

AMERICAN UNIVERSITY OF BEIRUT

SURVIVING TESTICULAR CANCER: THE LEBANESE
EXPERIENCE

by
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A thesis
submitted in partial fulfillment of the requirements
for the degree of Master of Science in Nursing
to the Rafic Hariri School of Nursing
of the Faculty of Medicine
at the American University of Beirut

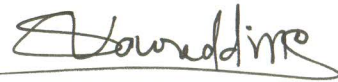
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May 2013

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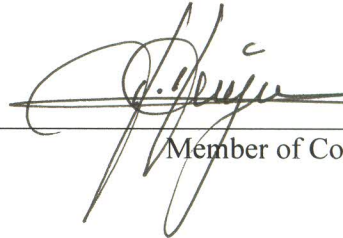
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ACKNOWLEDGMENTS

My recognition and gratitude are addressed to my academic and thesis advisor Dr. Samar Noureddine for her great guidance throughout the thesis process.

Special thanks are due to my thesis committee members Dr. Huda Abu-Saad Huijjer and Dr. Jocelyn DeJong for their support and follow-up.

Thanks to Dr. Ziad Salem and his clinic nurse Mrs. Hiba Asma and Dr. Muhammad Bulbul and his clinic assistants Mrs. Rania Sakr and Mrs. Samah Itani for helping me identify participants and putting me in touch with them.

I place on record, my sincere gratitude to my family, friends, and colleagues at the Lebanese Center for Palliative Care – Balsam for their constant encouragement.

AN ABSTRACT OF THE THESIS OF

Mohammad Mounib Saab for Master of Science in Nursing
Major: Nursing

Title: Surviving Testicular Cancer: The Lebanese Experience

Testicular cancer, though not very common in men, may have a great impact on their lives. The majority of those diagnosed with a testicular malignancy in Lebanon are below the age of 32 i.e. at the peak of their reproductive and professional lives. The purpose of this study was to describe the experience of Lebanese testicular cancer survivors, with a focus on their sexual life.

A qualitative descriptive design using semi structured interviews was utilized. A purposive sample of adults with testicular cancer was recruited from the clinics of an oncologist and an urologist. Inclusion criteria were: (1) holding the Lebanese nationality; (2) age between 18 and 50 years; (3) in remission for at least three years; (4) willing to share personal information. Data saturation was achieved after the seventh interview, but a total of eight participants were recruited. Interviews were conducted at a place and time chosen by each participant. The interviews were digitally recorded and transcribed verbatim in Arabic. The opening question was: "Tell me about your life since you got treated for testicular cancer." Probing was used for elaboration. Two to three weeks following the interview, the summary of each interview was read to participants over the phone for member check.

Qualitative content analysis was used to analyze verbal and non-verbal data obtained from the participants. Data collection and analysis took place concurrently. The themes that emerged from the collected data were: cultural views of cancer, concealing cancer diagnosis, cancer experience is a turning point in one's life, concern about fertility, coping with cancer and its consequences, and unaffected aspects of life. A number of categories were identified for each theme.

In the absence of related literature in Lebanon, the study findings provide an understanding of the experience of Lebanese testicular cancer survivors, which can be only described by the survivors themselves. The results suggest the need to educate patients about testicular cancer and address its effect on their fertility, which was a major concern in this sample. Oncology nurses can use this data in counseling testicular cancer patients.

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CHAPTER I

BACKGROUND AND SIGNIFICANCE

Cancer is one of the leading causes of death around the globe. It accounted for 13% of all deaths in the year 2008. About 70% of all cancer deaths took place in low and middle income countries (World Health Organization, 2013). Reproductive malignancies, though not the most common type of cancer in men, may have a great impact on their lives. These malignancies include testicular cancer, prostate cancer, and penile cancer. Testicular cancer is the most common cancer type in young males, affecting a total of 211,209 men in the United States (National Cancer Institute, 2013). According to the latest Lebanese National Cancer Registry (2003) testicular cancer accounted for 1% of the total cancer cases in Lebanon and 2.2% of cancer cases among males. Of those with testicular cancer, 21% were aged between 25 and 54 years, versus 5.2% in those 55 years and older and 4.1% in those younger than 25 years (National Cancer Registry, 2003).

Over 90% of testicular malignancies are germinal in nature; they develop in the sperm producing cells. There are two types of germ cell tumors, seminomas and nonseminomas (American Cancer Society, 2013). Seminomas are usually localized at time of diagnosis whereas nonseminomas are often found to be metastasized (Garner et al., 2005). Unilateral excision of one of the testes remains the primary treatment modality for testicular cancer. The surgery might be followed by chemotherapy and/or radiation therapy, depending on the staging of the disease (Dahl et al., 2005). The five-year relative survival rate for testicular cancer in the United States is 95% (National Cancer Institute, 2013). The literature on Lebanon lacks data regarding testicular cancer survival rates.

The life expectancy of Testicular cancer survivors (TCSs) worldwide is similar to that of the healthy male population. TCSs are expected to live 30 to 50 years following treatment. Hence, a big number of TCSs are expected to face problems pertinent to survivorship. These problems are secondary to cancer, its treatment, or both (Dahl et al., 2005). According to the National Cancer Institute (2013), around 80% of those diagnosed with a testicular malignancy are below the age of 44, which means that they are at the peak period of their reproductive life and at a key time for starting a career and building a family. As the number of TCSs increases, minimizing the effect of testicular cancer and its treatment on long term health and quality of life (QOL), specifically the survivors' sexual life and fertility, becomes paramount (Huddart et al., 2005).

Despite the availability of Lebanese studies that evaluate the effectiveness of cancer treatment modalities on the tumor per se, few are the studies that offer an understanding of what it means to live with cancer. Among these initiatives are two phenomenological studies conducted by Doumit et al. (2007) and (2010) at the American University of Beirut (AUB). The first study explored the lived experience of Lebanese cancer patients receiving palliative care and the second addressed the lived experience of Lebanese women diagnosed with breast cancer. None of Doumit's studies included testicular cancer patients as the first study aimed at examining the experiences of cancer patients in the last six months of their life and the second studied the experience of breast cancer patients. Moreover, there is an absence of studies in Lebanon that provide a profound examination of the TCSs' experience.

Fertility and masculinity may be impacted by testicular cancer. These two interrelated concepts were not sufficiently addressed in the literature on Lebanon despite the implications they both have on the man's life, especially in the Middle

Eastern culture where the gender norms are clearly defined and highly valued. Only Inhorn (2004) examined male infertility in Cairo, Egypt and Beirut, Lebanon. In her study, Inhorn (2004) framed male infertility as a condition that may lead to a sense of emasculation. She also discussed the secrecy and stigma that surround infertility in both the Egyptian and Lebanese cultures.

A common approach to the study of people's experiences with an illness and its impact on their lives is the examination of their quality of life (QOL). QOL is defined by the World Health Organization (1996) as the "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." (p.5). This definition reflects the multidimensional nature of QOL which includes, not only the physical manifestations of a disease, but also the sociocultural and environmental context that one lives in.

QOL questionnaires were used in studies on TCSs. Although such studies may cover some aspects of the experience of TCSs, they do not describe it thoroughly. This suggests that choosing a qualitative research design over a quantitative design has more value for describing the experience of TCSs, with a focus on its sexual aspects. Additionally, there is an absence of Lebanese qualitative studies that explore the experience of TCSs, thus leaving Lebanese healthcare providers with little information about the needs of this population. This may affect the quality of care delivered. This study serves as a substratum for other studies to profoundly examine the experience of TCSs with a focus on their sexual life. Knowing more about this topic would allow healthcare providers to address the needs of TCSs and would offer TCSs the chance to identify with those who went through a similar experience.

Originating in the nineteenth century, and guiding Dilthey's philosophy, Weberian sociology, and George Herbert Mead's social psychology, qualitative research is best defined as "a form of social inquiry that focuses on the way people interpret and make sense of their experiences and the world in which they live." (Holloway et al, 2002, p.3). Descriptive research that first appeared in history, philosophy, and anthropology, focuses on the way people make sense of their subjective reality and attach meaning to it. According to Holloway et al. (2002), qualitative research implies processes and meanings that cannot be studied or measured in terms of quantity, amount, intensity, or frequency. No qualitative studies were found that address the experiences of TCSs in Lebanon. A qualitative approach is most appropriate for the researcher to gain insight about the experience of TCSs, especially when it comes to a culture where this topic was not previously explored. The purpose of this study is to explore the experience of Lebanese TCSs with a focus on their sexual life.

CHAPTER II

LITERATURE REVIEW

Several studies were conducted to determine the long term effect of chemotherapy, surgery, radiation therapy, and other cancer treatment modalities on TCSs; however, no disease-specific QOL instrument for TCSs have been developed according to standardized guidelines (Dahl et al., 2005). Questionnaires developed to address TCSs have tackled both fertility problems and sexual functioning; nevertheless, none addressed other aspects of QOL or offered a holistic description of the experience of those who survived a testicular malignancy.

A. Main Findings of Previous Studies

Fleer et al. (2004) conducted a literature review to highlight findings concerning QOL and its domains in TCSs. MEDLINE, EMBASE, PsycINFO and CancerLIT databases were used to identify relevant publications. Selection criteria were: papers published in English between 1980 and October 2003, studies on patients with testicular cancer who were in complete remission, studies on physical, psychological, and social well-being, and papers in which subgroups of TCSs could be clearly identified. A total of 23 quantitative studies met the inclusion criteria. Findings from the reviewed articles offered an overview of the physical symptoms related to the long term effect of the disease and its treatment. Additionally, key significant QOL domains related to fertility, changes in body image, mental health, cognitive functioning, and social functioning were identified. The authors found that the literature lacked data regarding the influence of pretreatment issues such as "unemployment, economical worries, mental disorders, sexual and relational problems, and other physical illnesses" (Dahl et al., 2005, p.195)

on adaptation after treatment. Moreover, many studies had short follow up times, therefore long term effects of the disease on QOL could not be identified. Moreover, the studies used different validated and non-validated tools to address the same aspects of QOL, making comparison of findings difficult. The authors recommended that studies with larger samples are needed to increase the statistical power since reliability and generalizability were limited by small sample sizes in most of the reviewed studies.

