“A Crisis of Masculinity?”: The Intersection of Gender, Illness, and Selfhood in the Narratives of Prostate Cancer Survivors

Joseph Folco

A Thesis
in
The Department
of
Sociology and Anthropology

Presented in Partial Fulfillment of the Requirements
for the Degree of Master of Arts (Anthropology)
at Concordia University
Montreal, Quebec, Canada

April 2013

CONCORDIA UNIVERSITY

School of Graduate Studies

This is to certify that the thesis prepared

By: Joseph Folco

Entitled: “A Crisis of Masculinity?”: The Intersection of Gender, Illness, and Selfhood in the Narratives of Prostate Cancer Survivors

and submitted in partial fulfillment of the requirements for the degree of

Master of Arts (Anthropology)

Complies with the regulations of the University and meets the accepted standards with respect to originality and quality.

Signed by the final Examining Committee:

Dr. Satoshi Ikeda ________________________ Chair

Dr. Salinda Hess ________________________ Examiner

Dr. David Howes ________________________ Examiner

Dr. Marc Lafrance ________________________ Supervisor

Approved by ____

Chair of Department of Graduate Program Director

______________ 2013 ______________________________

Dean of Faculty

ABSTRACT

"A Crisis of Masculinity?": The Intersection of Gender, Illness, and Selfhood in the Narratives of Prostate Cancer Survivors

Joseph Folco

This thesis in Socio-Cultural Anthropology explores the way prostate cancer, as an illness experience, influences the masculinity and identity of survivors. It draws on theory from the subfield of Medical Anthropology and Masculinity Studies to demonstrate the complex relationship between gender, illness, and selfhood. Based on data collected during five months of fieldwork in Montréal in summer 2012, this research illustrates highlights the importance and strength of the narrative method in anthropological methodology, particularly when exploring issues related to illness and identity. In addition, it proposes possible future avenues of study in prostate cancer research such as how homosexual men, African-American or Afro-Caribbean men, and the partners and spouses of those diagnosed cope and understand the illness and its side effects. While this thesis focuses on Montréal, it demonstrates how prostate cancer is an individualized and personal experience, which can only be understood if a range of cultural and contextual factors is considered. In particular, understanding how cultural and sexual diversity impacts the illness experience of men differently is imperative for prostate cancer research, support groups and awareness programs, and both healthcare institutions and its practitioners.

DEDICATION

While a lot of effort and perseverance went into producing this thesis, it was only made possible by the support and dedication of my supervisor, other professors, friends, and family. Therefore, I would like to take this occasion to thank Dr. Marc Lafrance for his hard work, leadership, and dedication. Even when writing was discouraging, his positivity and enthusiasm helped to build up my confidence in both my writing and myself. I would also like to thank all the professors who shared their wisdom and experience with me, particularly: Dr. Christine Jourdan, Dr. Homa Hoodfar, and Dr. Ebba Olofsson. I would also like to thank Samantha Young for always lending an ear to listen, for her encouragement, and for staying confident in me even in those moments when I did not believe in myself. Also, I would like to show my appreciation for my colleagues and friends Sarah Parisio and Vanessa Salvatore for nights of endless chatter, hours of hard work, and for always supplying me with an abundance of tea! Finally, I would like to thank my parents Marilyn and Peter for their love and assurance, my brother Andrew for showing support and sharing different perspectives, and my grandmother Dorothy for believing in me my entire life regardless of what I decided to take on. I extend my heartfelt thanks and gratitude to each and every one of you because you have each made my graduate experience an incredible journey.

Table of Contents

Introduction

"God has given you one face, and you make yourselves another". –William Shakespeare
Hamlet (Act 3, Scene 1).

In William Shakespeare's famous play *Hamlet*, Hamlet confronts Ophelia and states, "God has given you one face, and you make yourself another", to suggest that people alter their personal image in front of others when confronted by some sort of large-scale disruption. Being diagnosed with an illness can disrupt the continuity of people's lives. More specifically, a disease such as prostate cancer that affects one in seven men (Saad & McCormack 2008) can cause men to re-evaluate their notions of identity, selfhood, and their relationships with friends and family. In addition, closely entwined with notions of selfhood, are socially and culturally produced conceptions about what it means to be masculine and feminine and how these ideas shape how one should respond to being ill. Over the course of the literature review, I will draw on a range of influential texts that use these concepts and theories in order to show why they are essential when researching the effect of prostate cancer on the masculine identities of survivors. Before I present the nature of my research in more depth, however, I will briefly describe prostate cancer and some of its treatments.

A Brief Overview of Prostate Cancer

Prostate cancer is a disease that occurs when cells in the prostate begin growing uncontrollably, leading to the formation of small tumours around the gland (Saad & McCormack 2008). It can be treated by three main procedures: radical prostatectomy, which involves the removal of the prostate surgically; brachytherapy, which is a kind of internal radiotherapy; and androgen deprivation or suppression therapy, which targets male hormones -- called androgens -- and prevents them from reaching prostate cancer cells (Taguchi 2003 and Saad & McCormack 2008). While each of the above procedures has varying degrees of success depending on the stage of prostate cancer (measured on what is known as the Gleason scale), each also has its own set of side effects. For example, men having undergone radical prostatectomy surgery or brachytherapy have reported bowel and urinary incontinence, erectile dysfunction, and a loss of libido or sex drive. These side effects are more prevalent in patients who have opted for the radical prostatectomy surgery; however, they have also been reported with less severity among men who have undergone brachytherapy. Patients who have chosen androgen deprivation therapy have reported erectile dysfunction, hot flashes, fatigue, a reduced or absent libido, and breast tenderness and growth of breast tissue (Saad & McCormack 2008).

These side effects can have a snowball effect by influencing men's sexuality, which in turn impacts their perception of masculinity, causing a disruption in the continuity of their lives and forcing them to negotiate and re-evaluate their initial pre-cancer identities as men. Due to the side effects of prostate cancer and the way it influences sexual relations with their partners and their relationships with family and friends, many men may be reluctant to speak about their illness experience with others. As masculinity is closely tied not only to virility, but also to physical and mental strength, showing any sign of emotion or weakness may jeopardize their identities and the role they seek to uphold. Therefore, to understand some of the reasons men may feel uncomfortable speaking about their illness experience with others, I will briefly turn to the work of sociologist Michael Kimmel and his pioneering research on masculinity.

Why is Masculinity Relevant to the Study of Prostate Cancer?

As Kimmel illustrates in his article “Masculinity as Homophobia: Fear, Shame, and Silence in the Construction of Gender Identity” (2008), masculinity is a “homosocial enactment” and is defined through a man’s interactions with other men: “We test ourselves, perform heroic feats, take enormous risks, all because we want other men to grant us our manhood” (Kimmel 2008:214). Similar to Kimmel, in her book *Masculinities* (2005), Connell argues that masculinity is a social product that is constantly being redefined and negotiated through men’s relationships with other men and women. Therefore, if men define their masculinity based on their ability to uphold particular social expectations associated with manhood such as physical and mental strength, stoicism, virility, and sexual prowess, showing any sign of weakness or the inability to uphold these expectations can jeopardize their sense of self-worth, their identity, and the position they occupy among other men. In this sense, if a man mentions a diagnosis with prostate cancer when interacting with other men, perhaps these men will pass judgment and assume that his ability to perform sexually and uphold his role as a husband will be hindered by a radical prostatectomy or brachytherapy. In a similar way, if a man diagnosed with prostate cancer discusses his illness with women, he may fear that they will view him as less masculine because is he unable to uphold particular expectations associated with masculinity in the West and thus view him as less desirable. These attitudes stem from the way our society conceives of how men should behave and live their lives: strong, healthy, and without illness. Using the perspectives of both these authors as a lens, it only stands to reason that prostate cancer survivors might feel uncertain about how to proceed and whether they should open up and tell their stories to others. Because gender, sexuality, conceptions of the ill body and ideas about how to perceive health and illness are social products, these can all shape the behaviors and decisions that individual men take and influence the way they understand their illness experience. In addition, a consideration of how sexuality is closely tied to definitions of masculinity is imperative to understand the behavior of men and whether they choose to share their stories with other men or women.

Furthermore, male sexuality is closely tied to contextual definitions of masculinity and is centered on the erect penis and the act of penetration (Marshall & Katz 2002, Arrington 2003, Brubaker & Johnson 2008, Loe 2006 and Potts 2000). A prostate cancer diagnosis forces men to rethink what it means to be a “sexual being” and then adapt their ill body to social expectations (Fracher & Kimmel 1987 and Zilbergeld 1992, cited in Fergus, Gray and Fitch 2002:305). Therefore, if men have undergone one of these procedures and have to deal with side effects that impact their sex life, their relationships with others, and how well they meet social expectations associated with male sexuality, they may be uncomfortable speaking about their illness experience with others, particularly other men. As I reflect on my fieldwork experience, it is clear that a complex relationship exists between prostate cancer, masculinity, sexuality, and conceptions of selfhood. To understand the implications of treatment side effects on the lives of survivors, it is has been important for me to examine what is both tangible and intangible, explained directly or displayed in uncertainties, hesitations, and non-verbal communication. By considering both the “said” and the “unsaid” and how they are implicated in the narratives of prostate cancer survivors, I hope to shed light on how this illness affects the physical and psychological well being of men and what measures can be taken in order to improve pre- and post-surgery care by ensuring that it is specific to the patient’s needs.

