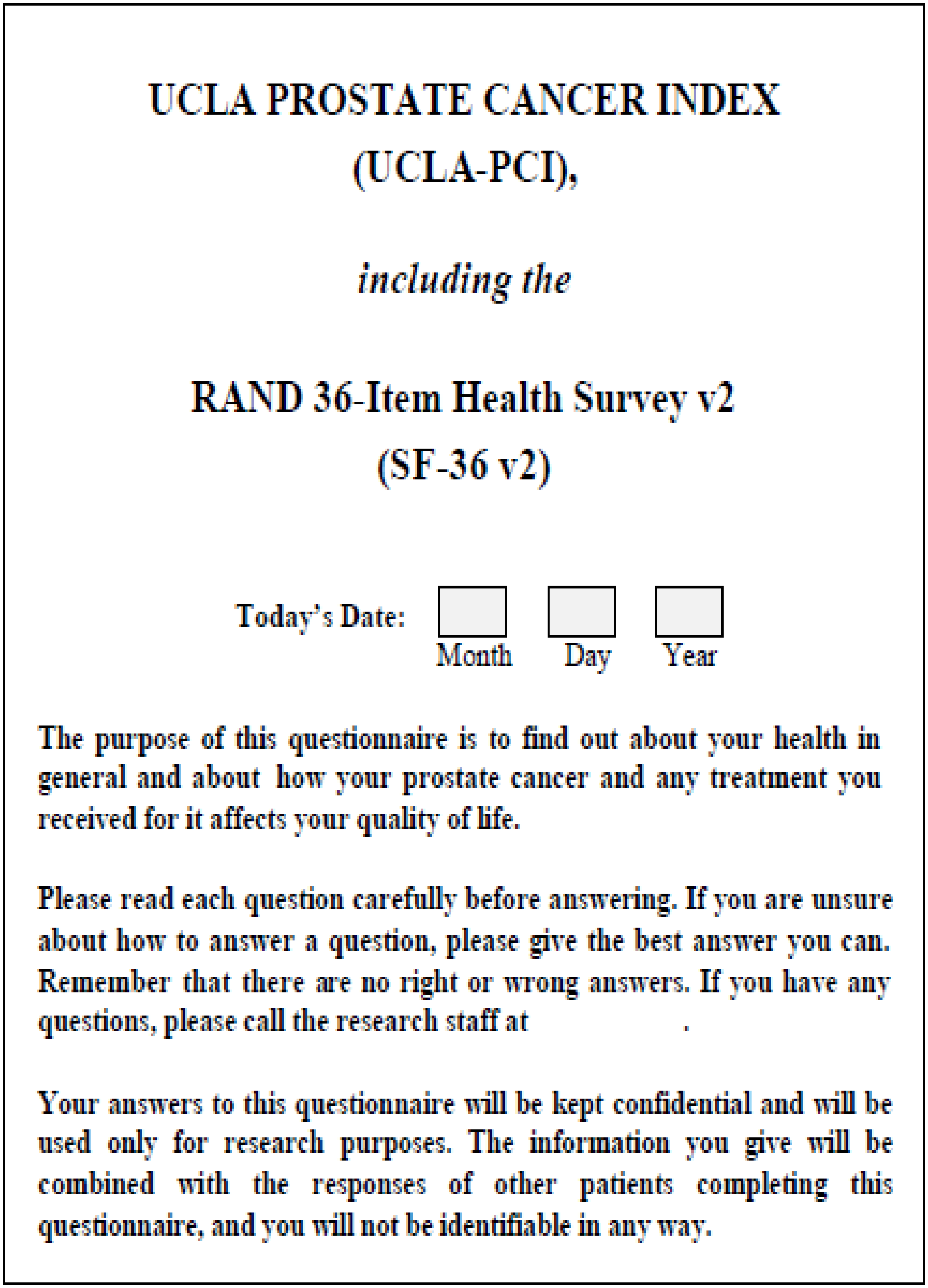
Comments:

Thank you very much for your time! Please remember to mail your completed questionnaire in the supplied envelope.

APPENDIX D

UCLA-PCI, INCLUDING THE RAND 36-ITEM HEALTH SURVEY V2 (SF-36 V2)

HEALTH-RELATED QUALITY OF LIFE



UCLA PROSTATE CANCER INDEX
(UCLA-PCI),

including the

RAND 36-Item Health Survey v2
(SF-36 v2)

Today's Date:	☐	☐	☐
	Month	Day	Year

The purpose of this questionnaire is to find out about your health in general and about how your prostate cancer and any treatment you received for it affects your quality of life.

Please read each question carefully before answering. If you are unsure about how to answer a question, please give the best answer you can. Remember that there are no right or wrong answers. If you have any questions, please call the research staff at .

Your answers to this questionnaire will be kept confidential and will be used only for research purposes. The information you give will be combined with the responses of other patients completing this questionnaire, and you will not be identifiable in any way.

Page 1

These first questions are about your <u>health in general</u>, BOTH RELATED and UNRELATED to your prostate cancer. We recognize that other diseases you may have in addition to your prostate cancer may affect your answers. Please give the best answer you can and remember there are no right or wrong answers.

1. In general, would you say your health is:

Excellent	1	(Circle one number.)
Very Good	2	
Good	3	
Fair	4	
Poor	5	

2. COMPARED TO ONE YEAR AGO, how would you rate your health in general now?

Much better now than one year ago	1	(Circle one number.)
Somewhat better now than one year ago	2	
About the same as one year ago	3	
Somewhat worse now than one year ago	4	
Much worse now than one year ago	5	

3. The following questions are about activities you might do during a typical day. <u>Does your health now limit you</u> in these activities? If so, how much?

(Circle 1, 2, or 3 on each line.)	**Yes, limited a lot**	**Yes, limited a little**	**No, not limited at all**
a. **Vigorous activities**, such as running, lifting heavy objects, participating in strenuous sports	1	2	3
b. **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3
c. Lifting or carrying groceries	1	2	3
d. Climbing **several** flights of stairs	1	2	3
e. Climbing **one** flight of stairs	1	2	3
f. Bending, kneeling, or stooping	1	2	3
g. Walking **more than a mile**	1	2	3
h. Walking **several hundred yards**	1	2	3
i. Walking **one hundred yards**	1	2	3
j. Bathing or dressing yourself	1	2	3

4. During the PAST FOUR WEEKS, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

(Circle one number on each line.)	**All of the time**	**Most of the time**	**Some of the time**	**A little of the time**	**None of the time**
a. Cut down on the amount of time you spent on work or other activities	1	2	3	4	5
b. Accomplished less than you would like	1	2	3	4	5
c. Were limited in the kind of work or other activities	1	2	3	4	5
d. Had difficulty performing the work or other activities (for example, it took extra effort)	1	2	3	4	5

5. During the PAST FOUR WEEKS, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

(Circle one number on each line.)	**All of the time**	**Most of the time**	**Some of the time**	**A little of the time**	**None of the time**
a. Cut down on the amount of time you spent on work or other activities	1	2	3	4	5
b. Accomplished less than you would like	1	2	3	4	5
c. Did work or other activities less carefully than usual	1	2	3	4	5

6. During the PAST FOUR WEEKS, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

(circle one number.)