Joly et al. (2002) evaluated the QOL and social problems in long term TCSs in a population-based case-control study. Seventy one TCSs from the Calvados General Tumor Registry in France joined the study and 119 healthy control subjects were matched by age and location of residence. Information was obtained using two questionnaires: the Medical Outcomes Study 36-item Short Form Health Survey (SF-36; a generic health perception questionnaire) and the European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire C30 (QLQ-C30) core questionnaire version 2 (Joly et al., 2002). Questions regarding sexuality were added. With a mean follow-up of eleven years, there was no significant difference in general symptoms scores and psychosocial problems between the cases and controls. What was significant is that TCSs reported more modification of their sexual life ($P = 0.04$), with a decrease in their sexual enjoyment ($P < 0.01$), decreased desire ($P = 0.02$), and infertility ($P < 0.01$) compared to controls. TCSs also reported difficulty borrowing specimens from sperm banks in order to conceive ($P < 0.001$). The authors concluded that long-term TCSs were able to cope with the consequences of their disease since they did not express impairment of health-related QOL or impairment in their social and professional life. However, impairment of sexual life and fertility remained the main physical long-term sequelae, along with the difficulty in borrowing from sperm banks.

As the number of survivors of testicular cancer increases, QOL issues become increasingly important. Based on the above statement, Rossen et al. (2009) conducted a long-term follow-up assessment of all testicular cancer cases treated at Aarhus University Hospital in Denmark between the years 1990 and 2000. A total of 401 TCS completed questionnaires concerning QOL (EORTC QLQ-C30), depression (Beck Depression Inventory-II [BDI-II]), and fatigue (Multidimensional Fatigue Inventory-20 [MFI-20]), in addition to health-related issues. On the basis of their treatment, informants were categorized as having received surveillance (orchiectomy) (n = 204), radiotherapy (n = 47), or chemotherapy (n = 150). The informants' scores were then compared to those of the reference group that comprised of 1,450 healthy subjects from the general population. It was found that QOL among testicular cancer patients was equal to that of healthy subjects in the reference group. However, patients who received chemotherapy reported more physical symptoms (Peripheral neuropathy, ototoxicity, and Raynaud-like phenomena) ($P < 0.0001$) compared to the reference group.

A cross-sectional study was conducted by Huddart et al. (2005) in order to address fertility, gonadal and sexual function in TCSs. Six hundred and eighty patients treated for testicular cancer were recruited and completed the EORTC QLQ-C30 questionnaire, the associated testicular cancer specific module that included questions on sexual activity, and a general health and fertility questionnaire. The informants were divided according to the treatment modalities they received: orchiectomy alone (n = 169), chemotherapy (n = 272), radiotherapy (n = 58), and both chemotherapy and radiotherapy (n = 81). It was found that chemotherapy had the most significant impact on hormonal levels namely testosterone ($P = 0.005$), follicular stimulating hormone (FSH) ($P = 0.005$), and luteinizing hormone (LH) ($P = 0.001$). Patients with low testosterone levels scored low on EORTC QLQ-C30 questionnaire, the general health

and fertility questionnaire, and the associated testicular cancer specific module that was designed to address QOL domains in TCSs. Concerning fertility, 30% of the patients reported trials to conceive, out of whom 77% were successful. The lowest success rates were noted after chemotherapy ($P = 0.028$). Those with high FSH levels had reduced fertility ($P = 0.001$). As a conclusion, gonadal dysfunction is common in patients with a history of testicular cancer regardless of the treatment modality. Those who receive chemotherapy are more prone to develop gonadal complications and tend to score low on QOL questionnaires. Although most patients preserve their fertility, the risk for infertility increases among those who are treated with chemotherapy. The authors recommended that all TCSs' gonadal functions should be screened on an ongoing basis (Huddart et al., 2005).

The above studies provide a baseline understanding of the long term survivorship problems of those who were previously diagnosed with and treated for cancer of the testes. All three studies are comparable in terms of the availability of a healthy matched comparison group and the tools used, with a mean follow-up of ten to eleven years. Furthermore, similar findings were obtained in the above studies in terms of fertility and sexual health whereby study participants scored low on items related to sexual health and fertility compared to healthy individuals.

Brodsky was the only researcher who addressed the needs of testicular cancer patients using a qualitative approach in two studies. Brodsky (1995) studied the views of 11 TCSs' about the impact of the disease on their lives via in-depth, open-ended interviews, using snowball sampling. The sample was recruited by mail via their oncologists. A formal face-to-face tape recorded interview was arranged with the participants. Open-ended questions such as "How did you discover that you had

testicular cancer?” (Brodsky, 1995, p.82) were asked. The findings revealed that the experience of living with testicular cancer affected the informants’ four selves: “Identification self, interpersonal self, body self, and achieving self.” (Brodsky, 1995, p.83). The author stated that the residual physical effects of the disease affected some of the patients’ relationships with others, whereas other informants reported that testicular cancer provided them with an opportunity to grow (Brodsky, 1995).

Brodsky (1999) later explored the experience of young men who underwent treatment for nonseminomatous testicular cancer in an ethnographic study using in-depth open ended interviews and field notes. He recruited a convenience sample of 15 patients with an average age of 35 years. Inclusion criteria were: “having nonseminomatous testicular cancer, receiving chemotherapy, and undergoing major surgery” (Brodsky, 1999, p.67). The informants chose the interview sites. Two interviews were conducted with each informant. The first interview was informal during which the researcher aimed at establishing rapport with the informant. The second interview was formal, tape recorded, and included questions about the experience of having testicular cancer. Field notes were taken during the second interview that lasted 90 minutes. The researcher identified the following themes: “disbelief, despair, under siege, physical and emotional challenge, and guarded optimism” (Brodsky, 1999, p.68). The researcher stated that findings from his study were congruent with those concerning males and their experiences with cancer and can assist in understanding the experience of testicular cancer patients.

In summary, the quantitative literature suggests that those who undergo aggressive testicular cancer treatment tend to score low on QOL domains that tackle sexual issues. Brodsky’s qualitative studies about testicular cancer showed that

experiencing this disease impacts various aspects of the participants' self-concept, body image, and social relationships.

In the absence of a profound examination of the QOL domains related to sexual health, a qualitative approach would help unveil the themes that might assist healthcare professionals to gain more understanding of the experience of Lebanese TCSs. The literature lacks qualitative studies of the experiences of TCSs, which leaves us with little information about the needs of this population except for the low scores patients had on the QOL domains related to sexual health. This gap led to the research question that was explored in this study, namely: What is the experience of Lebanese TCSs? And what are their sexual concerns?

B. Theoretical Framework

According to Sandelowski (2000, p.337), “qualitative descriptive studies are arguably the least theoretical of the spectrum of qualitative approaches, in that the researchers conducting such studies are the least encumbered by pre-existing theoretical and philosophical commitments.” Qualitative descriptive studies often draw from the naturalistic inquiry, which aims at studying the phenomenon of interest in its natural state rather than adhering to a theoretical view of this phenomenon (Sandelowski, 2000). Accordingly, the naturalist inquirer uses techniques that allow the phenomenon of interest to present itself as it would if it was not under study. In qualitative research, the conceptualization of the phenomenon under study is solicited from the participants and is based on their perspective, thus precluding the need for a prior theory to guide the study. In this study, the Lebanese TCSs' experience was defined by the TCSs

themselves rather than by pre-existing knowledge about the subject. Thus no theoretical framework was used as a basis for this inquiry.

CHAPTER III

METHODS

A. Research Design

This is a qualitative study where the qualitative descriptive approach was used to define the experience of TCSs, with a focus on the sexual aspect of their experience. According to Sandelowski (2000), certain qualitative research designs, namely phenomenological, grounded theory and ethnographic studies are not solely descriptive and are used to interpret phenomena. A qualitative descriptive design was chosen over a phenomenological design to elicit the experience of TCSs rather than examine the meanings that stand behind this experience. This does not imply that this study is free from an interpretive component given the sensitivity of the topic discussed. Additionally, the primary investigator (PI) served as the research tool and could not but employ some of his interpretations while reporting and analyzing the research findings. This study can guide more in depth investigation using a phenomenological approach since the trajectory of this patient population is quite different from that of other oncology patients, which may affect accessibility to this population.

B. Sample and Setting

A non-probability purposive sampling was used to obtain cases deemed information-rich for the purpose of the study. Those who were included in the study met the following criteria: (1) holding the Lebanese nationality; (2) aged between 18 and 50 years; (3) free from disease for a minimum of three years; and (4) willing to share

personal information and participate in the study. Patients excluded were those who did not consent to digitally recording the interview. Residents of Lebanon who do not hold the Lebanese nationality were also excluded since the investigator assumed that the cultural background of the participants was influential in shaping their experience as TCSs. The approval of the Institutional Review Board (IRB) at the American University of Beirut (AUB) was obtained. Initially, the plan was to recruit participants from the clinic of a renowned oncologist who has a diverse patient clientele from all over Lebanon. The oncologist sees over 40 patients per day with all kinds of malignancies, as opposed to other oncologists who are specialized in specific cancer types, such as breast cancer, head and neck malignancies and so on. The oncologist gave his written approval for the research team to recruit his patients for the study. The clinic nurse identified participants who fit the inclusion criteria from the clinic records. She called potential participants by phone using a standardized script in Arabic (Appendix I) to inform them about the study and asked those interested to participate to contact the PI, giving them his phone number. This measure was used to minimize intrusion of patient privacy. Those interested in participating contacted the PI in order to schedule an interview. An attempt was made to get a heterogeneous sample in terms of socioeconomic class and area of residence. In addition to the clinic recruitment, flyers about the study in Arabic (Appendix II) were hung in a renowned medical center's fertility clinic and sperm bank after obtaining the administration's approval. It was expected to recruit ten to twenty participants through these recruitment methods; however, only two participants were recruited from the oncologist's clinic whereas the flyers yielded no participants.

An amendment was submitted to the IRB to include an additional site for data collection. The clinic of a renowned urologist with varied clientele was included as a third site for data collection. A written approval from the urologist was obtained to

recruit participants from his clinic. The clinic assistant and the urologist were asked to identify potential participants. The assistant called potential participants by phone using a standardized script in Arabic (Appendix III) to inform them about the study and asked those interested to participate to contact the PI, giving them his phone number. Those interested in participating contacted the PI in order to schedule an interview.

A total of 23 TCSs from the clinics of both physicians, oncologist and urologist, were identified by the clinic nurse and assistant and their contact numbers were secured. Of the 23 TCSs, 15 did not participate for the following reasons: five did not answer the clinical assistant's phone calls, three had their phones off, and three were living abroad. Moreover, two TCSs informed the clinic assistant about their refusal to share their experience. After contacting the PI and knowing more about the study one TCS refused to have the interview digitally recorded, and one sounded hesitant and claimed that he had a kidney stone and not cancer. Thus only eight TCSs participated in the study.