Before delving into the main chapters of this thesis, I will turn to a section called “Methodology, Ethics, and the Researcher” where I will focus on the methodology I used in the field, some of the ethical concerns that I faced doing research on prostate cancer, and some of my personal biases as an anthropologist. Understanding the way this research was conducted, the challenges that I faced in fieldwork and the impact of my own personal biases is important to consider before exploring the content of my thesis. Many factors contributed to the degree of access I had in the field, the way I interacted with my informants, and the range of discussions in our interviews. Ultimately, this section illustrates the way that research on prostate cancer is individualized and about the lived experience of men. It sets up the rest of the thesis by demonstrating that instead of providing broad generalizations about my informants, I hope to shed light on the diverse lived experience of survivors and how it is linked with our society’s understanding of masculinity.

The section that will follow is labeled “Theoretical Framework” and will focus on the theoretical paradigms that have shaped how I understand my research topic. I draw on theoretical approaches from the subfield of medical anthropology and masculinity studies to illustrate the way that conceptions of the ill body and masculinity are culturally constructed. I explore seminal texts by Susan Sontag, Arthur Kleinman, Michael Kimmel, Raewyn Connell, and Emily Martin among others. To conclude this section, I explore Victor Turner’s theories of liminality and illustrate how this concept can also be applied to the prostate cancer experience. In addition, I use medical anthropologist Lisa

Stevenson’s work on suicide among the Canadian Inuit to demonstrate that silences, uncertainties, and hesitations should be considered as legitimate ethnographic objects.

The section entitled “Literature Review” that follows surveys additional literature from the fields of medical anthropology, gender studies, clinical oncology, and journal articles about men’s health, the role of the media and celebrity stories, and the sociology of health and illness. I explore previous research conducted on prostate cancer survivors and how they negotiate post-treatment identity and how treatment side effects have impacted their sexuality and relationship with their partners. To end this section, I survey literature on prostate cancer in the media and the impact of celebrities on screening procedures and awareness campaigns.

The first chapter of my thesis entitled “Early Fieldwork: Considering the Culturally Constructed Body”, explores an early encounter in my fieldwork that took place at a ProCure conference. This vignette served as a point of departure for both my fieldwork and the writing of this thesis because it demonstrates that there were/are, clearly, some taboo subjects in the medical community. In addition, this chapter explores some of the gaps in public education conferences and literature, particularly when it comes to understanding and addressing the lived experience of men with prostate cancer. I conclude the chapter with a brief outline of how I have organized subsequent sections and highlight the significance of considering masculinity, sexuality, and a social body that is culturally constructed in the biomedical discourse on prostate cancer.

The second chapter entitled “Masculinity in the Narratives of Prostate Cancer Survivors” begins by contextualizing the concept of masculinity by juxtaposing perspectives that are essentialized/biological and culturally constructed. While both sides are discussed, I shift my attention to the significance of considering the social expectations associated with masculinity in the West and illustrate that my thesis will be framed using the cultural constructionist model. I use excerpts from the narratives I collected during fieldwork to demonstrate the behaviors that my informants exhibited during our interviews. These behaviors are directly linked to the way survivors understand their lived experience of the illness and how they negotiate their masculine identity. Some of these behaviors include body language, silence, nonchalance, embarrassment, and evasiveness.

The third chapter entitled "Sexuality and the Prostate Cancer Experience" explores the way masculinity in the West is linked to sexual prowess, virility, and potency. In particular, it focuses on the role of the erect penis in how a man asserts his masculinity. Through the narratives of survivors, this chapter explores the link between prostate cancer treatment and how it impacts the sexuality and masculine identities of men. Victor Turner's theories of liminality are applied to prostate cancer and illustrate the importance of exploring the lived experience of men, as each survivor understands and responds to changes in their lives in particular ways. Later in this chapter, I explore how incontinence, similar to erectile dysfunction, is a side effect that can seriously impact the masculinity of survivors. To conclude, I present the work of masculinity theorists Kimmel, Connell, and Synnott. While Kimmel and Connell present a seemingly disparate view from Synnott, I use my findings to illustrate how both perspectives must be considered together when exploring the impact of an illness like prostate cancer on the masculinity of survivors.

In chapter four entitled “Acknowledging Difference”, I revisit the early vignette presented in the opening chapter about my experience at a ProCure conference. I explore the gap in research and support groups for prostate cancer with respect to two communities in Montréal: the gay and African-American communities. I conclude this chapter by addressing the implications of this gap for patient care. In particular, I suggest that the connection between masculinity and sexual and cultural diversity must be explored when addressing the individual needs of patients, particularly in a multicultural city like Montréal. Furthermore, this chapter illustrates how the lived experience of men and how they negotiate masculine identities must be considered when planning public education conferences, campaigns, and the content of prostate cancer literature.

Chapter five entitled “Doing Anthropology at Home” explores the shift in Anthropology since the 1960s pertaining to legitimate field sites and the growing trend of engaging in anthropological fieldwork “at home”. I use the work of Vered Amit (2001) to reflect on my own fieldwork experience and the challenges I faced. I explore the importance of learning to compartmentalize and separate fieldwork from personal responsibilities. I share moments from my time in the field where it was difficult to separate personal and professional engagements and illustrate the ways that I overcame these obstacles. I conclude this short chapter by providing a list of the skills I adopted in the field; ones that I feel are imperative when conducting fieldwork “at home”. These include: time management, organization, self-motivation, and stress management.

Chapter six entitled “Future Considerations for Research” outlines some additional topics that arose in my research that deserve more attention. In particular, I focus on the need for prostate cancer literature and public education conferences to consider the lived experience of men from different sexual and cultural backgrounds. In doing so, the medical community will be more inclusive and ensure that the needs of all men are addressed with the ultimately goal of improving patient care. In addition, I argue that future research should pay particular attention to the perspectives of urologists and nurses who work within the biomedical model. I conclude this chapter by exploring the need to consider the role of partners in the prostate cancer experience. Because prostate cancer impacts the sexual lives of both people in a relationship it may have a different impact psychologically depending on the role that is assumed: survivor and caregiver.

The final chapter of this thesis is the conclusion, which briefly summarizes the content of each chapter and the findings of my research. In particular, I write about the importance of using the narrative method when discussing an illness experience because it empowers the informant by allowing them to tell their own story. I conclude this final section by highlighting the importance of considering the lived experience of men with prostate cancer to sensitize medical professionals to diversity and make resources more inclusive and specific to the needs of patients.

Methodology, Ethics, and the Researcher

Methodology

My Master's Thesis in Social and Cultural Anthropology at the Department of Sociology and Anthropology of Concordia University endeavors to complement and add to the burgeoning literature on prostate cancer. In particular, my research explores the impact of the prostate cancer experience on survivors in Montreal and how it relates to conceptions of masculinity, identity, and selfhood. Due to my interest in the intersection of masculinity, health, and the experience of disease, my project is framed within the subfield of medical anthropology but has also heavily relied on masculinity studies. Through an analysis of the narratives of prostate cancer survivors and my field experiences, I demonstrate the nuanced relationship between the social and cultural construction of the body, illness and disease, conceptions of masculinity, identity, and selfhood, and the way these influence how men navigate different therapies and procedures offered in the sphere of Western biomedicine.

My fieldwork took place over the summer of 2012 and into the fall semester. The main methods that I used in the field were: observation, participant observation, and interviews. Throughout my participation in meetings and a conference, I recorded my observations with field notes when appropriate. I was in contact with the Québec Charity for Prostate Cancer, "ProCure", and met the team of event directors and researchers working at this organization. ProCure was founded in 2003 and its mission is to provide science and humanity with means to help prevent and cure prostate cancer. Its main research is geared at further developing their BioBank, which is a bank of donated biological materials and data on men with prostate cancer as well as those at risk of developing the disease. This BioBank seeks to further research on finding a cure for prostate cancer while creating awareness through public education conferences. ProCure operates in conjunction with four major Québec research institutions and their associated hospitals: the Montréal General and Royal Victoria Hospitals associated with McGill University (MUHC), Hospitals Notre-Dame and St-Luc associated with Université de Montréal (CHUM), Hôtel-Dieu Hospital associated with Université de Laval (CHUQ), and Fleurimont Hospital associated with Université de Sherbrooke (CHUS). In addition to ProCure, I have been in contact with and have found participants for my research through the West Island Prostate Cancer Support Group. Early in my fieldwork, I attended a public education conference, such as the one held on April 2, 2012 entitled "What's New in Prostate Cancer Treatment", where a urologist from the MUHC (McGill University Health Centre) lectured on the recent developments in his research and of ProCure. Both organizations (ProCure and the West Island Prostate Cancer Support Group) granted me permission to conduct research with their organizations and to closely collaborate (a copy of the email granting me permission can be found in the Appendix). In addition, these organizations assisted me in finding prostate cancer survivors who were willing to volunteer their time to participate in my research. In total, 13 men participated in in-depth interviews over the course of my time in the field (interview questions provided in the Appendix of this document) where they had the opportunity to share their narrative and illness experience. In addition, I have been in contact with approximately 5-10 additional men who I learnt from in a less formal context; these men were asked to provide context and answer basic questions.

Similar to Kleinman, the narrative method was fundamental to my thesis project because of the sensitive nature of my research. Consequently, I believe that by allowing my research participants to recount their illness experience, it enabled them to tell their story in a complete and empowering way and this contrasts with the current quantitative research on psychosocial factors. By using their own voice to situate and highlight the significance of the illness experience in their lives, the prostate cancer survivors in my research were be able to recount the way the diagnosis and treatment has influenced their personal identity and their relationships with close family and friends. Much of the literature found in medical journals about illness and health has tended to ignore the implications of disease on the individual and how it affects their conception of selfhood, and instead, focuses on issues that are relevant but at more of a macro-level. In this sense, Kleinman is a pioneering academic in the field because he is as much concerned with power structures and institutions as he is about individual illness experiences and the negotiating of identity.