Not at all	1
Slightly	2
Moderately	3
Quite a bit	4
Extremely	5

7. How much BODILY pain have you had during the PAST FOUR WEEKS?

(circle one number.)

None	1
Very mild	2
Mild	3
Moderate	4
Severe	5
Very severe	6

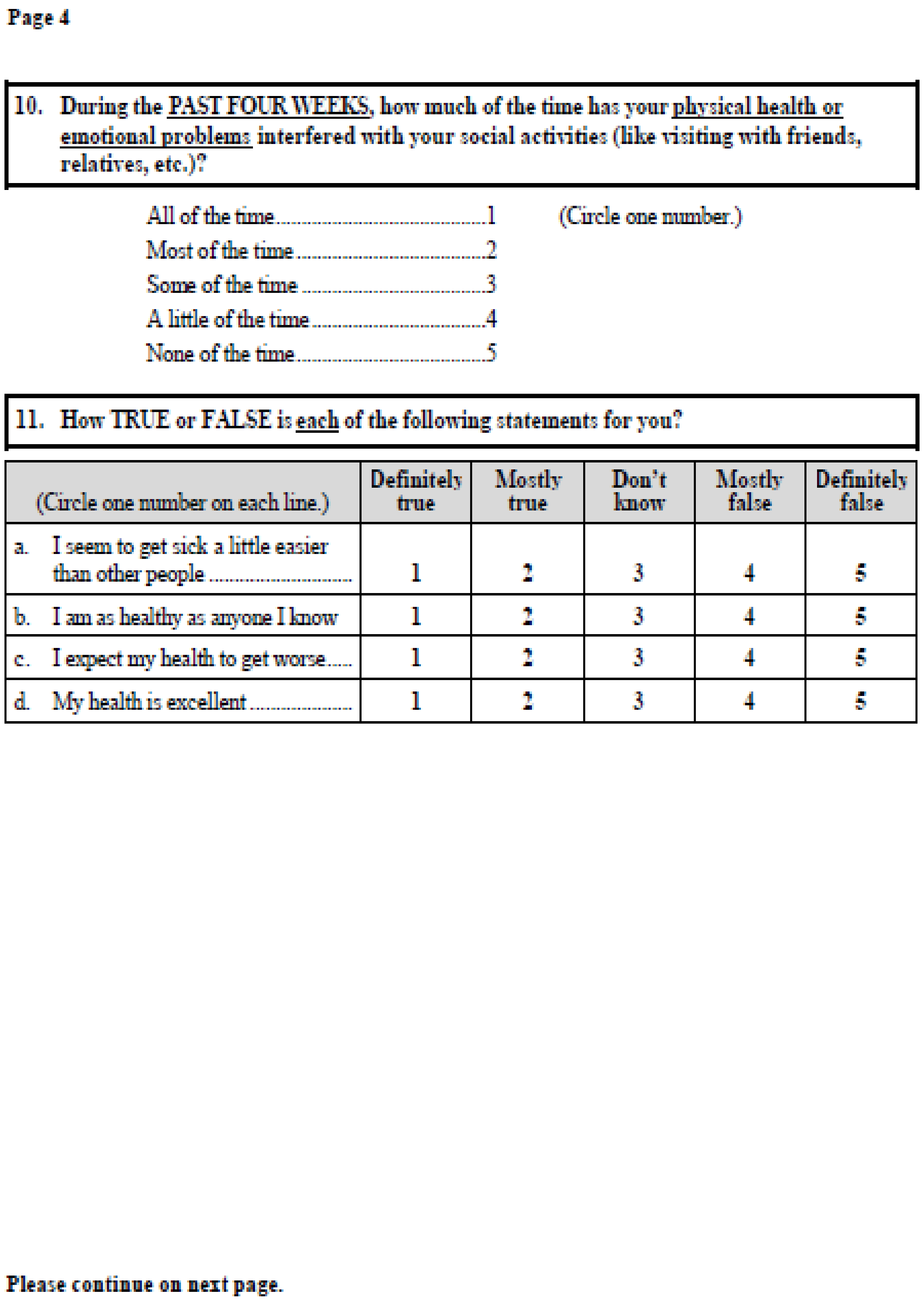
8. During the PAST FOUR WEEKS, how much did pain interfere with your normal work (including both work outside the home and housework)?

(Circle one number.)

Not at all	1
A little bit	2
Moderately	3
Quite a bit	4
Extremely	5

9. These questions are about how you feel and how things have been with you during the PAST FOUR WEEKS. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the PAST FOUR WEEKS...

(Circle one number on each line.)	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a. Did you feel full of life?	1	2	3	4	5
b. Have you been very nervous?	1	2	3	4	5
c. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5
d. Have you felt calm and peaceful?	1	2	3	4	5
e. Did you have a lot of energy?	1	2	3	4	5
f. Have you felt downhearted and depressed?	1	2	3	4	5
g. Did you feel worn out?	1	2	3	4	5
h. Have you been happy?	1	2	3	4	5
i. Did you feel tired?	1	2	3	4	5



Page 4

10. **During the <u>PAST FOUR WEEKS</u>, how much of the time has your <u>physical health or emotional problems</u> interfered with your social activities (like visiting with friends, relatives, etc.)?**

All of the time .... 1 (Circle one number.)
Most of the time 2
Some of the time 3
A little of the time 4
None of the time 5

11. **How TRUE or FALSE is <u>each</u> of the following statements for you?**

(Circle one number on each line.)	**Definitely true**	**Mostly true**	**Don't know**	**Mostly false**	**Definitely false**
a. I seem to get sick a little easier than other people	1	2	3	4	5
b. I am as healthy as anyone I know	1	2	3	4	5
c. I expect my health to get worse.....	1	2	3	4	5
d. My health is excellent	1	2	3	4	5

Please continue on next page.

URINARY FUNCTION

This section is about your urinary habits. Please consider ONLY THE LAST 4 WEEKS.

12. Over the LAST 4 WEEKS, how often have you leaked urine?

(Circle one number.)

Every day 1
About once a week 2
Less than once a week 3
Not at all 4

13. Which of the following best describes your urinary control <u>during the LAST 4 WEEKS</u>?

(Circle one number.)

No control whatsoever 1
Frequent dribbling 2
Occasional dribbling 3
Total control 4

14. How many pads or adult diapers per day did you usually use to control leakage <u>during the LAST 4 WEEKS</u>?

(Circle one number.)

3 or more pads per day 1
1-2 pads per day 2
No pads 3

15. How big a problem, if any, has each of the following been for you?

(Circle one number on each line.)	No problem	Very small problem	Small problem	Moderate problem	Big problem
a. Dripping urine or wetting your pants?	0	1	2	3	4
b. Urine leakage interfering with your sexual activity?	0	1	2	3	4

16. Overall, how big a problem has your urinary function been for you during the LAST 4 WEEKS?

No problem	1
Very small problem	2
Small problem	3
Moderate problem	4
Big problem	5

(Circle one number.)

BOWEL HABITS

This section is about your bowel habits and abdominal pain. Please consider ONLY THE LAST 4 WEEKS.