C. Data Collection

Data was collected between March, 2012 and February, 2013. After identifying and contacting potential participants, a face to face meeting was arranged with interested individuals. At the beginning of the interview, an informed consent in Arabic was obtained from those who agreed to participate and have the interview digitally recorded (Appendix IV). Participants were not asked to sign their names on the informed consent form in an attempt to preserve their privacy and anonymity, considering the sensitive nature of the topic under study. Instead, they were asked to tick a box if they agree to participate in the study and another box if they consent to digitally recording the interview. Each interview was conducted in a place chosen by

each participant. Anonymity was promised through informing the participants that fictitious names will be utilized once the study findings are disseminated. Participants were assured that the digital recordings and soft copies of the transcripts, summaries, field notes, and demographic data will be kept on the PI's personal computer and will be deleted following the completion of the study. Participants were also informed that all hard copies of the study documents will be kept in a locked cabinet accessed only by the PI and will be destroyed by the PI once the study is completed to ensure confidentiality of data. The right for full disclosure was ensured through informing the participants about the goal of the study, what is entailed in participating in the study, in addition to explaining to them about the risks and benefits from their participation. The participants were then informed that there will be no direct benefit for them participating in the study, and that no harm is expected beyond risks encountered daily. The investigator told the participants that the study findings and recommendations will be shared with healthcare providers to propose a change in practice in a way to better meet the needs of TCSs. Moreover, study participants were given the full right to refuse to participate or to withdraw from the study at any time. Participants were assured that refusal to participate will not affect the care they receive by their physicians. They were also told that they may be uncomfortable with some of the sensitive questions and will be assisted as needed. A clinical psychologist agreed verbally to have his contact information listed on a referral to counseling form (Appendix V). The plan was to provide those who display psychological distress with the form. None of the participants was referred to counseling since no psychological distress was noted.

Before each interview, demographic data namely age, marital status, highest level of education completed, and current occupation were collected in writing in English by the PI (Appendix VI). Data was collected using a combination of

unstructured open-ended individual interviews and observational field notes. Primarily, interviews were conducted in Arabic; however a few participants preferred to use the Arabic and English languages combined. Field notes were taken in English. The participants were asked to choose a suitable time and to find a calm and private setting to conduct the interview. Two participants chose to conduct the interview in their home, two chose to be interviewed at work and three participants chose the PI's office to talk about their experience. One participant chose to have the interview conducted in the PI's car since he was busy and couldn't find a private place to share his experience. All participants were alone during the initial interview. All interview sites were calm and private. Digital voice recording was of a high quality. The PI faced no technical problems while using the digital voice recorder. Only a few interviews were interrupted, and then resumed due to minimal interferences such as phone calls to the participants.

All interviews lasted between 14 and 36 minutes, with an average of 24 minutes and were all digitally recorded. Each interview started with an icebreaker: "How are you doing these days? Are you working? Studying? How is your overall health?" Next, each participant was asked: "Tell me about your life since you got treated for testicular cancer." The interviewer was an active listener and served as the research instrument. Probing questions were utilized to enrich the data being collected and to elicit more explanation of the phenomenon of interest. Probing questions used were: "What changed in your life since the diagnosis/treatment? How do you see yourself after you got treated? How was your sexual life affected after you got treated for testicular cancer? What about your personal relationships? Can you please tell me more about them? What about your sexual performance? What about your fertility? Were there any problems? Tell me more about them." (Appendix VII). Field notes were taken down throughout the interview to record nonverbal cues that were not identified using the

digital voice recorder. These notes captured emotional reactions made during the interview. The interview was transcribed verbatim following the initial encounter with each participant. Each interview was summarized in Arabic by the PI. Two to three weeks following the initial interview, participants were contacted by phone by the PI and asked to evaluate critically the summary of the interview and provide their feedback. All eight participants agreed on the summary, thus no corrections were made.

D. Data Analysis

"Qualitative content analysis is the analysis strategy of choice in qualitative descriptive studies." (Sandelowski, 2000, p.338). This strategy allows the researcher to analyze both verbal and non-verbal data obtained from the participants and was used in this study. Given the qualitative nature of this study, data collection and analysis took place concurrently. Qualitative content analysis is both reflexive and interactive since the researcher continuously modifies his data to accommodate new knowledge and insights. For example, as one of the participants mentioned prosthesis in relaying his experience, the PI sought information about whether or not prosthesis was used in subsequent interviews. Despite being the least interpretive among other qualitative data analysis methods, qualitative content analysis aims at understanding both the manifest and the latent content of data (Sandelowski, 2000).

Bracketing was used to prevent the researcher's preconceived ideas from affecting data analysis. The PI employed bracketing through keeping his preconceived ideas about the experience in check during each interview. Following data collection, codes were identified, then clustered and a category scheme was developed to organize the data obtained. Transcribed data were read carefully with a fresh eye in order to

identify underlying clusters of concepts. Following the development of a category scheme, the data were reread thoroughly and themes that connect the various categories were identified. Manual methods were used during the analysis phase of this study. Each category was translated to English, typed, printed, and color coded for differentiation. The categories were then clustered and synthesized into themes. Every core theme that flows from the categorical clustering of data collected was supported by excerpts from the participants to underline the influence of the phenomenon on their lives. Findings from the field notes were used to enrich the data through illustrating the reaction of the participants to the investigator's inquiries. At interview seven, no new themes emerged from the data, so one more interview was conducted to ensure data saturation and again no new data were elicited. Thus data collection was ceased at eight interviews.

E. Establishing Trustworthiness

In qualitative studies, trustworthiness is established through credibility, confirmability, dependability, and transferability (Holloway & Wheeler, 2002). Credibility in this study was enhanced by combining two data collection approaches, namely unstructured in-depth interviews and field notes, a method called triangulation. Confirmability was addressed by member check, whereby summaries of the interview data were shared with the study participants who were asked whether the summary reflected their experiences as perceived by them. Participants overall agreed with the PI's account of their experiences. Dependability was examined using intercoder reliability, whereby both the PI and the thesis adviser read through transcripts of all eight interviews independently and analyzed the data. The PI and the thesis adviser's

interpretations of the findings were then compared and areas of disagreement were discussed thoroughly in order to achieve consensus and clarify the data collected. There was very minimal disagreement between the PI and thesis adviser, thus supporting dependability of the data. Transferability was attempted through thickly describing the setting where the recording and field notes took place, in addition to noting the reaction of the participants to the interviewer's probing. Moreover, the sample itself was heterogeneous in terms of age of participants, their marital status, socioeconomic status, time since diagnosis, and type of treatment received, thus supporting transferability which is defined by Polit et al. (2012) as "the extent to which qualitative findings can be transferred to other settings or groups" (p. 745).

CHAPTER IV

RESULTS

Participants' ages ranged between 32 and 50 years, with a mean age of 41 years. Six participants were married and two were single. All participants were from different educational backgrounds ranging from elementary to graduate education. The sample included two businessmen, two managers, two skilled laborers, one engineer, and one bank employee. Participants were interviewed three to 15 years after completion of treatment, with a mean duration of six years. They underwent various treatment modalities; five underwent orchiectomy and chemotherapy, two underwent orchiectomy alone, and one underwent orchiectomy together with radiation therapy. When asked how their life is since they got testicular cancer, most participants answered positively, as if cancer and its treatment were behind them. The majority of participants reported preserved attributes following testicular cancer namely their functional health, sexual performance, and body image. Additionally, several participants identified numerous facilitators that made their transition from disease to cure easier. Only a few opted to describe the various stages they went through from diagnosis till the present time, whereby they described the shift they experienced from fear and anxiety upon learning of the diagnosis and undergoing treatment, to restored hope following cure.

This chapter presents the results with excerpts to exemplify the themes. Some of the excerpts are accompanied with field notes that captured emotional reactions made during the interview. Pseudonyms are used in referring to the participants. Six core themes emerged from data analysis. The themes were: cultural views of cancer,

concealing cancer diagnosis, cancer experience is a turning point in one's life, concern about fertility, coping with cancer and its consequences, and unaffected aspects of life.

A. Cultural Views of Cancer

In telling their stories, participants provided accounts that reflected the prevailing beliefs about cancer by society and themselves. The main cultural views revolved around the meaning of cancer and how cancer patients are perceived by others.

1. Cancer Means Suffering and Death

Cancer diagnosis and specifically the word "cancer" had a great impact on many of the participants and their families. Tarek's preexisting notion about cancer made him link it to suffering. He said: "*I know that the cancer patient will suffer... the situation became a mess, I was still wondering what is happening to me, then that's it, I have cancer.*" Khaleel and Adnan linked cancer to death. Khaleel said: "*We are talking about cancer... I am one of those who collapsed... I used to hear that cancer means death.*" Adnan said: "*You reach a stage when you directly say that it's over; I am gone because people think that cancer is fatal.*" Younes considered that cancer is one of the toughest experiences of his life. He said: "*It passed, I considered it one of the toughest experiences one can live... you live in a dilemma that you might live or might die, I think this is one of the toughest things one can endure.*"

2. Pitying Cancer Patients

Some participants expressed certain degree of distress due to the way people perceived them. Bassem conveyed his frustration from people's pity. He said: *"You see people saying sorry Bassem, I tell them why are you sad? I am not sad, why are you bowing your heads? Are you feeling sorry for me? Raise your heads; I am walking with a head held high."* Bassem also expressed loathing the sick label. He said with a firm voice: *"I was fighting with a policeman at the entrance of my shop; he said that he won't answer me because I am sick, so I pulled him to me and slapped him and told him I'll show you who the sick one is."* Younes concealed his diagnosis from certain people because of his fear from their reaction. He said: *"I hid it [cancer diagnosis] from some people who would look at me with a look full of pity."* On the other hand, Wassim talked about the way he perceived cancer patients and the pity he felt towards them before he got diagnosed with cancer himself. He said: *"It was the first fall for me. I used to look and say, Oh, poor man, look what is happening to him"*. Wassim also expressed the way he felt when medical students tried to conceal the cancer diagnosis from him. He said: *"In the hospital, four or five trainees reached my door and told each other please don't tell him what he has, Maybe he would get upset...but I know what I have!"*

B. Concealing Cancer Diagnosis

The initial reaction for many participants was not to tell anyone about their diagnosis. They first needed time to absorb and process the news before they could share it with others. However, many participants opted to keep it from others for a long time. Two reasons drove the decision not to tell others about the diagnosis: protecting the family and avoiding becoming the talk of the town.

1. Protecting the Family

Several participants chose to conceal cancer diagnosis from their families in an attempt to protect them from the bad news. Tarek refrained from informing his sister about his diagnosis because she lost a son for cancer. He said: *“My sister doesn’t know that I got sick with cancer... she still doesn’t know. I took chemotherapy and lost my hair and some occasions passed and I didn’t go out because I didn’t want anyone to see me and go tell my sister.”* Adnan created a plot to conceal his diagnosis from his mother. He said: *“My mother sure did not know because I think she would die if she knew... she has no idea about the subject... we spoke to the doctor and told him not to mention it.”* Adnan made his mother think that orchiectomy was actually a varicocele surgery.