Influenced by Kleinman, medical anthropologist Gay Becker's ethnography *Disrupted Lives: How People Create Meaning in a Chaotic World* (1997) influenced my research. In this compelling ethnography, she uses a narrative approach to examine disruption and continuity in different contexts and to enable her participants to tell their own stories:

> In this book, narrative is the primary path for examining disruption and continuity. I have chosen this path because I want to record the nature of life disruptions in people's own voices. Narratives, the stories that people tell about themselves, reflect people's experience, as they see it and as they wish to have others see it. (Becker 1997:25)

In particular, Becker uses narratives to both empower her research participants and to uncover through these personal accounts, broadly construed cultural concerns. This ethnography is a compelling example of how human research can be conducted in a manner that both benefits the researcher and empowers the participant; it has greatly influenced my thesis methodology because it shows the strength of the narrative method and how it can be used to better understand the way illness influences people's lives.

Using the methodology discussed above, I feel that my research has added to and enriched the existing body of literature on prostate cancer survivors, masculinity and hegemonic masculinity theory, theories of male sexuality, and theories of the ill body and illness as a cultural construction. In particular, I have employed the narrative approach outlined above to better understand the lived experience of prostate cancer survivors instead of subjecting them to rigid interviews and questionnaires. By enabling each man to tell their own story, it has allowed me to fully grasp the impact of a prostate cancer diagnosis on identity, sexuality, and a man's sense of masculinity. In addition, by reflecting on my fieldwork experiences and the stories of men from a different cultural background, I have illustrated the significance of considering cultural diversity and men with different gender and sexual identities when providing patient care. In doing so, the resources available to prostate cancer survivors can be more inclusive and specific to the needs of different communities.

Anthropological Methods and Prostate Cancer

While I feel that I was able to develop good relationships and collect fruitful data over the course of the five months I spent in the field, I also faced some obstacles. Due to the sensitive nature of my topic, conducting participant observation was difficult. As I write about in the opening chapter, I attended meetings with the board of directors of ProCure and two public education conferences on recent developments in prostate cancer research and treatment. While I was able to observe the interactions between men at the conferences and the way that questions were formulated during the question and answer period, there were few occasions for me to do any other participant observation. I believe that this is partly due to two major factors. As Hegelson and Lepore (1997) argue, prostate cancer involves parts of the male body that are not usually publicly discussed. Therefore, men may be are reluctant or hesitant sharing their experiences with a researcher that they do not know very well. Due to the short time that we have as master's students to conduct fieldwork, I feel that I may not have always established enough rapport with my informants, the kind that comes from several months of daily interaction.

Instead, I would be given the contact information of men who had been contacted through the two organizations and would call them and present my research and myself. Because many of these candidates worked during the day or were busy with other commitments, our conversations did not last long and they seemed eager to set up a time and date for the interview. Following the initial phone call, I would contact my informants by email or phone the day before our scheduled interview to confirm, whichever was more convenient for them. Once I arrived at their homes the day of the interview that were scheduled for an hour, I did not have much time to establish rapport or pick up from where our last conversation ended. As I discuss throughout my thesis, I came across informants who exhibited different behaviors like nonchalance, embarrassment, evasiveness, and dismissal. While these were hindering factors and made the interview process difficult, the limited time that I had to establish rapport and trust may have also influenced the level of comfort my candidates had in disclosing personal details. Furthermore, these attitudes are important and need to be considered as a legitimate ethnographic object as they shed some light on the relationship between masculinity and the lived experience of survivors.

The time constraint for establishing rapport may have also been partly due to the difficulty of compartmentalizing personal and professional commitments. As I mention in Chapter 5 of this thesis, “Doing Anthropology at Home”, one of the main obstacles of doing anthropological fieldwork at home is finding a healthy balance between the stresses of everyday life and the pressures and deadlines related to research. In addition, while I communicated with my informants after the interview and thanked them for their participation, had I been able to conduct a follow-up interview, they may have felt more comfortable speaking about private and personal details related to their experience. While limited rapport and time constraints on my end could have caused hesitations on the side of some informants, I believe that the topic itself was the most significant reason for my obstacles. While I had been working with ProCure and told them that I would share my results with them to complement and add to their research being conducted on prostate cancer, they seemed uncomfortable having a researcher who is not affiliated with them working with the organization.

During my first meeting with the organization in March 2012, I recall one of the members on the board of directors mentioning to me that my project is the first one to call upon ProCure for help. While they work alongside the Canadian Cancer Society and are affiliated with four teaching and research hospitals across Québec, there was a level of uncertainty that came from my participation. This uncertainty seemed to dissipate slightly when I sent them a copy of my summary protocol form and evidence of ethical approval, however I still felt a general unease when I was in contact with them. During my first meeting, I asked questions related to the services and resources that they offer and mentioned that I was interested in exploring in a future project, how men from minority groups are affected by prostate cancer. When I mentioned my concern for the gay and African American[1] communities, I knew that I had touched on a sensitive topic. While I am not making the assumption that this organization is primarily concerned with the needs of white, heterosexual, middle-upper class men, my comment seemed to affect their perception of both myself as a researcher and my project.

Following that meeting, I found it difficult to keep in touch with the organization, which may have been due to my comments in the previous meeting and how busy the staff was preparing for upcoming events. In particular, I felt that the enthusiasm they had initially shown had lessened and I felt myself working more independently of the organization than I had previously thought I would. I am thankful for the time that they took to meet with me and for the men that they were able to provide for interviews, even though five out of the six candidates were on the board of directors of the organization. Initially, they were supposed to send out a mass email to every member of ProCure, present them with my project and inquire about whether they would be interested in participating. After multiple exchanges with my contact at the organization, I was under the impression that instead of a mass email, they had only asked the board of directors

---

[1] This term will be used throughout my thesis and is not meant to be a homogenizing label. My two informants from the Caribbean and United States have granted me permission to use this term.

which suggests a degree of “message control”. As I will discuss in the following section, this led me to have a biased sample that I tried to counterbalance by contacting the West Island Prostate Cancer Support Group.

Before I reflect on my sample, it is important to mention that the West Island Prostate Cancer Support Group complemented ProCure and played a fundamental role in my research. In addition to being provided with a list of men, the organization sent out a mass email to which three men answered, showed an interest in my project and became informants. While it was difficult to conduct participant observation because of the limited activities and conferences that are held during the summer and fall, I have tried to attend independent events organized by members of the support group in the West Island. I will also be working with my informant Jerry, at organizing an event to spread awareness about prostate cancer in Montréal’s African American community. Therefore, while most of my research was dependent on the narratives shared by my informants because of limited participant observation, I will continue to interact with the men who I worked with on more personal projects. As men begin to open up and feel more comfortable discussing their experiences about prostate cancer in public, I believe that support and awareness will continue to grow, which would make anthropological inquiry into this illness more accessible.

Sample Bias

Throughout my fieldwork, I felt that I was able to gain insight into the way that prostate cancer and its treatments impacts masculinity, sexuality, and conceptions of selfhood. Due to the ethically sensitive nature of my topic, I decided to turn to an organization like ProCure to help me find participants who would be willing to share their story. As a result, I initially had access to a sample of men who were comfortable sharing their perspectives and as a result, they may not have had the same concerns or reservations as a survivor who is uncomfortable discussing their experience. Therefore, due to my ethical responsibility as a researcher and a topic like prostate cancer, I was only able to access a select group of men. While I was able to counterbalance the biased sample provided by ProCure by establishing a network with survivors at the West Island Support Group and interviews with two informants who are African American, my sample was not as diverse as I would have hoped. Even if my sample of informants had been more diverse however, I have demonstrated that prostate cancer is an individual experience and is understood based on a variety of factors: age, race, cultural background, gender identity, and sexual orientation. In particular, my thesis focused on the lived experience of survivors instead of making generalizations applicable to all men who have survived prostate cancer in Montréal. Nonetheless, it is important that I acknowledge the limited scope and perspectives I was able to obtain given the social characteristics of my informants.

My research participants were aged between fifty and eighty years of age, all heterosexual, and were predominantly middle-upper class Canadians. With the exception of Jerry and Ben who are African American with cultural roots in the Caribbean, all of my informants were white. While I have written a chapter about the significance of considering cultural and sexual diversity in patient care, my sample would have benefited from extensive interviews with members of both communities. Also, with the exception of James who is a general practitioner, my sample was composed of patients who had been diagnosed with prostate cancer. While the goal of my research is to understand the lived experience of survivors, I could have interviewed some urologists or nurses working with men diagnosed with prostate cancer to get a medical perspective on relationship between masculinity, sexuality, and identity. This would have complemented the narratives of the men I worked with and provided a more thorough and perspective on the topic.

While it is important to be reflexive about one's fieldwork experience and the sample of people with whom one works and collaborates, it is just as important to understand the role one has as an anthropologist in these interactions. In the subsequent section, I will reflect on my personal history and some of the social characteristics that could have influenced my relationships in the field.