17. How often have you had rectal urgency (felt like you had to pass stool, but did not) during the LAST 4 WEEKS?

More than once a day	1
About once a day	2
More than once a week	3
About once a week	4
Rarely or never	5

(Circle one number.)

18. How often have you had stools (bowel movements) that were loose or liquid (no form, watery, mushy) during the LAST 4 WEEKS?

Never	1
Rarely	2
About half the time	3
Usually	4
Always	5

(Circle one number.)

19. How much distress have your bowel movements caused you during the LAST 4 WEEKS?

Severe distress	1
Moderate distress	2
A little distress	3
No distress	4

(Circle one number.)

20. How often have you had crampy pain in your abdomen or pelvis during the LAST 4 WEEKS?

(Circle one number.)

Several times a day........................ 1
About once a day............................ 2
Several times a week...................... 3
About once a week.......................... 4
About once this month.................... 5
Rarely or never 6

21. Overall, how big a problem have your bowel habits been for you during the LAST 4 WEEKS?

(Circle one number.)

Big problem..................................... 1
Moderate problem........................... 2
Small problem................................. 3
Very small problem......................... 4
No problem...................................... 5

SEXUAL FUNCTION

The next section is about your sexual function and sexual satisfaction. Many of the questions are very personal, but they will help us understand the important issues that you face every day. Remember that your answers to this questionnaire will be kept confidential and will be used only for research purposes. Please answer honestly about THE LAST 4 WEEKS ONLY.

22. How would you rate each of the following during the LAST 4 WEEKS?

(Circle one number on each line.)	Very Poor	Poor	Fair	Good	Very Good
a. Your level of sexual desire?.........................	1	2	3	4	5
b. Your ability to have an erection?.................	1	2	3	4	5
c. Your ability to reach orgasm (climax)?.......	1	2	3	4	5

23. How would you describe the usual QUALITY of your erections?

(Circle one number.)

None at all.. 1
Not firm enough for any sexual activity.. 2
Firm enough for masturbation and foreplay only.......................... 3
Firm enough for intercourse... 4

24. How would you describe the FREQUENCY of your erections?

I NEVER had an erection when I wanted one	1	(Circle one number.)
I had an erection LESS THAN HALF the time I wanted one	2	
I had an erection ABOUT HALF the time I wanted one	3	
I had an erection MORE THAN HALF the time I wanted one	4	
I had an erection WHENEVER I wanted one	5	

25. How often have you awakened in the morning or night with an erection?

Never	1	(Circle one number.)
Seldom (less than 25% of the time)	2	
Not often (less than half the time)	3	
Often (more than half the time)	4	
Very often (more than 75% of the time)	5	

26. During the LAST 4 WEEKS did you have vaginal or anal intercourse?

No	1	(Circle one number.)
Yes, once	2	
Yes, more than once	3	

27. Overall, how would you rate your ability to function sexually during the LAST 4 WEEKS?

Very poor	1	(Circle one number.)
Poor	2	
Fair	3	
Good	4	
Very good	5	

28. Overall, how big a problem has your sexual function been for you during the LAST 4 WEEKS?

No problem	1	(Circle one number.)
Very small problem	2	
Small problem	3	
Moderate problem	4	
Big problem	5	

DEMOGRAPHIC & BRIEF MEDICAL QUESTIONS

29. How old were you on your last birthday?

________ (Enter age.)

30. How do you describe yourself?

White/Caucasian	1	(Circle one number.)
Black/African-American	2	
Latino/Hispanic	3	
Asian/Pacific Islander	4	
Multi-Racial	5	
Other: ______________		

31. Which of the following best describes your current relationship?

Living with spouse or partner	1	(Circle one number.)
In a significant relationship, but not living together	2	
Not in a significant relationship	3	

32. How much school did you complete?

Grade school or less	1	(Circle one number.)
Some high school or technical school	2	
High school or technical school graduate	3	
Some college	4	
College Graduate	5	
Graduate or professional school after college	6	

Please continue on next page.

33. Have you ever had any of the following medical conditions?

(Please circle yes or no for every item.)	Yes	No
a. Diabetes	1	0
b. Heart attack, chest pain	1	0
c. Stroke	1	0
d. Amputation	1	0
e. Circulation problems in your legs or feet	1	0
f. Asthma, emphysema, breathing problems	1	0
g. Stomach ulcer, irritable bowel	1	0
h. Kidney disease	1	0
I. Major depression	1	0
j. Seizures	1	0
k. Alcoholism or alcohol problems......................	1	0
l. Drug problems...	1	0
m. Current or past cigarette smoker..................	1	0

34. Are you now working at a paying job?

(Circle one number.)

Yes, full-time...1
Yes, part time...2
No, but looking for a job..3
No, retired..4
No, disabled...5

Comments:

Thank you very much for your time! Please remember to mail your completed questionnaire in the supplied envelope.

APPENDIX E

PERMISSION FROM DR. LETWIN TO TRANSLATE AND USE UCLA-PCI IN THE STUDY

Nasser Abu-El-Noor <nia1@zips.uakron.edu>

A permission to use the UCLA-PCI

4 messages

Litwin, Mark M.D. <MLitwin@mednet.ucla.edu> **Fri, May 22, 2009 at 6:14 PM**

To: Nasser Abu-El-Noor <nia1@uakron.edu>
Cc: "Lopez, Griselda" <GrLopez@mednet.ucla.edu>

Fine. You must make sure to use rigorous methods to do a translation that is both semantic and cultural. There are many upblished methods for such translations. Please send me a copy of the final version once translated. Thank you.

One of my staff members will send you the UCLA-PCI in English for you to work with.

Mark S. Litwin, MD, MPH
Professor of Urology and Health Services
UCLA Department of Urology
Box 951738
Los Angeles, CA 90095-1738
(310) 206-8183

From: Nasser Abu-El-Noor [nia1@uakron.edu]
Sent: Thursday, May 21, 2009 7:15 PM
To: Litwin, Mark M.D.
Subject: A permission to use the UCLA-PCI

Dear Dr. Litwin, Hello

I hope this email finds you well.

I am pursuing my PhD in health policy at the Department of Public Administration and Urban Studies and the University of Akron, OH. I

chose the topic of my dissertation to be "Quality of life and barriers
to health care of prostate cancer survivors resideing in Gaza Strip: A
discreptive study". I am planning to use the UCLA PROSTATE CANCER INDEX
including the RAND 36-Item
Health Survey v2 in my study after translating it into the Arabic Language.

In this email, I would like to get your permission to translate the
instruemtn and use it in my study.

Fianally, I would like to thank you very much for your help and wish
you all the best.