Khaleel was even more secretive; he tried several scenarios to hide his diagnosis. He said: *“My biggest worry was that I don’t want my parents to know about the subject... at that time I was able to do anything but face them... I told them that I have to undergo a surgery because I have a kidney stone... I took chemotherapy and told them that I am losing my hair while showering... I even visited a dermatologist to ask him in which conditions does the person lose hair other than taking chemotherapy because I don’t want my parents to know.”* Khaleel shed a few tears while talking about concealing his diagnosis from his family. Wassim chose to remain secretive about his diagnosis at first, but eventually told his parents the truth. He said: *“I didn’t want to bother them; I did hide the truth at first and then gradually started telling them the story.”* On the other hand, Dani was the only participant who did not know about his diagnosis until later in the course of his illness. He said: *“The doctors didn’t tell me, they told my father and my brother”*. When asked about the reason behind him not

knowing, Dani said: *“I don’t know maybe because it is cancer and they [his father and brother] are scared from telling me this stuff.”*

2. Avoiding Becoming the Talk of the Town

Some participants refrained from spreading the news about their cancer diagnosis primarily because of their fear from becoming the talk of the town. Younes concealed his diagnosis from many people in his entourage. He said: *“I avoided many people because they will ask why and how it happened... they would make you the center of their talks... I didn’t like that.”* Dani had the same concern as Younes; he lived in a small village and chose not to tell his neighbors or colleagues. He said: *“At work I kept my head shaved... I didn’t want to tell anyone... especially here in our village, if they knew that I was sick, the news would spread in the whole village. Thank God, nobody knows.”*

The participants were overall selective in choosing who to tell about their diagnosis besides their immediate family. For instance they would confide in only a few work colleagues or close friends.

C. Cancer Experience is a Turning Point in One’s Life

As seen in the review of the literature on Lebanon, testicular cancer is a rare disease, which leaves many people with little information about its detection, treatment, and prognosis. Most participants in this study reported not having heard about testicular cancer before being affected by it. Many discovered the disease accidentally and were not aware that it can actually be cured. Thus, going through the ordeal of the illness and

treatment, then proceeding to their usual life created a turning point for them. This change in their life was positive for the most part, such as motivating them to lead a health promoting life style or causing an increased self-esteem. However, for some participants, there were negative repercussions of this experience such as long term effects on their health or constant fear from recurrence.

1. Health Promoting Lifestyle

For some participants, cancer was seen as an opportunity to make positive changes in their life. Wassim for instance made key changes in his lifestyle. He refrained from unhealthy habits and implemented a health promoting lifestyle. He said: *“My life changed, all of it, it became healthy, I used to smoke and drink alcohol, my life was all hyper. I became calm and sporty. I stopped smoking and stopped alcohol... I followed a totally different diet.”*

2. Increase in Self-esteem and Growth

Many participants perceived that defeating cancer paved the way to a new start, causing a boost to their self-esteem, and an opportunity for them to grow. Bassem spoke about improving his life and moving forward. He said: *“As long as I have a good health and as long as my outlook on life is right, I want to move forward and not take a step back... I forgot about the past... I have to evolve and grow, I can't remain the same.”* When asked about the way he perceived himself after cure, Younes said: *“I felt stronger and my self-esteem increased.”* Wassim thought that his life changed significantly. He was smiling and said cheerfully: *“A new life was born for me, six to seven years ago my*

life ranged from minus infinity to zero, now my life is plus infinity and the sun is shining!”

3. Long Term effects of Cancer Treatment on Health

The negative influence of cancer and its treatment on the overall health of many of the participants was noted, especially among those who received chemotherapy or radiotherapy. Following chemotherapy, Younes’ creatinine increased. He said: *“After surgery I was supposed to take six cycles of chemo but I took five, I couldn’t take the sixth because my creatinine increased.”* When asked whether his creatinine dropped back to normal after chemotherapy, Younes said: *“My creatinine didn’t drop; it never came back to its normal value.”* An increase in serum creatinine is known to be a side effect of the chemotherapeutic agents used to treat testicular cancer. Another effect of chemotherapy was reflected in the decrease in Tarek’s activity level. Tarek talked about easy fatigability and physical exhaustion. He said: *“After chemo, I did a test for the nerves of my legs and arms; approximately 30% loss of function was seen. There was a time I used to play football but then I felt that my knees cannot hold me anymore so I stopped.”* Tarek also linked his infertility to chemotherapy. He said: *“Most probably my sperm won’t be back after chemo.”* Bassem also complained of fatigue and blamed it on chemotherapy. He said: *“My bones are not like they used to be, I am not strong like before because large amounts of chemo were given.”* Bassem also related chemotherapy to his inability to conceive. He said: *“Chemotherapy took my fertility away... I can’t have kids anymore.”* Like Bassem, Khaleel linked his treatment to infertility. He said: *“Cisplatin [chemotherapeutic agent] is one of the medications they gave in the treatment that I took... it is not possible for one to conceive after taking it.”* Similar to

chemotherapy, radiotherapy is also known to affect fertility. This cancer treatment modality caused Wassim to developed azospermia. He said: *“After radiotherapy, I did several spermograms and all of them showed zero sperm count.”*

4. Constant Fear from Recurrence

On top of the long term effects of cancer and its treatment, many participants expressed their fear from cancer recurrence. Tarek said: *“Up until now, from the time I do a CT scan... and the alfa feto... from the time they draw blood till the time I get the results, I feel that I am in a different world.”* This is a Lebanese expression that denotes anxiety and worrying. Adnan’s worry from recurrence pushed him to do frequent tests. He said: *“The doctor told me to do them [follow up tests] every six months but I am doing them every three months for reassurance.”* Compared to other participants, Younes’ fear of recurrence was predominant. He said: *“It becomes an obsession because you have something that might recur.”*

D. Concern about Fertility

As the participants engaged in telling their stories, they identified the possibility of infertility from cancer and its treatment as the main issue that their illness brought with it. These young men either were newlyweds at the time of diagnosis or were still single and dating. Fertility was an important aspect of their lives. For some, fertility served as a determinant of their identity as men and partners. This aspect reflected the Lebanese culture’s beliefs and expectations.

1. Pressure from Being the Only Son in the Family

Two participants talked about the pressure from being the only son in the family in terms of fertility and ability to conceive, so as to preserve the continuity of the family tree. Khaleel concealed his cancer diagnosis and subsequently the reason behind his infertility from his parents. He felt pressured to marry at a late age because of the cultural view of the only son in the family. He said: *“I was 40 years old in the year 2002, I was not young anymore. In Lebanon it is unusual for an only son to stay single till 40. Usually the only son marries early.”* Wassim was also his parents’ only son. He expressed the happiness his family and close friends felt after knowing that his wife is pregnant following several failed trials to conceive. He said cheerfully: *“What can I say! I am my parents’ only boy... if only you can see how the whole family felt, see how all the people who love us felt... people are now coming to congratulate me because my wife is pregnant.”* Wassim was very emotional as he reported his experience since he and his wife went through a lot and were about to adopt because they were on the verge of losing hope to conceive. His reaction substantiated the importance of having children for both him and his family.

2. Being Accepted/Rejected by Partner

Adnan’s fertility status did not affect his relationship with his wife. While he was concerned about his fertility, his wife’s only concern was him getting better. She told him: *“I don’t care, I don’t want kids, I just want you to get better.”* Dani, who was single at the time of diagnosis, had concerns about being rejected. He said: *“If I want to propose to a girl and she would know that I have only one testicle, she might reject me.”* Khaleel’s infertility had led to the termination of a serious relationship. He said: *“It*

[infertility] was a big problem; I was in a relationship with a girl, this [infertility] was a strong enough reason to terminate the relationship.” He sounded nostalgic and continued: “It started as a nice and serious relationship but it ended there and it affected me later on.” Three years after knowing about his infertility, Khaleel proposed to a woman and was honest about his fertility status. After informing her about his infertility, he told her: “Before you give me any answer, I will go and come back after two weeks so that you would take some time to think... I am a man who cannot have kids but I promise you I will do my best.”

The importance for a man to be able to conceive also shaped how Khaleel saw himself. “An infertile man... the way people perceive him makes him want to beat himself... I suffered... a man is about sex and kids to a certain extent”; that’s what Khaleel said when asked about the way he perceived himself after knowing that he was infertile.

E. Coping with Cancer and its Consequences

Participants relayed various means that helped them cope with the ordeal of their illness, its treatments, and consequences. The predominant coping strategy was faith in God. Coping was positive for the majority of these young men. Feeling supported by family members who were aware of their cancer diagnosis, in addition to the support provided by their physicians and healthcare providers acquaintances allowed several participants to cope with cancer and its treatment. On the other hand, some participants used emotional coping to avoid dealing with certain aspects of their experience.