Bias of the Researcher

In her book *A Guide to Qualitative Field Research* (2007), Bailey explores how anthropologists prepare for, engage in, and present the findings of their field research. In particular, she turns her attention to the significance of being reflexive about the personal and institutional factors that have contributed to an anthropologist's professional development. In one of the required master's courses at Concordia University, we explored the World Anthropologies debate (Restrepo & Escobar 2005), which explores the role of the anthropologist in the production of knowledge with a specific focus on the way that Western institutions often define the legitimacy of what we produce ethnographically. As a result, we often do not acknowledge the role that we play in the fieldwork encounter and do not view other epistemological approaches or ways of knowing as equally legitimate (Ribeiro 2006). Therefore, it is important that I acknowledge the role the institutions have played in shaping my perspectives and approaches as an academic.

In addition to my academic history, I have to also consider other social characteristics such as age, gender, race, ethnicity, sexual orientation, etc. For the purposes of my research, gender and age seemed to be most influential. By focusing on a topic that is strictly a male illness, being a male gave me access to both the field and my informants. My gender however may have also influenced the behavior of certain participants; attitudes of nonchalance and disinterest or emphasizing the role of sexuality may have been ways of reinforcing their sense of masculinity. As my informant Thomas did, asserting that sexuality was still central to the way he defined his manhood appeared to be a way for him to validate his identity. This brings me to the next significant social characteristic that needs to be considered: age. Because prostate cancer is an illness that impacts men over the age of forty (Saad & McCormack 2008), being a young researcher most certainly played a role while I was in the field.

As I recounted in the opening chapter when I discussed my experience at the ProCure conference, I immediately stood out when I walked into the room because of my age. Most of the men, who attended that evening, were between the ages of forty and eighty, and a few approached me inquisitively, wondering why I was there. Once I explained my reason for being there and my research project, my concern for their community legitimated both my attendance and taking notes. On other occasions however, I felt that my informants were hesitant and afraid of my perception of them given my age. By discussing private or sexual matters with a researcher that was often as old as their children or grandchildren, some men were reluctant or seemed uncomfortable sharing intimate details. On the other hand, some men emphasized their sexual exploits openly to demonstrate that sexuality is just as important now as it was when they were my age.

In addition, the age gap tended to make additional meetings outside the context of the interviews difficult. Despite our shared interest in creating awareness about prostate cancer, it seemed complicated for some of them to legitimize spending any additional time with me. My four informants Victor, Gerald, James, and Matthew however are avid tennis players and being a tennis instructor allowed me to establish rapport much easier and make spending time together more comfortable. In the coming months, I have promised to play doubles matches or give free lessons to thank them for having participated in my research. As these reflections demonstrate, it is important to acknowledge my role as an anthropologist and the personal and institutional factors that have shaped my perspective on prostate cancer and the fieldwork experience.

Ethical Concerns

The majority of my field research and data collection took place during interviews with informants and meetings with ProCure. While the narratives shared during these interviews were rich in detail, I will not be able to fully experience and understand the implications of having had prostate cancer and its possible impact on masculinity, identity, selfhood, and sexuality myself, and therefore, it was imperative that I closely collaborate and learn from them. While my father is a prostate cancer survivor himself and I have been able to witness first-hand the impact of the experience on both him and his family, I was open to having a man's partner attend the interviews or meetings if he desired. Due to the nature of illness as a "social experience" (Kleinman 1988), I accommodated participants like Victor, to ensure that they remain comfortable and supported.

In addition, each survivor who participated in my research and shared their narrative signed two consent forms that outlined my project, Concordia University's policy with regards to human research and their role within the research and their rights as a participant. I kept one of these forms for my records and each participant kept a copy with both my contact and supervisor's contact information. These interviews were recorded if my informant granted me permission and a pseudonym was used in the writing of the thesis to protect the individual and their right to anonymity and confidentiality. Working in the context of Québec, my interviews were conducted in either French or English depending on the preferred language of the participant and I thus carried both French and English copies of the informed consent document. Finally, I have informed each of my participants that after my research has concluded and my thesis has been submitted and accepted, I will provide a copy of my work to any informant.

Theoretical Framework

This thesis is framed within the subfield of medical anthropology while relying heavily on masculinity studies. Drawing on concepts and theoretical approaches from both streams, my research demonstrates the nuanced relationship between the social and cultural construction of the body, illness and disease, conceptions of masculinity, identity, and selfhood, and the way these influence how men navigate different therapies and procedures offered in the sphere of Western biomedicine. In what follows, I outline the different major theoretical approaches that have been used to frame my research, namely, theories related to the cultural construction of illness and of the ill body, masculinity and hegemonic masculinity theory, and Turner's theories of liminality.

Cultural Constructions of Illness and of the Ill Body

An influential text that has impacted scholarly work on health and illness over the past few decades is Susan Sontag's renowned book: *Illness as Metaphor* (1978). In this book, Sontag outlines the way that war metaphors are often used by survivors of diseases like cancer when explaining their recovery or suffering. In a section of her book focusing on cancer, she presents the way that a diagnosis with this disease can jeopardize many different aspects of people's lives: "Since getting cancer can be a scandal that jeopardizes one's life, one's chance of promotion, even one's job, patients who know what they have tend to be extremely prudish, if not outright secretive, about their disease" (Sontag 1978:8). In addition to outlining how illness can impact a person's life, Sontag also illustrates through the use of metaphors that the experience of being unwell impacts the body's functioning: "In cancer, the patient is 'invaded' by alien cells, which multiply, causing an atrophy or blockage of bodily functions […] [t]he cancer patient 'shrivels'

(Alice James' word) or 'shrinks' (Wilhelm Reich's word)" (Sontag 1978:14). She argues throughout the book that the use of linguistic devices such as the ones in the above example, leads to the shaming and discomfort of patients. Sontag suggests that a focus on lived experience without recourse to metaphors is a better approach. While the work of Sontag has been highly influential, she focuses so much of her attention on her contempt for the use of metaphor in discussions of illness that she ignores many of the other factors that may contribute to a person being secretive about their disease. In this sense, Sontag fails to account for all of the complexities associated with what is not said and why it is not said. While illness can jeopardize a person's job or chance of promotion, people may also be secretive about their disease when their role or identity is put into question. In this sense, Sontag seems to be ignoring issues of identity. By providing concrete examples drawn from lived experience, my research will hopefully complement and add to Sontag's analysis by demonstrating how culture shapes gender relations and how these in turn influence the way men deal with the effects of their illness in different settings.

To complement the work of Sontag (1978), and to provide additional context, Arthur Kleinman's book *The Illness Narratives: Suffering, Healing, and the Human Condition* (1988) will be used as it provides a comprehensive account of illness as a cultural construction, the relationships between health care professionals and patients, and ultimately the way that symptoms and suffering impact the individual and their families. Throughout this thesis, the terms "illness" and "disease" will not be used interchangeably. Building on the work of Kleinman, I will use the terms "disease" and " illness" in my thesis as concepts holding different definitions and meanings. "Disease" according to Kleinman is related to how the practitioner recasts illness in terms of theories of disorder and labels it. In this sense, disease is the problem from the practitioner's perspective and is broadly defined in the biomedical model as a set of symptoms, which lead to "[…] an alteration in biological structure or functioning" (Kleinman 1988:5-6). Closely connected with the diagnosis of the health care professional, "illness" is defined by Kleinman as how "[…] the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability" (Kleinman 1988:3). While both of these concepts are closely tied to how the individual experiences their diagnosis, disease is more closely tied to the relationship between doctor and patient, whereas illness is concerned more with how the individual themselves and their family experience their symptoms and suffering.

For the purposes of my research on prostate cancer survivors, I will be mostly concerned with how the diagnosis of disease influences the illness experience and how both of these in turn impact conceptions of masculinity, identity, and selfhood. Later in his book, Kleinman (1988) explores different diseases, one of them being cancer, and extrapolates on how it has impacted individual patients. In order to grasp a more thorough understanding of the illness experience, Kleinman uses the narrative method and allows the individual to tell their own story: "[…] patients order their experience of illness—what it means to them and to significant others—as personal narratives. The illness narrative is a story the patient tells, and significant others retell, to give coherence to the distinctive events and long-term course of suffering" (Kleinman 1988:49). While the recounting of an illness experience may change over time, as the person is able to reflect more on how it has impacted their life, Kleinman also points to how one's conception of being ill or healthy is highly influenced by the cultural context in which they live:

> Local cultural orientations (the patterned ways that we have learned to think about and act in our life worlds and that replicate the social structure of those worlds) organize our conventional common sense about how to understand and treat illness; thus we can say of illness experience that it is always culturally shaped. (Kleinman 1988:5).

In this sense, an individual's expectations about illness are altered through different social situations and webs of relationships and are thus shaped by cultural context (Helman 2007, Lorber & Moore 2002 and Hay 2008).

Influenced by the work of Kleinman (1988), medical anthropologist Gay Becker explores the way illness experience disrupts the continuity of peoples' lives and ultimately impacts conceptions of selfhood. In her book *Disrupted Lives: How People Create Meaning in a Chaotic World* (1997), Becker argues that balance and order begin in the body and therefore, when a body becomes ill, peoples' expectations about the life course become confused or unclear and they "[…] experience inner chaos and disruption" (Becker 1997:4). Following suit with many of the other authors whose work is presented in this section of the theoretical framework, Becker argues that one's expectations about the life course and the way illness is perceived is shaped by the norms of different cultural contexts. She argues that while continuity is a human need and a universal expectation across cultures, it is experienced differently depending on the socio-cultural context (Becker 1997). Throughout her ethnography, Becker presents the illness experiences of different men and women across geographic space and demonstrates the way these encounters have impacted notions of selfhood and identity. Due to the different social expectations placed on men and women in different societies, Becker argues that when faced with a disruption in the continuity of their lives, people may adapt in drastically different ways to fit their needs and circumstances. For example, in small-scale societies such as horticulturalists or foragers where women tend gardens or gather food close to the home, their form of adaption may be drastically different than that of a single working mother raising children in an urban context. Therefore, similar to Kleinman (1988), Becker uses a narrative approach to examine disruption and continuity in different contexts and to enable her participants to tell their own stories:

> In this book, narrative is the primary path for examining disruption and continuity. I have chosen this path because I want to record the nature of life disruptions in people's own voices. Narratives, the stories that people tell about themselves, reflect people's experience, as they see it and as they wish to have others see it. (Becker 1997:25).