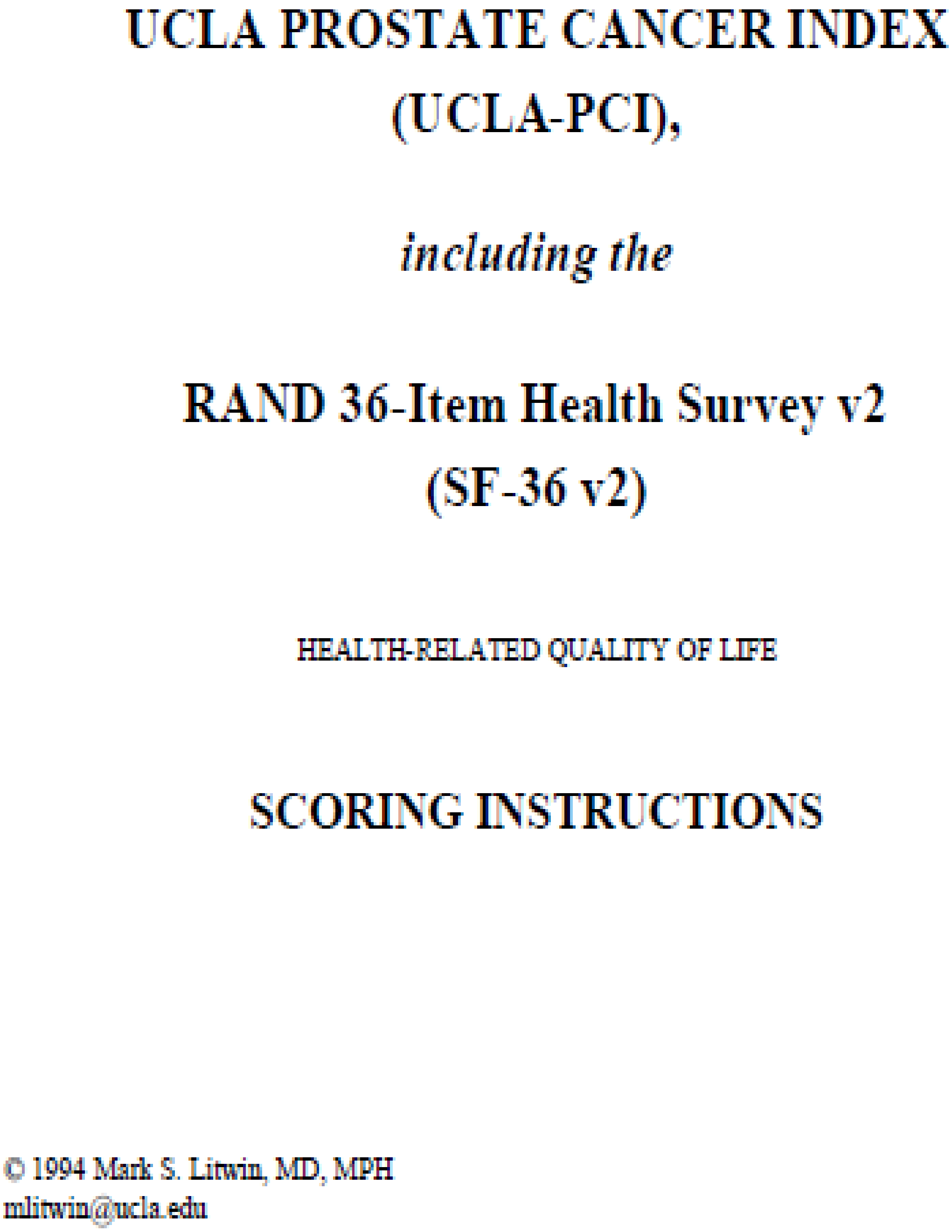
My background is nursing and I am interested to evaluate the HRQOL for
prostate cancer survivors in my country.
While I was searching for a topic for my dissertation, I remember that
there was a copy of the UCLA-PCI available on line. When I decided to
use it for my study, I searched the internet several times looking for
the instrument, but I never found it.
Sir, I hope that I can get your permission to use the instrument in my
study and I hope that you can instrunct me how I can get a copy of the
instrument.

Thank you very much for your help and wish you all the best.

Nasser Abu-El-Noor
Ph.D. Student
Public Administration and Urban affairs
The University of Akron

APPENDIX F

SCORING INSTRUCTIONS FOR UCLA-PCI



UCLA PROSTATE CANCER INDEX
(UCLA-PCI),

including the

RAND 36-Item Health Survey v2
(SF-36 v2)

HEALTH-RELATED QUALITY OF LIFE

SCORING INSTRUCTIONS

mlitwin@ucla.edu

Scoring Summary

The UCLA Prostate Cancer Index was developed by researchers at UCLA and RAND to measure health-related quality of life (HRQOL) in patients treated for prostate cancer. It addresses general HRQOL and organ-targeted HRQOL. The instrument has been validated psychometrically in this population. Reliability and validity statistics for the instrument are included in reference 7.

The Index contains three parts. This document explains the scoring rules for each of these parts. The components of the Index are:

1. RAND 36-Item Health Survey v2 (SF-36 v2)	Items 1-11	36 items
2. UCLA Prostate Cancer Index	Items 12-28	20 items
3. Sociodemographic Items	Items 29-24	18 items

The RAND 36-Item Health Survey was previously developed and published by RAND researchers and is presently used throughout the world as the premier instrument to measure general HRQOL. It assesses HRQOL in eight scales or domains.[1-3] Some researchers refer to the RAND 36-Item Health Survey as the "SF-36." The SF-36 scoring system is slightly different, though most experts in HRQOL feel that the two scoring mechanisms produce equivalent results. A small number of modifications were made to the original RAND 36-Item Health Survey, and the RAND 36-Item Health Survey v2 (SF-36 v2) was published in early 2001.