1. Faith in God

Most participants identified their faith in God as the primary reason for overcoming cancer at the time of diagnosis, during treatment, and afterwards. Bassem considered that cancer was sent from God and that it was God's will that took cancer away. He said: *"God gave me a gift... God gave me cancer and then took it away... he gave me the power to live in order to improve myself."* Adnan experienced high levels of stress following cancer diagnosis. When asked how he overcame the stress, Adnan said: *"I went back to my faith in God, increased prayers, and became closer to God."*

Fatalism was imbedded in some of the participants' responses; for instance, Khaleel said: *"My reliance is on God, maybe I am trying to satisfy myself or to make it easier on myself, but at the end, this is God's will."* Tarek, whose reliance on the creator helped him cope with his diagnosis and decide on the treatment, said: *"When the creator wants to do something, he just does it, this is a stage that I have to go through, that's the creator's will, I can do nothing about it... I trusted in God and started chemotherapy."* Likewise, Dani's faith in God helped him overcome the burden of chemotherapy. He said: *"Thank God, every time I go to the hospital, I say thank God."* Wassim's faith in God helped him surmount cancer, and the infertility that resulted from it. He said: *"We all worship our creator, but the faith I have in God and his prophets is extraordinary... I am a person with a strong faith... I started with the treatment, the doctor told me I don't have a big percentage [to conceive], I went to visit the shrine of a prophet, came back, and underwent the procedure and now my wife is pregnant, can you believe it?"*

2. Self-management and Empowerment

Some participants sought information about cancer and its prognosis in order to cope with their diagnosis. Tarek said: *“I used the internet and saw that there is 98 to 100 percent cure rate for my condition; even there are conditions where cancer was spread to the lungs and was then cured. Thank God my cancer was confined to my testicle only, that’s how I calmed myself.”* Adnan also used the internet to learn more about his diagnosis. He said: *“My wife and I searched on the internet and found out that my cancer is the mild one... this news made me feel better.”*

3. Being Supported by One’s Partner

The majority of participants felt supported by their partners, especially those who were married. Many participants talked about the closeness between them and their wives during the course of their illness and while dealing with the long term effects of cancer and its treatment. Wassim said: *“The good thing about her [his wife] is that she stood by my side... both of us, hand in hand, were able to overcome this bad stage and start a new life.”* The attitude of Tarek’s wife helped him overcome the shock after knowing his diagnosis. He said: *“My wife was next to me, she told me it will pass... we were both very close.”* Likewise, Adnan’s wife stood by his side throughout the whole experience. He said: *“My wife and I, we supported each other... she stood by my side and was considerate... I thank her and respect her a lot... our relationship became even better.”* Despite knowing about his infertility, Khaleel’s wife accepted to marry him in 2002 and they kept on trying to conceive till 2012. While talking about their failed trials to conceive, he said: *“When it [assisted reproduction] didn’t work, we used to get upset, both of us, at times she used to calm me down.”*

4. Being Supported by Healthcare Professionals

Participants alluded to the important role of their physicians in helping them cope with their illness. They reiterated how the supportive approach of their physician was instrumental in raising their hope in dealing with their cancer. One of the factors that helped Bassem endure his treatment was his relationship with his oncologist. He said: *“He gave me self-confidence; every time I tell him I am tired, he tells me that I am fine... he was fighting the disease with me.”* Younes’ urologist explained to him about his cancer and his prognosis, which made him feel at ease. He said: *“He helped boost my morale; he told me that we get upset it is cancer, but we are glad we can control it.”* After noticing Wassim’s shock, his urologist explained to him about his disease. Wassim said: *“My doctor told me, if you want to choose between these cancer types, yours is the mildest.”*

Moreover, knowing a healthcare provider helped many participants cope with cancer and its treatment. Younes’ brother was a nurse. He said: *“What really helped me is that I have a nurse with me... my brother is a nurse.”* Tarek’s physician was a family friend. He said: *“My doctor and I are close, he tried to make it easier on me, and he told me not to worry.”* Fouad felt comfortable talking about his diagnosis with his brother in law who happened to be a physician. He said: *“I was scared... what helped me is that my brother-in-law is a doctor and usually you talk to a relative you know to explain to you, and it was somehow comforting.”* Following his orchiectomy and before taking chemotherapy, Khaleel sought the opinion of a physician acquaintance. He said: *“There was a physician, he was a good friend and a relative... I used to go and meet him, he explained the situation to me and he somehow made me feel at ease.”* Physicians and acquaintances who happened to be healthcare professionals served as a solid support system for most of the participants. Many TCSs mentioned “comfort” and

“reassurance” while talking about healthcare professionals who were involved in their care during cancer, its treatment, and following cure.

5. Knowing Someone with One Testicle

Another factor that helped some participants cope with their condition was their knowledge of men who were living with one testicle, as was the case with Adnan and Younes. Adnan said: *“I know a lot of men with this problem and they continued their lives normally.”* Younes had a friend who was living with one testicle because of testicular torsion. He said: *“I know someone who has been living with one testicle for a long time. It was not cancer, it was torsion. I know him well and I know he has kids. That’s another factor that helped me cope.”* Although none of the men living with one testicle served as a direct source of support, knowing that these men are leading a normal life gave some of the participants a sense of reassurance and hope.

6. Emotional Coping: Avoiding Bad News

Some participants opted not to seek information about the negative consequences of their illness, in terms of its effect on their fertility or its spread beyond the testicles. Both Bassem and Tarek refused to do a spermogram following chemotherapy. Nervousness was noted in Bassem’s voice as he talked about his fertility. He lowered his voice and said: *“I don’t think I can have kids... my doctor told me to do a sperm count, I refused, I was afraid the result would affect my psychological wellbeing... I didn’t do it”.* Bassem even refused sperm banking. He said: *“My doctor told me to store sperm in the sperm bank, I refused. When God wants me to have a child he will give me one.”* Tarek did sperm banking and kept on renewing his account, i.e.

donating a specimen every year, but did not undergo a spermogram after the completion of his treatment. He said: *“I used to renew my sperm bank account but did not want to do the sperm count... I did not want to know that I cannot have kids anymore... every time I visit my doctor I ask him for a request to do a sperm count but then I throw the request away.”*

Younes was aware that his cancer is not confined to his testicle only but did not go into the details of the metastasis. He said: *“I still do CT chest, abdomen, and pelvis, there’s something, what do you call it? Something very mild and stable.”*

F. Unaffected Aspects of Life

As noted before, all participants started the interview by stating that their life is good and they are in good health at the current time. Most of them were able to preserve elements of their physical and psychological health as shown below.

1. Functional Health

None of the participants reported functional impairment throughout their experience. An example is Younes who said: *“Chemo is a bit tiring... I used to take the day off and then go to work a day or two after chemo.”* When asked whether chemotherapy annoyed him, Tarek said: *“when I first took chemo I did not feel anything... the second day or the third day after chemo I used to go to work... I got nauseous a few times but everything was tolerated.”* Adnan started a new job a day prior to his orchiectomy. He said: *“A day before surgery, I started a new job. I went and signed my contract and then went to the hospital. This also made me decide not to take*

chemical treatment.” Adnan then laughed and said: “I don’t want them to be afraid of me. If they saw me tired because of treatment they would say that their new employee is about to die.” Still the tiredness from treatment was temporary and none of the participants stopped working as a result of their illness.

2. Sexual Performance

The majority of participants denied a decline in their sexual performance. An example is Wassim who, when asked whether his sexual performance changed, laughed and said: *“No no, thank God it’s completely the opposite... my sexual life improved.”* When asked the same question, Bassem also laughed then lowered his voice so that his wife in the other room won’t hear him and said: *“My sexual performance was very good; I am still like before. We used to laugh, my wife and I, and I used to tell her chemo is improving my performance.”*

A few participants reported lack of sexual contact with their partner at the time of diagnosis and during treatment. Adnan said: *“Sex is a kind of pleasure; you won’t do it well if you weren’t comfortable. During the first stage you will definitely not think about it... I was feeling down at first but after I was done, everything got back to normal.”* Tarek said: *“from the time I underwent the surgery until I finished chemo there was no sexual contact because everything was a mess. I was afraid the chemo I was taking would affect the baby in case my wife got pregnant... my sexual performance after chemotherapy was not affected... I thought that something would change in my sexual performance since I lost a testicle, but nothing changed.”*

Fouad was the only one who reported a decline in his sexual desire; however he did not show distress because of it. He said: “*It [cancer] affects the desire somehow*” when asked by how much his desire dropped, Fouad said confidently: “*It decreased by 25 percent.*”

3. Body Image

Only few participants complained of a mild change in their body image. Most of the participants did not mention anything about body image changes. Younes said: “*it’s all about the looks, and the looks don’t really matter to me.*” Likewise, when asked whether his body image was altered, Wassim said: “*Not at all, not at all, not in any way.*” Adnan and Dani were those who reported mild changes in their body images. When asked about his body image following orchiectomy, Adnan laughed and said: “*At first, you notice changes in your clothes while sitting, and you lose the balance, they [genitals] become in one place... this bothered me in the beginning but now it’s normal just like anything else.*” When asked the same question, Dani answered: “*When I use the bathroom and when I shower, I feel there is something missing, a testicle is missing, but it does not affect me at all.*”

When asked whether the resected testicle was replaced by a prosthesis, seven participants said that they refused to introduce a foreign object into their body and one said that his physician did not offer him this option. Some of the participants expressed their fear from the side effects of the prosthesis and others said that an artificial testicle would not have any additive benefit to their sense of manhood.

Adnan refused to have his testicle replaced with an artificial one because he was concerned about the long term effects of the foreign body. He said: *“I did not put a prosthesis, I don’t want this stuff to enter my body. It might cause me problems on the long run.”* However, the fact that Adnan had one missing testicle affected his manhood. He said: *“You feel, at a certain point, that your manhood is affected.”* Dani also refused the prosthesis due to his fear from its side effects. He said: *“Nobody recommended it [the prosthesis]... it might cause me pain or might affect my second testicle.”* Like Adnan and Dani, Younes had a concern about the prosthesis. He said: *“I refused because it’s only about the appearance, I was afraid that the prosthesis would cause infections and other problems.”* Younes believed that a missing testicle does not affect manhood. When asked whether his manhood was affected, he said: *“No, manhood is not this way.”* Wassim expressed his refusal of the prosthesis since, for him, an artificial testicle does not define manhood. He said: *“It [the prosthesis] is of no importance to me, this is not what will make me a man. I don’t feel anything is missing.”* Overall, the participants did not feel that a prosthesis can benefit their body image after the loss of their testicle.

In summary, the findings reflected societal views about cancer, cultural beliefs that shaped how the participants coped with their illness, and the main aspects of life that were affected by this experience.

CHAPTER V

DISCUSSION

This study serves as the only effort made to describe the experience of Lebanese TCSs and explore various aspects of their lives. Generally speaking, the study findings are congruent with those of similar studies that address long term testicular cancer survivorship. In this chapter, results from the study will be discussed in line with pertinent literature and the cultural context of the study.

“Culture is the most significant factor that affects how the individual perceives health.”(Saca-Hazboun et al, 2011, p.282). For many participants, culture played an essential role in defining cancer as a source of suffering or even death. Moreover, several participants displayed an aversion to the pitiful reactions people had towards them after learning of their diagnosis. These findings are consistent with those of a study conducted by Doumit et al. (2007) about the lived experience of Lebanese cancer patients receiving palliative care. Dislike for pity was identified as a core theme since it pushed many participants to perceive themselves as weak and hurt. Additionally, Doumit et al. (2007) tackled the way the Lebanese society perceived cancer as a debilitating disease and a source of suffering and death. Pity also appeared in another study conducted by Doumit et al. (2010) on Lebanese women living with breast cancer. In this study, the association of cancer with death caused many participants to take time to believe that this cancer can actually be cured. This echoes the guarded optimism found by Brodsky (1999). It is also worth mentioning that most participants never heard of testicular cancer before and did not know about it. A number of participants discovered the disease accidentally while seeking help because of their inability to

conceive. Some saw blood in the ejaculate and others noticed a change in the size of the affected testicle. Many participants stated that they never heard of testicular cancer until they were diagnosed with the disease which reflects lack of knowledge of this condition and its detection. The suffering and fear of death anticipated by participants support the interpretation of their lack of knowledge about this condition since, unlike the majority of other malignancies, testicular cancer is short lived and curable.