In particular, Becker uses narratives to both empower her research participants and to uncover through these personal accounts broadly construed cultural concerns. This ethnography is a compelling example of how human research can be conducted in a manner that both benefits the researcher and empowers the participant; it will play a significant role in my thesis as it shows the strength of the narrative method and how it can be used to better understand the way illness influences people's lives in a way that is relevant to the participants themselves.

Also influenced by Kleinman, Cecil Helman in her book *Culture, health, and illness* (2007) provides an overview of the subfield of medical anthropology and the lens it uses to explore the role of culture in shaping peoples' perceptions of disease, illness, and the adequate procedures used to treat them in different contexts. In particular, Helman argues that medical anthropology is geared towards investigating how people in different cultures and social groups explain the causes of ill health and to whom they turn when they are ill. This subfield of cultural anthropology endeavors to flesh out how cultural background impacts many aspects of people's lives such as: beliefs, behaviors, perceptions, rituals, family structure, diet, attitudes to illness, pain and other misfortunes, which all may have significant implications for health and health care (Helman 2007). Medical anthropologists research the way culture shapes peoples' perceptions of their bodies and the bodies of others, illness, disease, and how these issues should be addressed and by whom. In doing so, they essentially study human suffering and its impacts on the individual and the larger social group. Helman writes: "The culture and background in which we grow up teaches us how to perceive and interpret the many changes that can occur over time in our own bodies and in the bodies of other people […] [Medical anthropology] is the study of human suffering, and the steps that people take to explain and relieve that suffering" (Helman 2007:1-3).

In a similar vein, Lupton in her book *Medicine as Culture: Illness, Disease and the Body in Western Societies* (1994), explores health and illness from a social constructivist perspective, and how it is based on a series of inter-related constructions which are dependent upon the socio-historical settings in which they occur. In particular, Lupton explores Foucault's writing on sexuality and the body and uses it as a platform to elaborate on the sexually active, "healthy body". According to the author, a sexually active body is a "[…] primary site at which contesting discourses compete for meaning, particularly in the fields of medicine and public health" (Lupton 1994:26). Lupton is primarily concerned with how culture influences the way illness and disease are perceived within different contexts and how these in turn influence institutional frameworks concerned with health and health care.

While Helman (2007) and Lupton (1994) provide an accessible account of medical anthropology, some of its main theoretical frameworks and topics of inquiry, other anthropologists and sociologists studying health and illness have delved much deeper into the intersection of how illness and disease are culturally constructed. In their comprehensive book *Gender and the Social Construction of Illness* (2002), Lorber & Moore similarly explore the influence of culture on the perception of health and illness in different societies and contexts while also examining how it intersects with the gendered lives of both men and women. In every society, Lorber & Moore argue that symptoms, pain, and weaknesses associated with being ill are shaped by cultural and moral values and relationships with others. In the West, the authors argue that being healthy constitutes a state in which people can accomplish both what they have to and want to do, whereas illness is "[…] something that disturbs the physiological equilibrium of the body" (Lorber & Moore 2002:1).

It is clear from the research of Helman (2007), Lupton (1994), and Lorber & Moore (2002) that culture shapes what constitutes a "healthy body" versus an "ill body" within a given social context. A further contribution of Lorber & Moore's work however is a thorough analysis of how gender relations are deeply rooted in cultural understandings of health and illness. As gender is embedded in the major social institutions of society (these include the economy, the family, politics, and the medical and legal systems), it has a significant impact on how men and women are treated in different aspects of social life, particularly in the health sector. In this sense, the gendered body in its specific cultural context "[…] is the framework for the analysis of the social construction of illness" (Lorber & Moore 2002:5). Furthermore, due to biological differences between men and women and the gendered roles that they assume, it is clear that there are different expectations associated with masculine and feminine attitudes toward health. As I will demonstrate below, cultural norms influence gendered expectations concerning help-seeking behaviors, decisions with respect to particular medical procedures, and the recovery from an illness experience.

While Lorber & Moore (2002) provide a thorough discussion of how gender is intimately tied to cultural constructions of illness and disease, they also outline the biomedical model of illness prevalent in Western societies. The biomedical model assumes that disease is a deviation from normal physiological functioning and that diseases have specific causes that can be located in the ill person's body: "[…] illnesses have the same symptoms and outcome in any social situation, and […] medicine is a socially neutral application of scientific research to individual cases" (Lorber & Moore 2002:2). By exploring this model, the authors thread the intersection of gender and culture throughout their discussion while shifting focus to the way medicine is practiced from an institutional perspective. In particular, Lorber & Moore extrapolate on the patient-physician relationship and illustrate how an ideal illness from the perspective of a medical practitioner is one that produces an unambiguous diagnosis, is followed by an effective treatment that will cure the disease by removing disruptive and painful symptoms, and that will ultimately restore the patient to normal functioning. This conception of an "ideal illness" clearly illustrates how integral the social context is to every part of illness. For example, the biomedical model is one shaped by cultural and moral values of the West, which outlines how an illness would be ideally diagnosed and treated. Therefore, in every cultural context, what is considered "normal" functioning and an appropriate treatment method is a social product: “From recognition and attention to symptoms through actions while sick, to coping with recovery or a chronic condition or dying, all a patient’s social characteristics have an effect” (Lorber & Moore 2002:7).

While Lorber & Moore (2002) provide a comprehensive account of how gender intersects with the cultural construction of health and illness in the West, their work leaves a few loose ends. The book is entitled *Gender and the Social Construction of Illness*, however the authors allot most of their attention to the way that gender and culture have shaped institutions such as biomedicine in primarily White Western contexts. Their work would have been even more thorough if they had included more cross-cultural examples on how illness and health are culturally constructed and mediated by varying conceptions of gender and not focus as much attention on Western biomedicine and its approaches to healing and treatment. In addition, Lorber and Moore present a macro perspective on the way that understandings of illness and gender are tied to culture but do not provide enough examples of patients’ lived experience. In my thesis, I will dedicate a chapter to an early fieldwork experience where I participated in a ProCure conference. During a question-answer period at the end of the presentation, one of the participants raised the issues of masculinity and prostate cancer in the Caribbean and how it impacts the behavior of men when they immigrate to Canada. To my surprise, the question was pushed aside and was never answered. While my research pertains to prostate cancer survivors in Montréal, I will draw on this example to demonstrate the importance of considering cross-cultural examples and understandings of illness and masculinity. Furthermore, I will draw on the narratives of men in my sample to illustrate the significance of examining the lived experience of survivors to ensure that patient care is specific to the needs of the individual. Due to globalization and the multicultural fabric of Montréal, it is imperative that physicians and health organizations consider different cultural attitudes about prostate cancer if they are to be better equipped to provide even support to a diversity of patients (see Chapter 4: "Acknowledging Difference").

Similar to Lorber and Moore (2002), anthropologist Emily Martin explores the intersection of culture and gender in order to shed light on the gender stereotypes hidden within the scientific language of biology in her article, "The Egg and the Sperm: How Science has Constructed a Romance Based on Stereotypical Male-Female Roles" (1991). This article is a fundamental text in gender studies and in the subfield of medical anthropology because it bridges illness and gender and the natural sciences with the social sciences. Throughout her work, Martin fleshes out the way the sperm and the egg are depicted in scientific discourse around reproductive biology and argues that these rely on stereotypes central to our cultural definitions of male and female.

By investigating different medical textbooks on biology and reproductive health, Martin illustrates in this compelling article that the sperm is cast as active and powerful whereas the egg is depicted as passive: "The egg is seen as large and passive. It does not *move* or *journey*, but passively is 'transported', 'is swept', or even 'drifts' along the fallopian tube. In utter contrast, sperm are small, 'streamlined', and invariably active […] Their tails are 'strong' and efficiently powered" (Martin 1991:489). She demonstrates by the end of her article that these stereotypes not only imply that the female biological processes are less worthy than those of their male counterparts, but ultimately, that culturally constructed gender stereotypes and scientific discourse are tightly interwoven. The article however, only explores the intersection of gender and illness in the scientific discourse of the West and does not explore other examples beyond biomedicine. In this sense, similar to Lupton & Moore (2002), Martin's text is a comprehensive account of issues pertinent to the Western biomedical model and could have provided perspectives concerning reproductive health in different cultural contexts to both contrast and supplement her findings about the West.