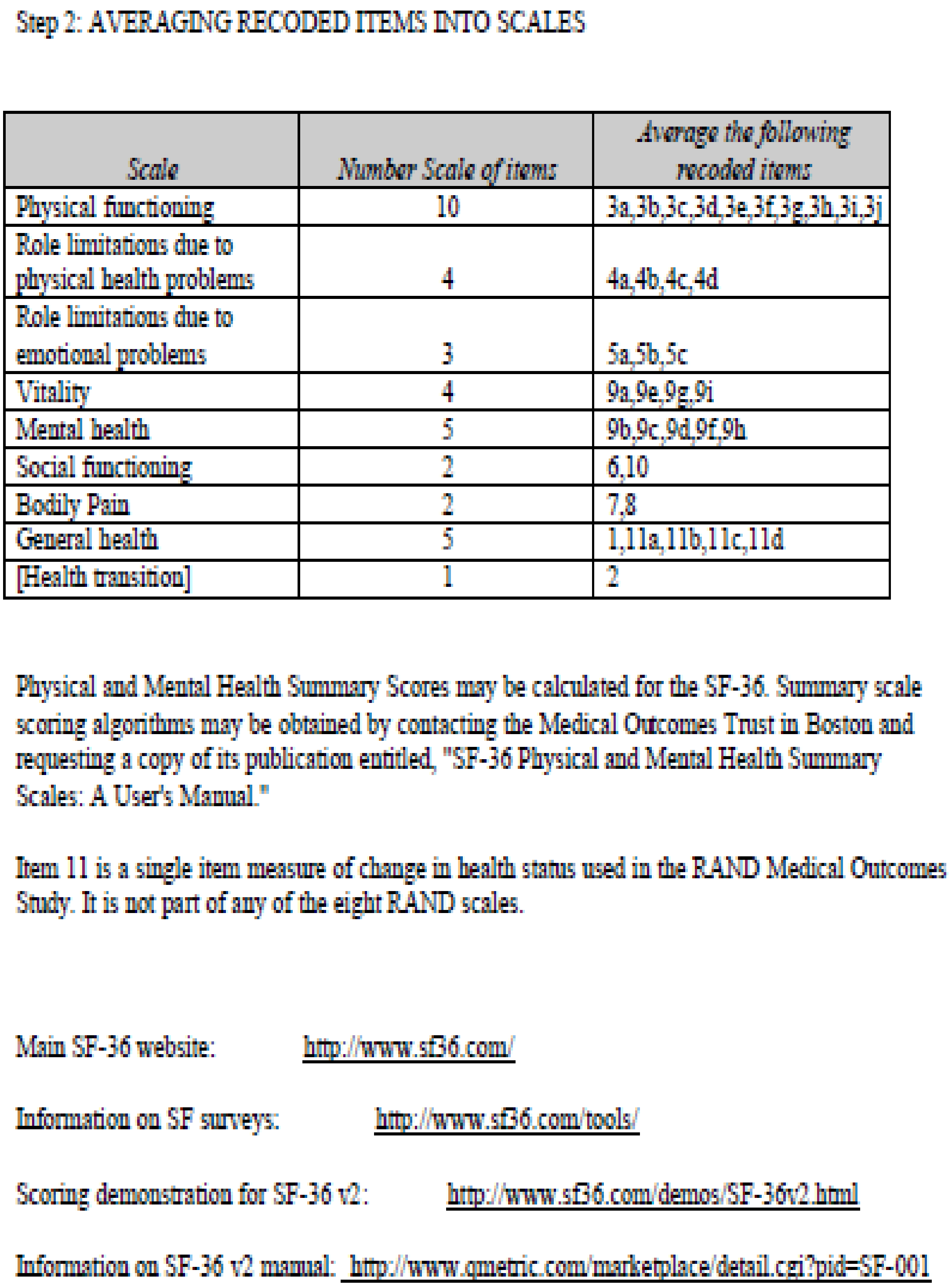
Comparison data using the SF-36 scoring system is well-documented.[4]

The UCLA Prostate Cancer Index assesses disease-specific, organ-targeted HRQOL in six scales or domains that are of special concern to men treated for prostate cancer. It was developed for use as an adjunct to the RAND general HRQOL scales.[5-7] It has been translated into Spanish[8] and is presently in use in over 200 studies throughout North America, Europe, and Japan. Other publications with the UCLA Prostate Cancer Index are listed in the reference section below.

The RAND 36-Item Health Survey v2 is scored in two steps. First, the response for each item is recoded with a value from 0-100 according to the table below. Second, an average value is calculated for the items in each of the eight scales, according to the table on the next page. Missing data are ignored and the scale score is calculated without the missing item. If more than 50% of the items are missing from any one scale, it cannot be calculated.

Step 1: RECODING ITEMS

Item Numbers	*Change original response category from*	*To recoded value of*
3a, 3b, 3c, 3d, 3e, 3f, 3g, 3h, 3i, 3j	1	0
	2	50
	3	100
2, 4a, 4b, 4c, 4d, 5a, 5b, 5c, 9b, 9c, 9f, 9g, 9i, 10, 11a, 11c	1	0
	2	25
	3	50
	4	75
	5	100
7	1	100
	2	80
	3	60
	4	40
	5	20
	6	0
1, 6, 8, 9a, 9d, 9e, 9h, 11b, 11d	1	100
	2	75
	3	50
	4	25
	5	0



Step 2: AVERAGING RECODED ITEMS INTO SCALES

Scale	*Number Scale of items*	*Average the following recoded items*
Physical functioning	10	3a,3b,3c,3d,3e,3f,3g,3h,3i,3j
Role limitations due to physical health problems	4	4a,4b,4c,4d
Role limitations due to emotional problems	3	5a,5b,5c
Vitality	4	9a,9e,9g,9i
Mental health	5	9b,9c,9d,9f,9h
Social functioning	2	6,10
Bodily Pain	2	7,8
General health	5	1,11a,11b,11c,11d
[Health transition]	1	2

Physical and Mental Health Summary Scores may be calculated for the SF-36. Summary scale scoring algorithms may be obtained by contacting the Medical Outcomes Trust in Boston and requesting a copy of its publication entitled, "SF-36 Physical and Mental Health Summary Scales: A User's Manual."

Item 11 is a single item measure of change in health status used in the RAND Medical Outcomes Study. It is not part of any of the eight RAND scales.

Main SF-36 website: http://www.sf36.com/

Information on SF surveys: http://www.sf36.com/tools/

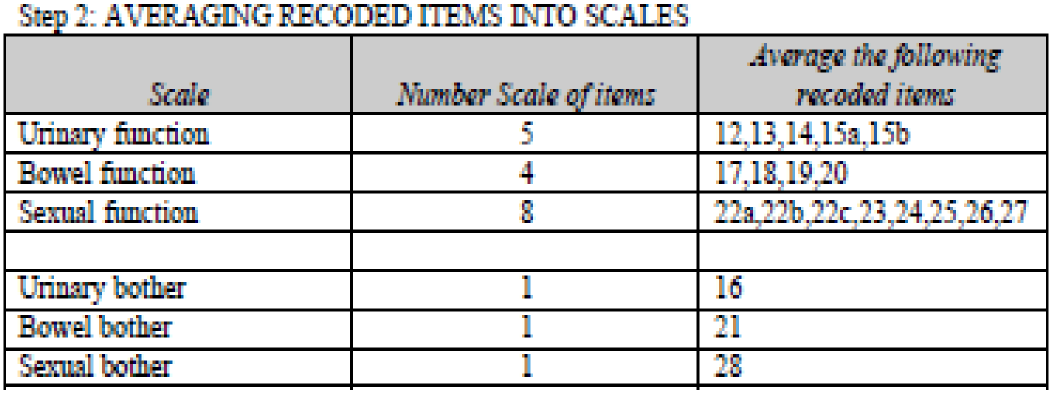
Scoring demonstration for SF-36 v2: http://www.sf36.com/demos/SF-36v2.html

Information on SF-36 v2 manual: http://www.qmetric.com/marketplace/detail.cgi?pid=SF-001

The UCLA Prostate Cancer Index is also scored in two steps. First, the response for each item is recoded with a value from 0-100 according to the table below. Second, an average value is calculated for the items in each of the three function scales, according to the table on the next page. The recoded values for the three bother items are the scores for the bother scales. Missing data are ignored and the scale score is calculated without the missing item. If more than 50% of the items are missing from any one scale, it cannot be calculated.