In the Lebanese culture, the family is still perceived as an influential unit that nurtures its members and contributes to their growth. Additionally, in the Lebanese culture, only sons are usually expected to marry and conceive since their offspring will be holding the family name. This was identified as a source of distress and pressure for certain participants. Many TCSs chose to conceal their cancer diagnosis from their families and surrounding in an attempt to protect them from the bad news and to prevent becoming the talk of the town. Though not verbalized explicitly, some participants concealed their diagnosis to protect themselves from their families' reaction to the news. These findings are consistent with those of Doumit et al. (2007), whereby several participants expressed their worry about their families and significant others. They also identified themselves as a burden and a source of worry to their loved ones. Worries and concerns about families were not found in the studies by Brodsky (1995) and (1999). Participants in the studies by Brodsky (1995) and (1999) did not mention concealing their cancer diagnosis from their families or trying to protect them from bad news. Their focus was on their own experience and concerns rather than those of their families. One reason could be the individualistic nature of the American society versus the collectivist nature of the Lebanese society. The only time participants in the study by Brodsky (1995) mentioned their families, was when they expressed the closeness they felt between them and their loved ones following cancer treatment.

Fertility was identified by the majority of participants as one of the most important and sensitive topics during cancer aftermath especially that many were newlyweds and looking forward to start a family at the time of diagnosis. Additionally, the concern of parents regarding their sons' ability to conceive was identified as a major stressor, especially among those who were their parents' only sons. On the other hand, in the studies by Brodsky (1995) and (1999), participants did not express their families' concerns about their fertility.

These findings again highlight the importance the Lebanese culture attaches to fertility and the involvement of one's family in these issues. In her ethnographic study of infertility in the Middle East, Inhorn (2004) found that "Infertility is not only a stigmatizing and potentially emasculating condition for Middle Eastern men, but the technologies designed to overcome it add additional layers of stigma and cultural complexity." (p. 163). Though none of the Lebanese TCSs expressed a sense of emasculation because of assisted reproductive techniques, some believed that fertility demarcates manhood; therefore, when fertility is affected, masculinity becomes at stake. Nieman et al. (2006) tackled the late effects of cancer treatment on the fertility of cancer survivors. Tension and rejection in intimate relations was identified among the psychosocial concerns cancer survivors have. Data from the study on the experience of Lebanese TCSs agree with findings of Nieman et al. (2006), especially that many TCSs regarded their fertility status as an important predictor of whether they will be accepted or rejected by their partners.

The cancer experience as a whole served as a turning point in the lives of many participants. Some of the changes inflicted by cancer were regarded by a number of participants as positive since they gave them strength and contributed to their growth. On the other hand, certain changes were perceived as negative and led to long term

changes in health as well as constant fears and worries. Positive changes perceived by Lebanese TCSs are similar to those identified by participants in the study by Brodsky (1995) whereby they reported a renewed appreciation of life. Furthermore, Lebanese TCSs perceived the cancer experience as an opportunity for emotional growth and prosperity, especially that they overcame death and endured the suffering of cancer treatment. Similar findings pertinent to growth and self-actualization were identified in another study conducted by Brodsky (1999) about the experience of young testicular cancer patients who underwent cancer treatment.

Many participants reported fertility problems and inability to work for long hours or engage in the sports they used to enjoy prior to cancer diagnosis. They identified cancer treatment as the primary reason for their fertility problems and the decline in their capacity to endure physical effort. Many participants, especially those who received chemotherapy, said that their bodies are not the same anymore, with a few reporting having some aches or less strength than before. These findings concur with those by Rossen et al. (2009) who reported that patients who received chemotherapy reported more physical symptoms compared to healthy subjects from the general population and Fosså et al. (2003) who found that chronic fatigue among TCSs exceeds that of the general population. In their study about fertility, gonadal, and sexual function in TCSs, Huddart et al. (2005) found that 30% of TCSs reported trials to conceive. Failure to conceive was noted among those who received chemotherapy, as was found in this study. It was concluded that those who take chemotherapy are at a higher risk for infertility. The findings from all three studies support the insights obtained from Lebanese TCSs.

Besides the long term effects of cancer and its treatment on health and fertility, participants were concerned about cancer recurrence; some even described it as an obsession. Skaali et al. (2009) explored fear of cancer recurrence among 1336 long term TCSs. Participants were recruited from five Norwegian university oncologic departments. They were asked to fill a questionnaire about their medical and social status. They were then asked to complete tools on mental distress, fatigue, QOL, coping, self-esteem and neuroticism. Participants were also asked to report any fear of cancer recurrence in the past week. The authors found that 31% of the participants displayed fear from cancer recurrence, which was positively correlated with mental distress, fatigue and neuroticism. It was concluded that fear from recurrence is common among long term TCSs. The study findings reflect the same concerns that Lebanese TCSs have regarding cancer recurrence.

Participants utilized various means to cope with their illness, its treatment, and aftermath. Faith in God was regarded by all participants as the primary factor that allowed them to move forward with their lives. Participants perceived God as a comforting figure that held their hand throughout their experience. "Reliance on God and divinity" (p. 313) was identified by Doumit et al. (2007) as a core theme in the study about the lived experience of Lebanese cancer patients receiving palliative care. Additionally, participants in the current study dwelled on how the disease was sent by God and how only God could take it away. Likewise, fatalism was evident when participants attributed their disease to God's will. Findings from these two studies strongly support "Faith in God" as an imperative strategy used by Lebanese TCSs to cope with cancer, its treatment and long term effects, and is at the core of the Lebanese cultural beliefs in response to health and illness.

The majority of participants who had partners stated that they felt supported by their partners throughout the cancer experience. The vital role partners played surfaced when TCSs were asked about the strategies they used to cope with the long term effect of cancer and its treatment, especially infertility. Most of the participants stated that the whole cancer experience pulled them closer to their partners and strengthened the bond between them. Similar findings were identified in the study by Brodsky (1995), where participants verbalized their appreciation of those who were emotionally involved in their care.

Interestingly, some participants refused to know details about their disease and others refused to know whether they can conceive or not. Though they did not want to know bad news, some of the participants said that they thought they could not conceive anymore. According to these participants, knowing about their fertility status might affect their psychological wellbeing. It is believed that this coping strategy was sought by some of the participants because of its protective effect. Surprisingly, similar findings were presented by Brodsky (1995) in a study conducted in the United States two decades ago. Brodsky (1995) said: “Interestingly, a few had chosen to remain ignorant, yet were curious about their fertility status.” (p. 88).

Ancillary findings that appeared exclusively in this study and were poorly explored or supported by the literature served, to a certain extent, in allowing the participants to cope with cancer, its treatment, and its consequences. These strategies included: seeking information about cancer, being supported by healthcare professionals, and knowing someone with one testicle. Most of participants are young, educated, and have access to resources such as books, journals, and the internet. Many TCSs utilized these resources to read about their disease and its treatment. Knowing that

testicular cancer is curable was reassuring to many participants; it allowed many to cope with their diagnosis and look forward to cure.

The participants' physicians played a vital role in dissipating the anxiety associated with cancer and its treatment. Some participants said that their physicians fought the disease with them, which helped them cope better throughout their experience. In the Lebanese culture, physicians are more available to their patients compared to the West; doctors often give their mobile phone numbers to their patients and answer their concerns outside the confines of the clinic. This aspect facilitates the coping process and provides another source of social support. Moreover, having a physician or a nurse in their families or entourage played a positive role in helping some of the participants cope, as they felt that there is always someone they can revert to. Additionally, seeing other men living with one testicle and leading normal lives was reassuring to some of the participants and gave them a sense of relief and hope to build a family and advance in their lives.

Certain attributes were preserved following cancer and its treatment. These attributes include: functional health, sexual performance, and body image. None of the TCSs reported work impairment. Participants were either still in the same job, started their own business, or moved to a better job. Following cancer, many participants seemed determined and looked forward to grow. Their outlook on their professional life shifted to the better. These findings are congruent with those of Brodsky (1995) whereby many participants perceived professional growth as a means for self-achievement and prosperity.

All study participants denied a decline in their sexual performance. Only one participant said that his desire rather than performance declined, which was not

perceived as distressing to him or to his wife. Participants who adopted a healthy lifestyle following cancer and its treatment reported an improvement in their sexual performance. Sexual enjoyment was absent for many participants during cancer and its treatment either because of the treatment side effects, fear from harming their partner, or due to the stress associated with cancer diagnosis. Sexual enjoyment became normal following cure. These findings are similar to those in the study by Brodsky (1995) whereby only two men reported a decline in orgasmic sensation because of cancer treatment and one man said that sex was nice and decent but not as enjoyable as it used to be.

Only a few Lebanese TCSs reported changes in their body image. Following orchiectomy, some of participants felt that “something” is missing. Nevertheless, the feeling of loss was short-lived and eventually all participants got used to not having a second testicle. They all refused to have their excised testicle replaced by a prosthesis either due to the fear from its perceived side effects or because they found no need for it. Participants in the study by Brodsky (1995) went through the same stages. They were first shocked to see alterations in their body image following surgery and treatment; however these feelings declined with time regardless of whether they agreed to replace the resected testicle with a prosthesis or not. Those who reported distress were those who underwent a major surgery that left a scar, which was not the case in Lebanese TCSs. Like Lebanese TCSs, none of the participants in the study by Brodsky (1995) reported feeling different following orchiectomy and their sense of manliness remained unscathed.

A. Limitations

A number of limitations need to be considered in interpreting results of this study. Given that a qualitative research method was used in this study, the sample recruited cannot be considered representative of all Lebanese TCSs. This is a population difficult to recruit, considering that these patients do not follow up with their physicians on a regular basis. This leaves many patients untraceable due to possible changes in their contact information. Only those who were reachable via the clinic of their physicians and those who agreed to participate and consented to have the interview digitally recorded were recruited into the study. Non-probability purposive sampling is considered among the best sample selection methods since it allows the researcher to obtain cases deemed information-rich for the purpose of the study. Additionally, study findings cannot be generalized; instead transferability was sought through recruiting a sample heterogeneous in economic status, duration of cure and type of treatment received, which could provide a reasonable representation of this patient population.

Considering the sensitive nature of the study, participants may not have been totally forthcoming in their description of their experiences. Additionally, some aspects of this experience might not have been shared thoroughly given that data collection was limited to one face to face interview only. Although the interviewer was a man of similar age to them, it is possible that some participants may have skipped some details or exaggerated while describing their experience. This is expected since this topic is not commonly addressed in the Lebanese society and an open discussion of sensitive topics such as sexuality and fertility remains a taboo for the majority of people in this society.