To complement and add to the work of Helman (2007), Lupton (1994), Lorber & Moore (2002), and Martin (1991), American anthropologist Cameron Hay provides a cross-cultural example of how illness and disease are culturally defined and understood among the rural Sasaks of Lombok, Indonesia. In his article "Reading Sensations: Understanding the Process of Distinguishing 'Fine' from 'Sick'" (2008), Hay explores how sensations become symptoms after an interpretation of these sensations as "abnormal". According to Hay, the way that sensations become symptoms is a social process that is culturally defined: "[…] the transformation process from 'vague and disconnected' sensations into symptoms is a social one. Sensations become significant, they become symptoms, when others legitimate them as significantly impacting one's being-in-the-world" (Hay 2008:203). In this sense, because health and illness are culturally constructed, an individual's conception of the "normal" and the "abnormal" or of "healthy body" and "ill body" are highly contingent on their social relations with members of their group and the context in which these relations take place (Hay 2008 and Lorber & Moore 2002). Medical anthropologists like Arthur Kleinman and Byron Good who have done research in China and Iran respectively, have similarly found that the recognition and interpretation of symptoms varies dramatically across social-cultural settings and across different circles of a given social-cultural setting (Kleinman 1980;

Kleinman & Good 1985, cited in Hay 2008:201). Therefore, depending on the social circle and its associated relationships (these could include family, friends, health care professionals and/or community healers such shamans or practitioners of alternative medicine), individuals are likely to understand their sensations, symptoms, and illness experience in drastically different ways. This is fundamental, as it demonstrates that different constructions of illness and health can exist both between and within cultural settings.

Hay demonstrates how sensations considered "normal" in the West may be viewed as "abnormal" and a risk to health among the Sasaks of Lombok and therefore, are highly contingent on cultural conceptions of a "healthy body" versus an "ill body":

> Coughs and runny noses were so much a part of daily life, particularly for children, that they were rarely seen as sensations worth noting […] Sensations that were potentially problematic and carried one to the in-between space of 'less-than-healthy' (*kurang sehat*) were identified with the word *sakit* meaning 'sick' or 'painful'. For example, people would say that they had a *sakit sedot* (sick throat) or a *sakit tiang* (sick stomach). Such phrases meant that they had a worrisome or painful sensation whose location could be labeled. (Hay 2008:2007)

In addition, the Sasaks view themselves as "less-than-healthy" because they are constantly in danger of becoming sick. In their society, sickness lurks everywhere and they experience their world as one "full of dangers, always threatening their health" (Hay 2008:209). This example clearly exemplifies how the body cannot be viewed as a pre-cultural entity but rather, similar to health and illness; it is a product of one's social relations and environment (Shilling 2005). Overall, this is a useful article because it juxtaposes approaches to medicine and health in the West with how it is understood in rural Indonesia by demonstrating that perceptions of "healthy bodies" and "ill bodies" are culturally determined. While my work will focus on prostate cancer survivors in

Montréal, I will endeavor to shed some light on the experiences of non-Canadian born men who have immigrated to Canada. Similar to Hay, I will demonstrate the importance of adopting a critical cross-cultural approach to understanding health and illness.

Masculinity and Hegemonic Masculinity Theory

Conceptions of masculinity are intimately tied to the way an ill person experiences and understands their illness and this is because gender is culturally constructed. In particular, it is clear from the studies conducted about how men self-identify after a diagnosis with prostate cancer (Belizzi & Blank 2006, Belizzi & Blank 2007 and Park, Zlateva & Blank 2009) that the social expectations placed on men in different cultural contexts greatly impact both the way they behave and the way they negotiate and perform their identities. An example of this is illustrated in Sontag's highly influential book *Illness as Metaphor* (1978), where she outlines the way that survivors (particularly men) often adopt war metaphors when describing their illness experience. This is supported by the studies conducted by Belizzi and Blank (2006, 2007) where the majority of participants identified as prostate cancer "survivors" and "conquerors" rather than "victims" or "patients". In this sense, war metaphors become a way for men who feel weakened by illness to reformulate said weakness in heroic terms. Therefore, through the use of metaphors and different self-identity labels, it is clear that both conceptions of masculinity and illness are culturally informed.

In the second edition of her book *Masculinities* (2005), Connell explores masculinity and demonstrates the way it is carried out in everyday life through sets of actions, behaviors, and in the relationships between men and between men and women.

She begins her book by juxtaposing essentialist/biological explanations of masculinity with theories of social constructivism that view masculinity as more of a cultural product:

> Two opposing conceptions of the body have dominated discussion of this issue in recent decades. In one, which basically translates the dominant ideology into language of biological science, the body is a natural machine, which produces gender difference—through genetic programming, hormonal difference, or the different role of the sexes in reproduction. In the other approach, which has swept the humanities and social sciences, the body is a more or less neutral surface or landscape on which a social symbolism is imprinted. (Connell 2005:45-6).

While Connell presents both perspectives on masculinity, she adopts a framework more aligned to the latter, one that views masculinity and the body as socially defined. To understand how masculinity is enacted in everyday life, Connell argues that we need to explore the processes and relationships through which men and women live gendered lives. In addition, she argues that in order to understand gender, we must go beyond it and see how it relates to and intersects with class, race, and global inequality: "To understand gender, then, we must constantly go beyond gender. The same applies in reverse. We cannot understand class, race, or global inequality without constantly moving towards gender" (Connell 2005:76). Therefore, according to Connell, an intersectional analysis is imperative to fully uncover the enmeshed relationship between social factors and relations at both a micro- and macro-level.

Connell outlines and fleshes out the complexities of hegemonic masculinity theory and how this type of masculinity shapes the acts and behaviors of men and their relationships with others. Connell begins her discussion of this theory by exploring the roots of the word "hegemony", derived from Antonio Gramsci's analysis of class relations: it refers to the "[…] cultural dynamic by which a group claims and sustains a leading position in social life" (Connell 2005:77). She then applies this concept to "hegemonic masculinity" by demonstrating how this approach to gender relations is one which legitimizes patriarchy and guarantees the dominant position of men and the subordination of women. Connell illustrates that the behaviors men adopt in their relationships with other men and women plays into the "patriarchal dividend" which enables them to gain "[…] honour, prestige and the right to command" (Connell 2005:82).

While both of Connell's books on masculinity have largely contributed to the fields of gender and masculinity studies, sociologist Anthony Synnott argues that her pro-feminist position paints all men with the same brush and presents them as power hungry villains. Although patriarchy is deeply embedded in the social structures and institutions of societies in the West, her analysis—as Synnott demonstrates—presents men as entities void of emotions and feelings, whose sole purpose is to subordinate women for their own benefit. My research will use much of Connell's framework about masculinity as socially and culturally defined, but will hopefully also shed light on the nuanced relationship between the social expectations of men and how they actually feel. I will use the perspectives presented by Connell and Kimmel and juxtapose them with Synnott's in a later chapter (see Chapter 3: "Sexuality and the Prostate Cancer Experience"). In doing so, I will demonstrate that both perspectives must be considered together when understanding the lived experience of survivors, particularly how they negotiate masculine identity with the physical changes to their body. In this sense, I seek to move away from the dehumanizing elements of Connell and Kimmel's work on men and instead, provide narratives that will reveal the lived experience of prostate cancer survivors and how they deal with the diagnosis and recovery process.

In another one of Connell's texts co-authored with Messerschmidt entitled, "Hegemonic Masculinity: Rethinking the Concept" (2005), they outline how hegemonic masculinity might only apply to a minority of men but represents the most honored way of being a man. In particular, they explore how masculinity is not a fixed entity embedded in the body but rather, configurations of practices that are accomplished in social action and that can differ depending on social setting (Connell & Messerschmidt 2005). The authors also explore the ways that the concept of hegemonic masculinity has been criticized; it is framed within a heteronormative conception of gender that ignores difference and exclusion within gender categories. Similar to Connell's book *Masculinities* (2005), the authors illustrate the way that masculinities and identities are contextually dependent and therefore, there exist many different conceptions of masculinity:

> The importance of masculine embodiment for identity and behavior emerges in many contexts […] Bodies participate in social action by delineating courses of social conduct—the body is a participant in generating social practice. It is important not only that masculinities be understood as embodied but also that the interweaving of embodiment and social context be addressed. (Connell & Messerschmidt 2005:851)

In this sense, in order to understand the way that masculinity is embodied by men, it is important to see it as a concept that is not fixed, but rather, constantly redefined by cultural context and by men's relationships with both other men, and women. While this article is useful because it problematizes the concept of hegemonic masculinity and how it is often framed within heteronormative gender relations, the authors still appear to make generalizations that do not apply to all men. In particular, it seems that Connell & Messerschmidt both fail to address the lived experience of men and the way they struggle to uphold what is deemed socially acceptable "masculine behavior". Therefore, they argue that masculinity is culturally constructed, however they do not provide any examples of how it is played out in everyday life outside the West nor do they emphasize how masculinity can change over time. Furthermore, Connell & Messerschmidt seem to present men as beings on a determined quest to subordinate women. In doing so, they rely too heavily on a macro-scale approach that does not consider the lived experience of masculinity. While my research will focus on prostate cancer survivors in Montréal, it is my responsibility to indicate in my thesis that the data I collect about the intersection of masculinity, illness, and selfhood is not representative of all Western men, but rather, a set of narratives based on individual experience that will demonstrate, like Petersen (2009): pluralized masculinities and the heterogeneous character of men's lives.