Step 1: RECODING ITEMS

Item Numbers	*Change original response category from*	*To recoded value of*
12,13,19,23	1	0
	2	33
	3	67
	4	100
14,26	1	0
	2	50
	3	100
15a,15b	0	100
	1	75
	2	50
	3	25
	4	0
16,18,28	1	100
	2	75
	3	50
	4	25
	5	0
17,21,22a,22b,22c,24,25,27	1	0
	2	25
	3	50
	4	75
	5	100
20	1	0
	2	20
	3	40
	4	60
	5	80
	6	100



Step 2: AVERAGING RECODED ITEMS INTO SCALES

Scale	*Number Scale of items*	*Average the following recoded items*
Urinary function	5	12,13,14,15a,15b
Bowel function	4	17,18,19,20
Sexual function	8	22a,22b,22c,23,24,25,26,27
Urinary bother	1	16
Bowel bother	1	21
Sexual bother	1	28

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For further information contact:

Mark S. Litwin, MD, MPH
UCLA Department of Urology
Box 951738
Los Angeles, CA 90095-1738
USA
Fax: (310) 267-2623
Email: mlitwin@ucla.edu

APPENDIX G

A PERMISSION FROM DR. IBTISSAM SABBAH TO USE THE ARABIC VERSION OF THE SF-36.

Nasser Abu-El-Noor <nia1@zips.uakron.edu>

Re: Arabic Sf-36

---

ibtissam sabbah <imsab@terra.net.lb> **Sat, May 16, 2009 at 12:57 PM**
To: nia1@uakron.edu

monsieur;
je vous envoie la version de SF-36 utilise dans notre etude au Liban et valide dans la population generale, cependant, l'auteur de SF-36 recommande d'avoir son autorisation avant l'utilisation pour des raisons de commercialisation de sa part
bon travail et bon courage de notre part
Dr. Ibtissam SABBAH DROUBI
Universite libanaise Saida, LIBAN
----- Original Message ----- From: "nabil droubi" <nsdroubi@inco.com.lb>
To: <imsab@terra.net.lb>
Sent: Wednesday, May 13, 2009 3:01 PM
Subject: FW: Arabic Sf-36

-----Original Message-----
From: Nasser Abu-El-Noor [mailto:nia1@uakron.edu]
Sent: Wednesday, May 13, 2009 4:53 AM
To: nsdroubi@inco.com.lb
Subject: Arabic Sf-36

Dear Dr. Droubi, Hello

My Name is Nasser Abu-El-Noor. I am from Palestine, Gaza Strip and
works as a lecturer at the College of Nursing at the Islamic

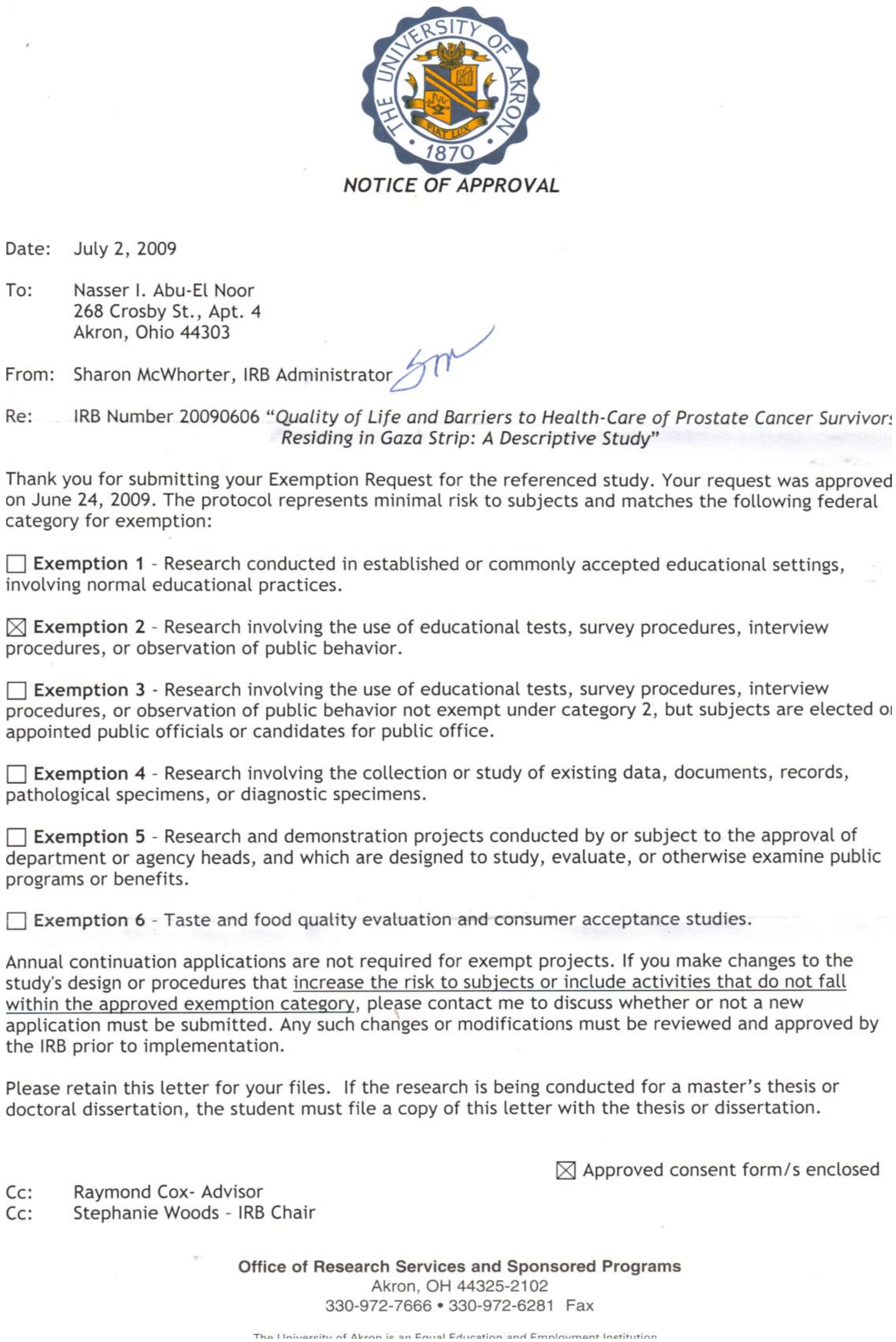
University-Gaza. At the time being, I have a study leave to have my
Ph.D in Health Policy from the Department of Public Administration and
Urban Studies at the University of Akron, Ohio, U.S.A.
I am at the time being preparing for my dissertation which has the
topic "Quality of life and barriers to health care of prostate cancer
survivors in Gaza Strip: A descriptive study". Along with the UCLA
Prostate Cancer Index (UCLA-PCI), I am using the SF-36 to measure the
general quality of life. I was very pleased that you and your
colleagues have worked to translate the SF-36 into the Arabic Language
and checked it for reliability and validity.
I hope that you will be generous and give me a permission to use your
translated instrument in my study. If so, I hope that you can send a
copy of the Arabic version.

Thank you very much for your help and cooperation.

Nasser Abu-El-Noor
Ph.D. Student
Public Administration and Urban affairs
The University of Akron

APPENDIX H

APPROVAL OF THE INTERNAL REVIEW BOARD (IRB)
AT THE UNIVERSITY OF AKRON



NOTICE OF APPROVAL

Date: July 2, 2009

To: Nasser I. Abu-El Noor
268 Crosby St., Apt. 4
Akron, Ohio 44303

From: Sharon McWhorter, IRB Administrator

Re: IRB Number 20090606 "*Quality of Life and Barriers to Health-Care of Prostate Cancer Survivor*
Residing in Gaza Strip: A Descriptive Study"

Thank you for submitting your Exemption Request for the referenced study. Your request was approved on June 24, 2009. The protocol represents minimal risk to subjects and matches the following federal category for exemption:

☐ **Exemption 1** - Research conducted in established or commonly accepted educational settings, involving normal educational practices.