Data was collected and transcribed in Arabic, the researcher's native language. Themes, categories, and supporting excerpts were then translated to English, which leaves room for altering the meaning behind the data collected. This error was unlikely

since the researcher is fluent in both Arabic and English languages. Additionally, translated themes, categories, and supporting excerpts were double checked by the researcher and thesis advisor for their accuracy. Accidental alteration of the data was also prevented by double checking the transcribed data by the interviewer and the thesis adviser. Moreover, the thesis adviser and interviewer analyzed all interviews and data independently and compared their findings thoroughly and areas of disagreement, which were minimal, were discussed and clarified.

To minimize unavoidable alterations of the data and to ensure accurate understanding of the information collected, the interviewer probed the participants in the event of an unclear reaction during the interview. Moreover, member check supported the researcher's interpretation of the data, since participants agreed to the summary shared two to three weeks following the interview. Bracketing was also used to prevent the researcher's preconceived ideas from affecting data analysis. This is established through bringing to one's awareness his/her preconceived ideas about the experience under study and keeping them in check during the interviews (Polit et al., 2012).

Additionally, the interviewer continuously discussed the research process with the thesis adviser for further advice. The thesis adviser read through transcripts of interviews separately and interpreted the obtained results prior to comparing them with those of the researcher. This method was sought to yield trustworthy data.

CHAPTER VI

CONCLUSION AND RECOMMENDATIONS

The study findings provide a rich description of the experience of Lebanese TCSs. This is the first and only study on this population in Lebanon using this approach. Despite some similarities between the experience of Lebanese TCSs' and that of TCSs in the West, this study provides a rich description of the experience of Lebanese TCSs, which can be only explored by the survivors themselves. Additionally, some findings reflect the peculiarities of the Lebanese culture, such as the concern about fertility and protecting the family from bad news.

Oncology nurses play a key role in addressing cancer patients' needs and concerns through educating them about the side effects of cancer and its treatment. Such educational offerings lack topics that tackle sexuality and fertility, which leaves the patients with several unanswered questions. The findings of this study will be disseminated to oncology nurses and physicians in order to inform them of these patients' concerns. The findings may inform counseling these patients in a way that addresses the identified areas of concerns. Moreover, as women are counseled to do regular breast exams, the findings suggest that young men ought to be counseled to do regular testicular self-exam for early detection of this curable disease. Awareness campaigns about this problem can be done in schools and colleges to cater to the young men that constitute the highest age risk group. Both, education about testicular self-exam and awareness campaigns help address the lack of knowledge men in this study expressed regarding testicular cancer and its detection.

Many TCSs expressed their sense of relief after knowing someone or hearing about someone living with one testicle and leading a normal life. Thus one recommendation from this finding is to arrange informal support groups that would put newly diagnosed testicular cancer patients in touch with long term survivors. Such support groups would help new cases cope with their illness and would give them a better insight about what awaits them during and after treatment. TCSs who are cured may be asked if they agree to have their phone numbers shared with newly diagnosed patients to help them in case they have concerns they need to share or questions they want to ask.

The literature in Lebanon lacks studies that address the psychosexual needs of cancer patients, a subject that remains a taboo bounded by societal constraints. This study could be replicated to include various patient populations who survived a disease or received a treatment that might have affected their fertility, sense of manhood, or sexual performance. A phenomenological approach may be used to capture the experience of those who are still receiving treatment for testicular cancer and get more in-depth data about the topic. In order to better capture the disease trajectory, patients can be recruited soon after diagnosis and followed up.

APPENDIX I

TELEPHONE RECRUITMENT SCRIPT: THE
ONCOLOGIST'S CLINIC

Hello, my name is Hiba, I am the nurse in Dr. Ziad Salem's clinic.

There is a study that is being conducted by Dr. Samar Nouredine, a faculty member at the Hariri School of Nursing, American University of Beirut, about those who were cured from testicular cancer in order to know more about their experiences following their treatment.

Mohammad Saab, a Master's of Science in Nursing student at the American University of Beirut will be collecting the data for this study by interview.

Participation in this study is voluntary. If you refuse to participate, this will not affect your relationship with your doctor.

In case you are interested in participating in the study, please contact Mohammad Saab at 03-45984. If you have questions about the study itself, do not hesitate to call Dr. Samar Nouredine at 03-579451.

Thank you for your time

مرحباً, إسمي هبة أنا الممرضة في عيادة الدكتور زياد سالم

في دراسة عم عملها الدكتورة سمر نور الدين، أستاذة في كلية الحريري للتمريض في الجامعة

الأميركية في بيروت. تسعى الباحثة لمقابلة رجال من عمرك من أجل سؤالهم عن صحتهم. نتوقع

أن تستمر المقابلة حوالي النصف ساعة إلى الساعة. سيحدد مكان وزمان المقابلة حسب ما

يلائكم.

محمد صعب، ممرض مجاز وطالب ماجستير بالتمريض بالجامعة الأميركية في بيروت ، رح

يجمع معلومات لهيدي الدراسة.

المشاركة في هيدي الدراسة هي طوعية. ما حتتاثر علاقتك مع طبيبك في حال رفضت المشاركة

بهيدي الدراسة.

في حال وافقت انك تشارك في الدراسة، يرجى الاتصال بمحمد صعب على الرقم 03-045984

إذا كان عندك أسئلة عنالدراسة، ما تتردد بالاتصال بالدكتورة سمر نور الدين على الرقم 03-

579451

شكراً على وقتك

APPENDIX II

FLYER

Are you someone who:

- 1) Got cured from testicular cancer since three years or more
- 2) Holds the Lebanese nationality
- 3) Is between 18 and 50 years of age

We are conducting a study titled: “Surviving Testicular Cancer: The Lebanese Experience” to explore the experience of Lebanese testicular cancer survivors. You will be invited for an hour long interview to share your experience.

If you are interested in participating, call the researcher Dr. Samar Nouredine, Hariri School of Nursing, American University of Beirut on 03/579451 for further information.

Thank you



INVITATION TO PARTICIPATE IN A RESEARCH STUDY

Are you someone who:

- 1. Got cured from testicular cancer since three years or more**
- 2. Holds the Lebanese Nationality**
- 3. Is between 18 and 50 years of age**

We are conducting a study titled:

“SURVIVING TESTICULAR CANCER: THE LEBANESE EXPERIENCE”

**to explore the experience of Lebanese testicular cancer survivors.
You will be invited for an hour long interview to share your experience.**

**If you are interested in participating, call the researcher *Dr. Samar Noureddine*,
Hariri School of Nursing, American University of Beirut on **03/579451** for further information**

هل أنت شخص:

(1) شفي من سرطان الخصية (Testicular Cancer) منذ ثلاث سنوات أو أكثر

(2) يحمل الجنسية اللبنانية

(3) يتراوح عمره ما بين الـ18 و الـ50 سنة

نحن نجري دراسة بعنوان: "مرحلة ما بعد سرطان الخصية: التجربة اللبنانية" لاستكشاف تجربة

الناجين من سرطان الخصية. ستتم مقابلتك لمدة ساعة من أجل معرفة تجربتك الشخصية.

إذا كنت ترغب في المشاركة، نرجو منك الاتصال بالدكتورة سمر نور الدين، كلية الحريري

للتمريض، الجامعة الأميركية في بيروت على الرقم 579451/03

شكرا



دعوة للمشاركة في بحث علمي

هل أنت شخص:

١. شفي من سرطان الخصية (Testicular Cancer) منذ ثلاث سنوات أو أكثر
٢. يحمل الجنسية اللبنانية
٣. يتراوح عمره بين الـ٨٠ والـ٥٠ سنة

نحن نجري دراسة بعنوان:

"مرحلة ما بعد سرطان الخصية: التجربة اللبنانية"

لاستكشاف تجربة الناجين من سرطان الخصية.
ستتم مقابلتك لمدة ساعة من أجل معرفة تجربتك الشخصية.

إذا كنت ترغب في المشاركة، نرجو منك الاتصال بالدكتورة سمر نور الدين،
كلية الحريري للتمريض، الجامعة الأميركية في بيروت على الرقم ٠٣/٥٧٩٤٥١

APPENDIX III

TELEPHONE RECRUITMENT SCRIPT: THE UROLOGIST'S CLINIC

Hello, I am the clinic assistant of Dr. Mohammad Bulbul.

I am calling you because Dr. Bulbul thought you may be interested in participating in a study that is being conducted by Dr. Samar Nouredine, a faculty member at the Hariri School of Nursing, American University of Beirut. The researcher is seeking men in your age group and wants to interview them about their health. The interview is expected to last around half an hour to one hour; the place and time will be planned at your convenience.

Mohammad Saab, a registered nurse and Masters student in nursing at the American University of Beirut, will be collecting the data for this study.

Participation in this study is voluntary. If you refuse to participate, this will not affect your relationship with your doctor.

In case you are interested in participating in the study, please contact Mohammad Saab at 03-045984. If you have questions about the study itself, do not hesitate to call Dr. Samar Nouredine at 03-579451.

Thank you for your time.

مرحبا، أنا مساعدة الدكتور محمد بلبل.

أنا عم بتّصل فيك لأن د. بلبل فكّر إنك ممكن تكون مهتم بالمشاركة في دراسة عمّعملها الدكتورة

سمر نور الدين، أستاذة في كلية الحريري للتمريض في الجامعة الأميركية في بيروت. تسعى

الباحثة لمقابلة رجال من عمرك من أجل سؤالهم عن صحتهم. نتوقع أن تستمر المقابلة حوالي

النصف ساعة إلى الساعة. سيحدد مكان وزمان المقابلة حسب ما يلائمك.

محمد صعب، ممرض مجاز وطالب ماجستير بالتمريض بالجامعة الأميركية في بيروت ، رح

يجمع معلومات لهيدي الدراسة.

المشاركة في هيدي الدراسة هي طوعية. ما حتتاثر علاقتك مع طبيبك في حال رفضت المشاركة

بهيدي الدراسة.

في حال وافقت انك تشارك في الدراسة، يرجى الاتصال بمحمد صعب على الرقم 03-045984

إذا كان عندك أسئلة عن الدراسة، ما تتردد بالاتصال بالدكتورة سمر نور الدين على الرقم 03-

579451

شكرا على وقتك

APPENDIX IV
INFORMED CONSENT FORM

Investigator: Dr. Samar Nouredine

Address: Hariri School of Nursing, American University of Beirut
Beirut, Lebanon

Phone: 9613579451

Site where the study will be conducted: American University of Beirut, Hariri School of Nursing.