The book entitled, *Men's Health: Body, Identity, and Social Context* (2009), is a collection of articles written by different authors on the intersection of masculinity, health, and identity. In the first chapter by Courtenay entitled, "Theorising Masculinity and Men's Health", men's health behaviors are surveyed and are tied to masculinity and understood through hegemonic masculinity theory. According to the author, men use health beliefs and behaviors to demonstrate dominant and hegemonic masculine ideals, which subordinate lower-status men and women by upholding patriarchy (Courtenay 2009). Some of these behaviors involve men being less likely to exhibit help-seeking behaviors because their bodies are supposed to be infallible and unsusceptible to weakness and illness: "When a man does experience an illness or disability, the gender ramifications are often great, illness 'can reduce a man's status in masculine hierarchies, shift his power relations with women, and raise his self-doubts about masculinity' (Charmaz 1995:268, cited in Courtenay 2009:15). Similar to Connell in both of the sources outlined above, Courtenay presents hegemonic masculinity as the idealized form of masculinity at any given place and time (Connell 2005, Connell & Messerschmidt 2005 and Courtenay 2009). This particular chapter illustrates how the way men approach health and respond to illness are both culturally driven and influenced by the norms and expectations surrounding masculinity in different social settings. While this chapter was a useful introduction to how masculinity impacts men's conceptions of health and illness, examples or case studies could have been included to support his arguments and data. In this sense, his work would have benefitted from an empirical underpinning and thus, through my own research, I endeavor to fill the gaps left by Courtenay through the use of narratives and in-depth interviews with prostate cancer survivors. Therefore, because Courtenay relies heavily on hegemonic masculinity theory like Connell, his work suffers from the same limitations: it ignores the lived experience of men.

In another chapter of the same book entitled "Positioning Prostate Cancer as the Problematic Third Testicle", Oliffe begins by briefly outlining prostate cancer as a disease and the procedures and therapies available to men once they have been diagnosed. Echoing the work by Courtenay in the opening chapter of the book, Oliffe argues that men approach prostate cancer and health behaviors in a way that is shaped by masculinity: "Men's stoicism about health and illness matters has been described over many years, and no doubt many men ascribe to silence rather than […] self-disclosure" (Oliffe 2009:50). In particular, the author demonstrates how the concept of hegemonic masculinity and the cultural ideals associated with masculine behavior such as self-reliance, stoicism, and sexual prowess, become problematized by a man's diagnosis with prostate cancer. To conclude the chapter, Oliffe discusses the role of the prostate in male sexuality; both in heterosexual and homosexual sex acts, and he demonstrates how masculinities and identities are renegotiated throughout the experience of prostate cancer.

Discussed earlier, Kimmel's article "Masculinity as Homophobia: Fear, Shame, and Silence in the Construction of Gender Identity" (2008), argues that manhood is socially constructed and historically shifting. Similar to Connell (2005) and Reeser (2010), Kimmel explores how masculinity is constantly in flux and being redefined by men's relationships with both other men, and with women. In this sense, men are highly dependent on their social interactions with other men to negotiate their masculine identity. Kimmel also outlines the way that masculinity and manhood are organized primarily around homophobia: "Homophobia is more than the irrational fear of gay men, more the fear we might be perceived as gay" (Kimmel 2008:214). Overall, Kimmel's argument of masculinity as "homosocial enactment" will be significant to my thesis because men's openness to speak about their prostate cancer with others is closely enmeshed with conceptions of masculinity (Oliffe 2009). Towards the end of the article, Kimmel argues that men feel more powerful when they are part of a group than when they stand individually. I will explore this point in more depth with my research, particularly when I observe the interactions of prostate cancer survivors in a group setting at different events versus how they behave individually in an interview setting. Although it is an influential text, he seems to propose only one type of masculinity, the one that heterosexual men strive to uphold. If homophobia is the central organizing principle of our cultural definition of manhood, how do homosexual men define their masculinity? Do pluralized masculinities exist for Kimmel?

While Connell (2005) and Kimmel (2008) present masculinity theory from a pro-feminist perspective, Synnott brings a different approach to the discussion. In his book, *Rethinking Men: Heroes, Villains and Victims* (2009), Synnott begins by outlining the arguments of both Kimmel and Connell and criticizes them by arguing that men are both hegemonic and in crisis and that these are not mutually exclusive categories. He presents the "masculinity quotient" to illustrate the way that masculinity is not based on rigid categories, but rather, a continuum:

> So we have the low MQ wimps, sissies, fags, nerds and all those other negative epithets applied to omega males, especially at high school during the adolescent developmental stage of manhood, the medium MQ average guys, and the high MQ alpha males, the supermen, the hyper-masculine at the other end. (Synnott 2009:22).

Synnott also explores the way that feminists often present men as villains whose goal is to subordinate women with the goal of upholding patriarchy. In contrast, Synnott argues that by homogenizing men as hegemonic, feminists ignore the possibility that men are victims, they homogenize women as subordinate and ignore those who are hegemonic, and they often ignore the intersection of race, class, and gender (Synnott 2009). In addition, he criticizes Connell's concept of the "patriarchal dividend" and instead argues for the "patriarchal tax": "[…] the high costs men pay for being men e.g. no special protective legislation, systematic discrimination in health, education, welfare and justice systems, especially low income and minority men, the draft etc." (Synnott 2009:258).

Synnott's work is significant because it fills in many of the gaps left by other scholars in the field of masculinity studies. In particular, he proposes a perspective that looks more closely at the lived experience of men instead of adopting a lens that views them as dehumanized, perverted, and emotionless entities. While he presents a different perspective on masculinity theory by highlighting some of the weaknesses of the arguments made by Kimmel and Connell, he neglects the way that patriarchy is still very much embedded in social structures and institutions. In her book *The Sexual Contract* (1988), Carole Pateman outlines how social institutions and contract theory is a product of patriarchal discourses and relations. While it is important to view masculinity along a continuum instead of relying on rigid categories and broad generalizations, if understanding gender is highly dependent on the relationships between men and women, the cultural context in which these interactions take place, and the range of social factors that contribute to social expectations of masculinity and femininity, one must consider the implications and consequences of patriarchy. In this sense, Connell and Kimmel tend to see only patriarchy while Synnott tends to ignore it. As I discussed earlier in this section, I endeavor for my research to show the necessity of finding a balance between both extremes when exploring the diverse needs and lived experience of survivors.

Additional Theoretical Approaches

An additional theoretical approach that will be used to frame my thesis is Victor Turner's theory of liminality. During Turner's fieldwork among the Ndembu of Zambia in the late 1960s, he explored life cycle rituals and argues that each life cycle has three phases: separation, transition, and reintegration (Turner 1969; cited in Miller et al. 2010:293). In the initial phase of "separation", the person undergoing the ritual is separated physically, socially, and symbolically from normal life. An example of this phase is when a baby is baptized in the Catholic faith; the child is put into a white gown and is transition into another phase of the life cycle. The second phase described by Turner is the transition or "liminal" phase where the person is no longer their previous status but is not yet a member of the next stage (Turner 1969; cited in Miller et al. 2010:294). This particular phase involves the person learning the specialized skills that will equip them for their new status. The final stage of the life cycle that Turner describes is labeled “reintegration”. This last stage occurs when the initiate emerges and is welcomed by the community and adopts their new status in society.

While Turner’s concept of liminality has been associated with rites of passage cross-culturally, I feel that it can also be applied to the prostate cancer experience. For my research on prostate cancer, Turner’s phases will be used to illustrate how some men have adapted their sexual lives to the side effects of prostate cancer treatments and have begun reintegrating themselves and moving on. For others however, doubts about whether they chose the best treatment and the inability to accept how the effects have impacted their lives leaves men in a liminal space between the reality they once knew and the uncertainty of the future.

The final theoretical approach that will be used to frame this thesis is linked to silence, uncertainty and hesitations in fieldwork. In her book chapter “The Suicidal Wound and Fieldwork among Canadian Inuit”, medical anthropologist Lisa Stevenson reflects on the significance of considering uncertainties and hesitations as a legitimate ethnographic object. She begins by elaborating on an early fieldwork encounter with a young boy named Paul who had just recently lost his uncle. Stevenson explains that Paul’s sister was convinced their uncle came back to life as a raven and is living behind their house. While it is uncertain whether the raven is actually Paul’s dead uncle, she posits that it is just as important to listen for moments of hesitation that disrupt what is known for sure: “I want to think, then, about the possibility in fieldwork of listening for hesitation—listening for that which persistently disrupts the security of what is known for sure" (Stevenson 2009:56). By acknowledging moments when the facts falter, Stevenson feels that professional distance between ethnographer and informant is dissolved permitting them to embark on a mutual project of discovering the world. This chapter is useful to my research because it reflects a crucial aspect of my methodological approach. Because prostate cancer involves parts of the body that are not publicly discussed (Hegelson & Lepore 1997), it will be imperative that I look for uncertainties, hesitations, and moments of discomfort to gain the trust of my informants and to more fully understand their experiences both avowed and unavowed.

Literature Review

Prostate Cancer Literature and Studies of Prostate Cancer Survivors

An understanding of how illness and health are influenced by cultural context is imperative for research being conducted on the intersection of illness, gender, and conceptions of selfhood and identity. In addition to the body of literature in the fields of medical anthropology and gender studies, it is important that I also consider the literature already published on prostate cancer survivors and how the illness experience has impacted their relationships and overall lifestyle. This literature includes sources from: clinical oncology, and journal articles about men's health, the role of the media and celebrity stories, and the sociology of health and illness. In their article "Cancer-related identity and positive affect in survivors of prostate cancer" (2007), professors of Human Development and Family Studies, Belizzi and Blank, explore the extent to which prostate cancer survivors adopt a particular cancer-related identity during a period of one to eight years after diagnosis through the use of questionnaires. According to the authors of this study, the majority of men identified as "someone who has had cancer" (a thing of the past), a "survivor" or as "someone who has conquered cancer", instead of labels like "victim" or "patient" (Belizzi & Blank 2007). The use of the term "conqueror" by the participants of this study dovetails nicely with Sontag's argument in her book *Illness as Metaphor* (1978), where she argues that war metaphors are often employed when an ill person discusses their past suffering or illness experience. In addition, the use of the term "conqueror" may also be closely tied with the social construction of masculinity, particularly theories of hegemonic masculinity discussed earlier in the theoretical framework section. Belizzi and Blank (2007) conclude their study by stating that their findings show that years after successful treatment with prostate cancer, survivors feel little need to form a significant part of their identity around their cancer experience.