☒ **Exemption 2** - Research involving the use of educational tests, survey procedures, interview procedures, or observation of public behavior.

☐ **Exemption 3** - Research involving the use of educational tests, survey procedures, interview procedures, or observation of public behavior not exempt under category 2, but subjects are elected o appointed public officials or candidates for public office.

☐ **Exemption 4** - Research involving the collection or study of existing data, documents, records, pathological specimens, or diagnostic specimens.

☐ **Exemption 5** - Research and demonstration projects conducted by or subject to the approval of department or agency heads, and which are designed to study, evaluate, or otherwise examine public programs or benefits.

☐ **Exemption 6** - Taste and food quality evaluation and consumer acceptance studies.

Annual continuation applications are not required for exempt projects. If you make changes to the study's design or procedures that increase the risk to subjects or include activities that do not fall within the approved exemption category, please contact me to discuss whether or not a new application must be submitted. Any such changes or modifications must be reviewed and approved by the IRB prior to implementation.

Please retain this letter for your files. If the research is being conducted for a master's thesis or doctoral dissertation, the student must file a copy of this letter with the thesis or dissertation.

☒ Approved consent form/s enclosed

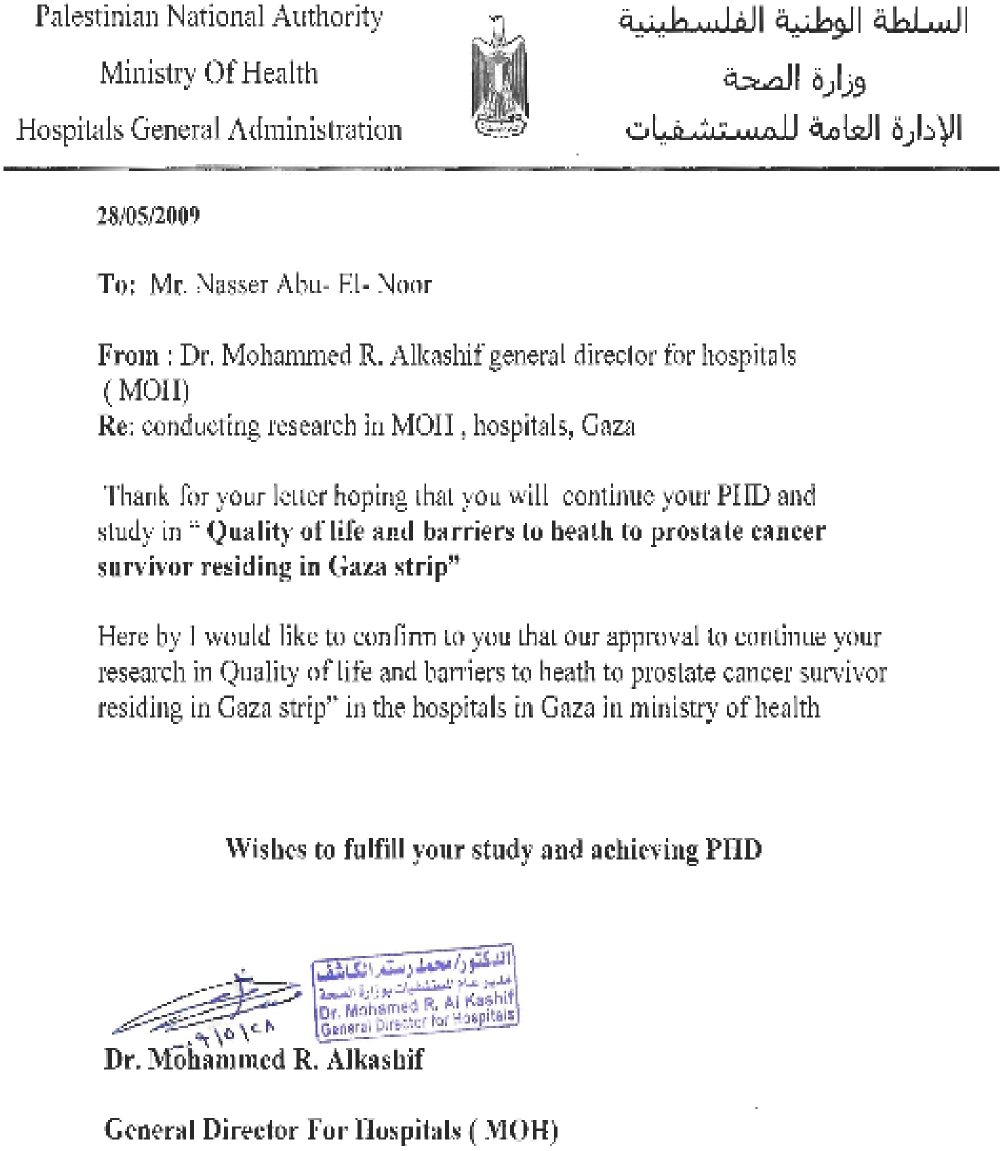
Cc: Raymond Cox- Advisor
Cc: Stephanie Woods - IRB Chair

Office of Research Services and Sponsored Programs
Akron, OH 44325-2102
330-972-7666 • 330-972-6281 Fax

The University of Akron is an Equal Education and Employment Institution

APPENDIX I

APPROVAL OF PALESTINIAN MINISTRY OF HEALTH TO CONDUCT THE STUDY



Palestinian National Authority
Ministry Of Health
Hospitals General Administration

السلطة الوطنية الفلسطينية
وزارة الصحة
الإدارة العامة للمستشفيات

28/05/2009

To: Mr. Nasser Abu- El- Noor

From : Dr. Mohammed R. Alkashif general director for hospitals (MOH)
Re: conducting research in MOH , hospitals, Gaza

Thank for your letter hoping that you will continue your PHD and study in " **Quality of life and barriers to heath to prostate cancer survivor residing in Gaza strip"**

Here by I would like to confirm to you that our approval to continue your research in Quality of life and barriers to heath to prostate cancer survivor residing in Gaza strip" in the hospitals in Gaza in ministry of health

Wishes to fulfill your study and achieving PHD

الدكتور/ محمد رستم الكاشف
مدير عام المستشفيات بوزارة الصحة
Dr. Mohamed R. Al Kashif
General Director for Hospitals

٩/٥/٢٨

Dr. Mohammed R. Alkashif

General Director For Hospitals (MOH)

APPENDIX J

APPROVAL OF HELSINKI COMMITTEE TO CONDUCT THE STUDY

Palestinian National Authority
Ministry of Health
Helsinki Committee

السلطة الوطنية الفلسطينية
وزارة الصحة
لجنة هلسنكي

التاريخ3/6/2009

Name:

الاسم: **ناصر أبو النور**

I would like to inform you that the committee has discussed your application about:

نفيدكم علماً بأن اللجنة قد ناقشت مقترح دراستكم حول:-

Quality if life and Barriers to health Care of prostate cancer survivors in Gaza Strip :descriptive study

In its meeting on June 2009
and decided the Following:-
To approve the above mention research study.