You are being asked to participate in a research study conducted at the American University of Beirut. Please take time to read the following information carefully before you decide whether you want to take part in this study or not. Feel free to ask your doctor if you need more information or clarification about what is stated in this form and the study as a whole.

1) Purpose of the research study and overview of participation

The purpose of this study is to explore the experience of Lebanese testicular cancer survivors with a focus on their sexual health.

You will be among ten to twenty Lebanese testicular cancer survivors who will be interviewed. The participants are being recruited through the oncologist or urologist's clinic and by flyers advertising the study that were put in the American University of Beirut Medical Center.

You will be asked to participate in a face to face interview that will be digitally recorded and might take between 40 and 60 minutes. The digital recordings will be kept on the researcher's private computer and will be deleted at the end of the study; taking

notes might take place during the interview. Two to 3 weeks later, the interviewer will call you again to share with you a summary of the interview and ask you whether it reflects your experience correctly. This may be done by face to face meeting, over the phone or any other way you choose. You will be asked about your experience after being cured from testicular cancer. Participation in this study is voluntary. You are free to refuse participation. If you refuse, this will not affect your care in any way. Your participation is assured to be completely anonymous; your name will not be used in reporting results. Fictitious names will be utilized once the study findings are displayed.

Your confidentiality and your privacy will be totally respected by keeping your responses in a locked cabinet accessible only to the primary investigator.

2) Risks of participating in the study

We do not expect significant risks from your participating in this study. You may feel emotional discomfort when answering some sensitive questions. In case that happens we will stop the interview and give you the choice of whether to resume or withdraw from the study. In case you need assistance from a counselor, we will provide with that information. Counseling expenses are not covered in this study.

3) Benefits of participating in the study

Although there is no direct benefit to you from participating in the study, your participation will provide us with very important information, which will help us better understand the experience of young Lebanese testicular cancer survivors, specifically their sexual health. The results will be displayed to healthcare professionals to ensure better care.

4) Alternative ways to conduct the study

Interviewing you is the only method to meet the purpose of the study

If you agree to participate in this research study, the information will be kept confidential. Unless required by law, only the researcher and the ethics committee will have direct access to your medical records.

Investigator's Statement:

I have reviewed, in detail, the informed consent document for this research study with the informant, the purpose of the study and its risks and benefits. I have answered all the participant's questions clearly. I will inform the participant in case of any changes to the research study.

Name of Investigator

Signature

Date and Time:

Informant's Participation:

I have read and understood all aspects of the research study and all my questions have been answered. I voluntarily agree to be a part of this research study and I know that I can contact Dr. Samar Nouredine at 03-579451 in case of any questions. If I feel that my questions have not been answered, I can contact the Institutional Review Board for human rights at 01-350000 Extension: 5445. I understand that I am free to withdraw this consent and discontinue participation in this project at any time, even after agreeing to participate, and it will not affect my benefits. I know that I will receive a copy of this informed consent.

If you agree to participate in this study kindly put an (X) inside the square below.

I agree to participate in this study

If you agree to have this interview digitally recorded, kindly put an (X) inside the square below.

I agree to have this interview digitally recorded

اسم الباحث: د. سمر نور الدين

عنوان الباحث: كلية الحريري للتمريض، الجامعة الأميركية في بيروت

بيروت، لبنان

هاتف: 3579451-961

مكان إجراء البحث: كلية الحريري للتمريض، الجامعة الأميركية في بيروت، بيروت، لبنان.

أنت مدعو للمشاركة في بحث علمي يجري في الجامعة الأميركية في بيروت. الرجاء أن تأخذ

الوقت الكافي لقراءة المعلومات التالية بعناية قبل أن تقرر ما إذا كنت ترغب في المشاركة في هذه

الدراسة أم لا. لا تتردد في استشارة طبيبك إذا كنت بحاجة إلى مزيد من المعلومات أو إلى

أي توضيح حول ما ورد في هذه الموافقة

1) وصف البحث العلمي وهدفه و تفسير مجرياته

الهدف من هذه الدراسة هو استكشاف تجربة اللبنانيين الناجين من سرطان الخصية مع التركيز

على صحتهم الجنسية.

سوف تكون من بين الـ 10-20 لبناني الذين سيتم مقابلتهم بعد أن نجوا من سرطان الخصية. يتم

اختيار المشاركين عبر عيادة طبيب الأورام أو عيادة طبيب المسالك البولية و عبر نشرات

إعلانية عُلفت في المركز الطبّي للجامعة الاميريكيّة في بيروت.

سوف يطلب منك أن تشارك في مقابلة مسجلة على آلة تسجيل رقمية وجهاً لوجه مع الباحث.

سوف تستغرق هذه المقابلة ما بين الـ 40 و الـ 60 دقيقة. سيتم الحفاظ على التسجيلات الرقمية

على حاسوب الباحث الخاص وسوف يتم إحائها عند انتهاء الدراسة. قد يتم تدوين

بعض الملاحظات خلال المقابلة. سوف يتصل بك المقابل بعد 2 إلى 3 أسابيع ليطلعك على

ملخص المقابلة من أجل التأكد بأن الملخص يعكس تجربتك بشكل صحيح. قد يتم عرض

الملخص عبر مقابلة وجهاً لوجه معك، عبر الهاتف أو أي وسيلة أخرى من اختيارك. سوف تُسأل

عن تجربتك بعد أن شفيت من سرطان الخصية. المشاركة في هذه الدراسة طوعية. لديك

كامل الحرية لرفض المشاركة. في حال رفضت أن تشارك في هذا البحث، لن يؤثر رفضك على

الرعاية الخاصة بك بأي شكل من الأشكال. سيتم الاستعانة باسم مستعار بدلاً من اسمك الحقيقي

لتأمين السرية. لحفظ سرية المعلومات وحفظ خصوصيتك، ستبقى أجهزتك في خزانة مغلقة بحيث لا

يمكن لأحد الحصول عليها غير الباحث.

2) مخاطر المشاركة في الدراس

لا نتوقع أية مخاطر هامة من جراء مشاركتك في هذا البحث. قد تشعر بانزعاج عاطفي عند

الإجابة على بعض الأسئلة الحساسة. في حال حدث ذلك فإننا سوف نوقف المقابلة و نعطيك

الخيار لإكمال المقابلة أو الانسحاب من الدراسة. سوف نقدم لك المعلومات اللازمة في حال كنت

بحاجة إلى مساعدة من مستشار نفسي. لا تتم تغطية نفقات المشورة النفسية في هذه الدراسة.

3) فوائد المشاركة في الدراسة

على الرغم من أنه ليس هناك فائدة مباشرة لك من المشاركة في هذه الدراسة، إن مشاركتك سوف تزودنا بمعلومات هامة لمساعدتنا على فهم تجربة الشباب اللبنانيين الناجين من سرطان الخصية بصورة أفضل، و بالأخص، تجربتهم الجنسيّة. سيتم عرض نتائج هذه الدراسة على أخصائيين في

القطاع الصحي لضمان رعاية أفضل لمرضى سرطان الخصية

4) طرق بديلة لإجراء الدراسة

المقابلة هي الطريقة الوحيدة لتحقيق الهدف من هذه الدراسة.

في حال وافقت على المشاركة في هذه الدراسة، ستبقى المعلومات سرّية. ما لم ينص عليه القانون،

لن

يتمكن أحد غير الباحث ولجنة الأخلاقيات من الوصول إلى المعلومات الخاصة بك.

موافقة الباحث:

لقد شرحت بالتفصيل للمشارك في البحث الطبي طبيعته و مجرياته وتأثيراته السلبية و فوائده. و

لقد أجببت على كل أسئلته بوضوح. وسوف أعلم المشترك بأي تغييرات في مجريات هذا البحث.

توقيع الباحث او الشخص المولى

اسم الباحث أوالشخص المولى الحصول

الحصول على موافقة المشترك

على موافقة المشترك

التاريخ و وقت المقابلة

موافقة المشترك:

لقد قرأت استمارة القبول هذه وفهمت مضمونها. تمت الإجابة على أسئلتى جميعها. وبناء عليه فأنتي, حراً مختاراً, أجاز إجراء هذا البحث و أوافق على الاشتراك فيه، وإني أعلم أن الباحثة د. سمر نور الدين وزملاءها ومعاونيها أو مساعديها سيكونون مستعدين للإجابة على أسئلتى، وأنه باستطاعتي الاتصال بهم على الهاتف 03-579451. و إذا شعرت لاحقاً أن الأجوبة تحتاج للمزيد من الإيضاح فسوف أتصل بأحد أعضاء لجنة الأخلاقيات (01- 350000 المقسم: 5445). كما أعرف تمام المعرفة بأنني حر في الانسحاب من هذا البحث متى شئت حتى بعد

الموافقة دون أن يؤثر ذلك على العناية الطبية المقدمة لي.

أعلم أي سوف أحصل على نسخة طبق الأصل عن هذه الموافقة.

الرجاء وضع إشارة (X) في المربع أدناه إذا كنت موافق على المشاركة في هذا البحث:

أوافق على المشاركة في هذا البحث

الرجاء وضع إشارة (X) في المربع أدناه إذا كنت موافق على التسجيل الصوتي لهذه المقابلة:

أوافق على التسجيل الصوتي لهذه المقابلة

APPENDIX V

REFERRAL TO COUNSELING FORM

Below is the name of the counselor that you will be referred to. Counseling expenses are not covered in this study.

Counselor name: Dr. Michael Khoury

Phone number: 03-409860

إسم المستشار النفسي الذي سوف يتم إحالتك إليه أدناه، لا تتم تغطية نفقات المشورة النفسية في

هذه الدراسة.

اسم المستشار النفسي: د. مايكل خوري

رقم الهاتف: 03-409860

APPENDIX VI

DEMOGRAPHIC DATA FORM

Code number: _____

Demographics:

Age in years: _____

Marital status: _____

Highest level of education completed: _____

Current occupation: _____

APPENDIX VII

INTERVIEW GUIDE

Opening question: Tell me about your life since you got treated for testicular cancer.

Probing questions:

What changed in your life since the diagnosis/treatment?

How do you see yourself after you got treated?

What about your overall health?

What about your sexual life?

What about your personal relationships? Can you please tell me more about them?

خبرني عن حياتك بعد ما خلصت العلاج من سرطان الخصيتين

كيف بتشوف حالك بعد انتهاء العلاج؟

كيف صحتك العامة؟

شو بالنسبة لحياتك الجنسية؟

كيف علاقاتك الشخصية؟ فيك تخبرني أكثر عنهم؟

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