و ذلك في جلستها المنعقدة لشهر 6 2009
و قد قررت ما يلي:-
الموافقة على البحث المذكور عاليه.

Signature
توقيع

Member
عضو

Member
عضو

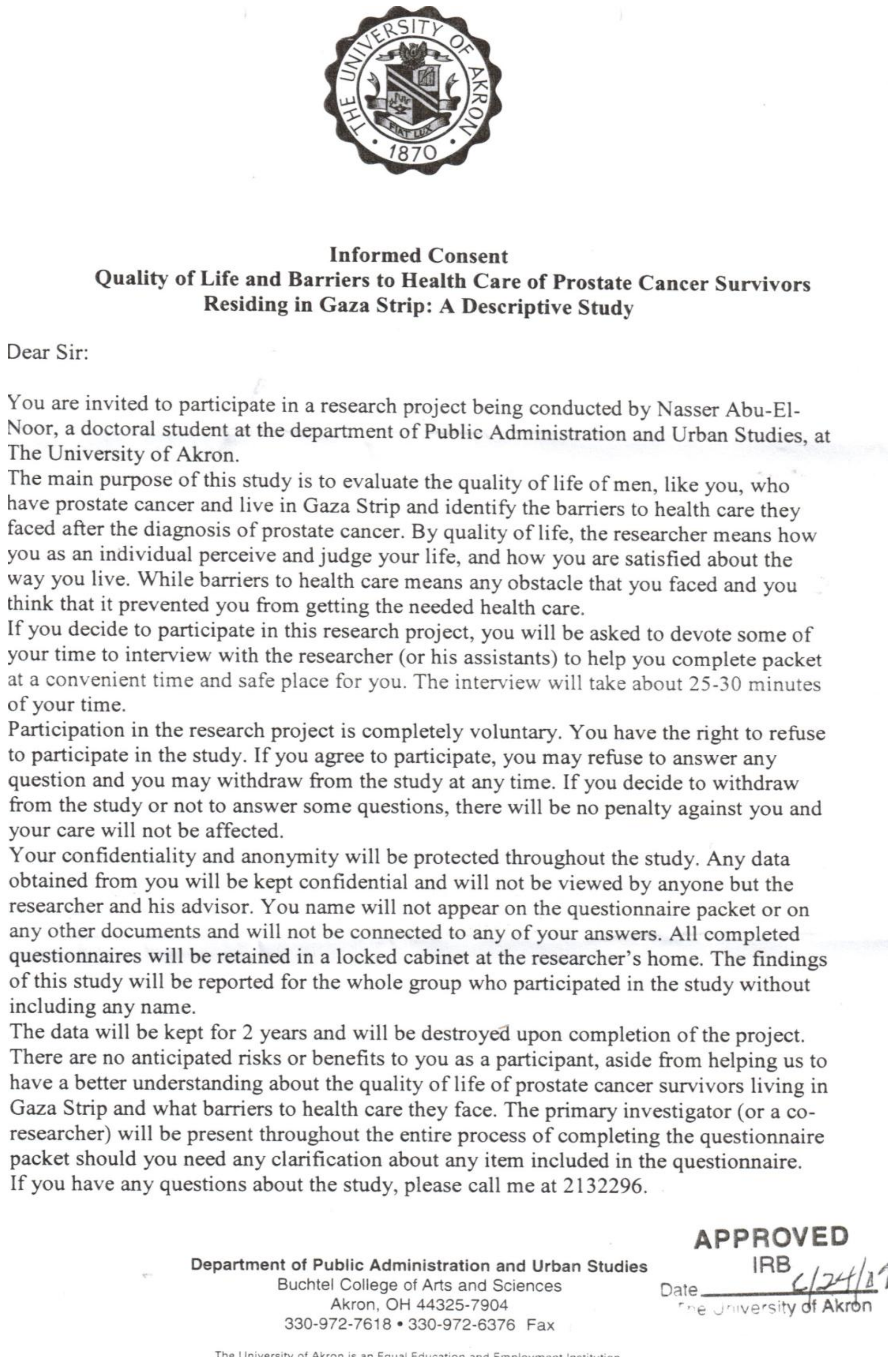
Chairperson

Conditions:-

- ❖ Valid for 2 years from the date of approval to start.
- ❖ It is necessary to notify the committee in any change in the admitted study protocol.
- ❖ The committee appreciate receiving one copy of your final research when it is completed.

APPENDIX K

CONSENT TO PARTICIPATE IN THE STUDY



Informed Consent

Quality of Life and Barriers to Health Care of Prostate Cancer Survivors Residing in Gaza Strip: A Descriptive Study

Dear Sir:

You are invited to participate in a research project being conducted by Nasser Abu-El-Noor, a doctoral student at the department of Public Administration and Urban Studies, at The University of Akron.

The main purpose of this study is to evaluate the quality of life of men, like you, who have prostate cancer and live in Gaza Strip and identify the barriers to health care they faced after the diagnosis of prostate cancer. By quality of life, the researcher means how you as an individual perceive and judge your life, and how you are satisfied about the way you live. While barriers to health care means any obstacle that you faced and you think that it prevented you from getting the needed health care.

If you decide to participate in this research project, you will be asked to devote some of your time to interview with the researcher (or his assistants) to help you complete packet at a convenient time and safe place for you. The interview will take about 25-30 minutes of your time.

Participation in the research project is completely voluntary. You have the right to refuse to participate in the study. If you agree to participate, you may refuse to answer any question and you may withdraw from the study at any time. If you decide to withdraw from the study or not to answer some questions, there will be no penalty against you and your care will not be affected.

Your confidentiality and anonymity will be protected throughout the study. Any data obtained from you will be kept confidential and will not be viewed by anyone but the researcher and his advisor. You name will not appear on the questionnaire packet or on any other documents and will not be connected to any of your answers. All completed questionnaires will be retained in a locked cabinet at the researcher's home. The findings of this study will be reported for the whole group who participated in the study without including any name.

The data will be kept for 2 years and will be destroyed upon completion of the project.

There are no anticipated risks or benefits to you as a participant, aside from helping us to have a better understanding about the quality of life of prostate cancer survivors living in Gaza Strip and what barriers to health care they face. The primary investigator (or a co-researcher) will be present throughout the entire process of completing the questionnaire packet should you need any clarification about any item included in the questionnaire.

If you have any questions about the study, please call me at 2132296.

APPROVED
IRB
Date 6/24/1
The University of Akron

Department of Public Administration and Urban Studies
Buchtel College of Arts and Sciences
Akron, OH 44325-7904
330-972-7618 • 330-972-6376 Fax

This research project has been reviewed and approved by The University of Akron Institutional Review Board for the Protection of Human Subjects. Questions about your rights as a research participant can be directed to Ms. Sharon McWhorter, Associate Director, Research Services, at 1-330-972-7666 or 1-888-232-8790

I consent to participate in this project.
Signature: ________________________________. Date: _______________.

University of Akron is an Equal Education and Employment Institution

APPROVED
IRB
Date 6/24/09
The University of Akron