In a second article entitled "After Prostate Cancer: Predictors of Well-Being Among Long-Term Prostate Cancer Survivors" (2006), published in the American Cancer Society Journal, Belizzi and Blank explore a range of factors related to the well being of survivors. In particular, they focus on how hope, optimism, the use of coping strategies, and primary treatment predict well being among prostate cancer survivors through the use of questionnaires. The study was geared at understanding psychological well being after treatment for prostate cancer (Belizzi & Blank 2006). In addition, Belizzi and Blank argue that men who handle stress better and had a "positive affect" claimed to have adapted and coped with their disease, whereas survivors with "negative affect" who reported having a more difficult time handling stress in their lives, reported higher rates of depression (Belizzi & Blank 2006:2131). While these two studies shed light on how prostate cancer impacts the identity, sexuality, and lifestyle of survivors, they are problematic because both samples only consist of heterosexual men. Furthermore, the questionnaires consisted of rigid categories that did not permit participants to elaborate on their experience in greater depth, and only men who had been diagnosed early and who have good prognoses dominated the sample of the second study.

Similar to the two studies by Belizzi and Blank (2006, 2007), in their article "Prostate cancer: embodied experience and perceptions of masculinity" (2002), medical sociologists Chapple and Ziebland explore how treatment for prostate cancer affects men's bodies, their roles, and sense of masculinity. At the beginning of their article, the authors explore the idea that "men don't cry" and that many men do not engage in help-seeking behavior. In addition, Chapple and Ziebland argue that many men diagnosed with prostate cancer share the fear that the consequences of surgery or treatments may negatively impact their libido and ability to achieve an erection when engaging in intimate relations. In both cases, men's approaches to help-seeking behaviors and concerns about possible side effects are closely tied to Western conceptions of masculinity and about maintaining a highly virile image and identity (Chapple & Ziebland 2002).

Later in the article, the authors outline the two most prevalent procedures available to men who have been diagnosed: radical prostatectomy and hormone therapy. Both of these procedures are outlined at great length and the possible side effects of each are discussed in relation to conceptions of identity and masculinity. For example, urinary and bowel incontinence, erectile dysfunction, and loss of libido have been reported for patients having undergone both radical prostatectomy surgery and brachytherapy radiation. Chapple and Ziebland end their article by arguing that both the physical body and culture should be considered when trying to understand what it means to be masculine and how illness may affect men's sense of masculinity. While this article is significant to my own research, the authors outline masculinity as being a static and bounded concept and seem to ignore that it is constantly being redefined and that different conceptions of "masculinity" exist. In particular, they ignore that masculinity is constantly redefined through men's relationships with other men and with women, and due to social change. Furthermore, the authors do not acknowledge that a range of pluralized masculinities exist within one space and can be shaped by factors such as race, ethnicity, social class, and sexuality.

In their article published in the Journal of Clinical Oncology entitled, "Patients' Perceptions of Quality of Life After Treatment for Early Prostate Cancer" (2003) Clark et al. explore how different patient groups, depending on the procedure they have chosen, perceive "cancer control". "Cancer control" in the context of this article is related to the degree to which men feel their cancer has been cured by a particular treatment. According to the authors, patients who have decided to have a radical prostatectomy reported high levels of confidence, whereas those who chose watchful waiting were less confident. In other words, higher levels of confidence seem to be associated with "taking action" and this is strongly linked to masculinity. Patients who reported greater cancer control were often associated with positive scores for sexual intimacy and their sense of masculinity. In addition, the findings of Clark et al. demonstrate that greater masculine self-esteem was associated with the conviction that a well-informed choice regarding their procedure was made. While this article is important because it outlines the difficulties associated with making an informed decision about which procedure to pursue, the authors use the term "masculinity" without an in-depth discussion of its complexity. The term "masculinity" seems to be discussed without actually being clearly defined or operationalized. Consequently, an understanding of how conceptions of masculinity and femininity are cultural products is overlooked. Instead, masculinity is framed as pre-cultural, an essentialism, and biological.

Another article concerning the well being of men diagnosed with prostate cancer is entitled "Men's Adjustment to Prostate Cancer: The Role of Agency and Unmitigated Agency" (1997). In this text, social scientists Hegelson and Lepore argue that because more men live with prostate cancer than die from it, it is important to understand the link between the diagnosis and illness experience and its associated emotional, social, sexual, and physical impairments (particularly in the context of 'everyday lived experience'). In particular, the authors claim that adherence to the male gender role may impede their adjustment to prostate cancer because the treatments "[…] [affect] sexuality and control over bodily functions" (Hegelson & Lepore 1997:252). By impacting sexuality and control over bodily functions, which is important to maintaining and reinforcing masculinity, Hegelson and Lepore argue that this type of cancer did not receive as much media attention as others because it affects parts of the body that people do not publicly discuss.

Another useful article that deals with the intersection of gender, illness, and culture is entitled "Effect of Sex and Gender on Psychosocial Aspects of Prostate and Breast Cancer" (2001) by psycho-oncologist Alexander Kiss and general internist Siegfried Meryn. The authors explore how men diagnosed with prostate cancer deal with their suffering and illness in a different way than women do with breast cancer, specifically with respect to discussing their experience with others through the use of interviews and questionnaires. In particular, Kiss and Meryn highlight that masculinity is defined differently because men do not want to show weakness. Therefore, men seem to adapt their definitions of masculinity to uphold the social expectations placed on them especially when their manhood is challenged:

> If you ask men (colleagues or patients) what masculinity means for them, most are astonished, some make jokes, and you seldom get a consistent answer. How men are socialized and act as men is seldom reflected but constantly practiced in social interaction, influenced by beliefs and behaviors such as being hard and strong. (Kiss & Meryn 2001:1056).

In contrast, during stressful times most women diagnosed with breast cancer want to talk about it and share their feelings with others, as it is seen as more socially acceptable for them to speak about illness and weakness. According to the authors, this is due to norms of "emphasized femininity" and their emphasis on weakness, dependence, and vulnerability. They conclude their article by illustrating that while men often rely on communication with their partner and doctor when making a decision about which prostate cancer treatment to undergo, most men would rather not speak about their illness experience with others. This article was very useful as it juxtaposed the experiences of both men and women and demonstrates how the cultural construction of gender roles greatly determines the way disease and diagnoses are handled and understood. Similar to many other studies conducted on prostate cancer however, this article focuses primarily on heterosexual men and women and how they deal with their illness experience. In this sense, by outlining the experiences of both men and women with cancer, it sheds light on the culturally prescribed gendered expectations associated with coping strategies and reactions to being unwell.

In their article "Self-identity After Cancer: 'Survivor', 'Victim', 'Patient', and 'Person with Cancer'" (2009), authors Park, Zlateva and Blank explore, primarily through questionnaires, the way different cancer-related identities may impact interactions with healthcare providers, including those in general internal medicine. Similar to the study conducted by Belizzi and Blank (2007), the most common identity or label was "survivor" and seems to be associated with active involvement and better psychological well being. Park, Zlateva and Blank however outline that while the label "survivor" was the most common, many participants sometimes adopted other identifications simultaneously and these include: “victim”, “patient”, and “person with cancer”. According to the authors of this study, understanding cancer-related identity is important because it can help to tailor “[…] practice in a patient-centered way and can provide the context for enabling these patients to incorporate their cancer experience into the broader context of their health most effectively” (Park, Zlateva & Blank 2009:434). While this article is useful because it illustrates how individual patients experience and self-identify in relation to their illness, it does not explore many of the other factors that may contribute to choosing a particular label; social expectations and the cultural constructions of gender may influence a participant’s decision to choose one label over the other.

To conclude this section of the literature review, I will briefly present two other important texts written from a medical perspective that will be used in my research. The books by Saad & McCormack entitled *Understanding Prostate Cancer* (2008) and Taguchi entitled *Private Parts: An Owner’s Guide to the Male Anatomy* (2003) outline in great depth the role of the prostate in the body and during sexual encounters. In both of these texts, the approach is focused mostly on the body and its physiological functioning and a particular conception of masculinity seems to be implicitly assumed and not explicitly discussed. These two texts are geared at raising awareness about prostate cancer by discussing both early and long-term symptoms of the cancer, some of the procedures that are offered, how each of these procedures impact sexuality, and some of the side effects of each treatment. While the other sources in this portion of the literature review have focused on more of a social science approach to how prostate cancer impacts a man’s lifestyle and relationships with others, these two books approach the topic from a more medical and biological perspective and present to the reader the different resources and treatments available. After reading these two texts, I feel that it is important to bridge the gap between the work conducted by social scientists interested in health and medical practitioners, if treatments and therapy are to be more patient-centered. In particular, the books by Saad & McCormack (2008) and Taguchi (2003) do not focus on any of the possible social factors that may play into a patient choosing one procedure over another or how the ill body and gender are closely connected.

Theories of Male Sexuality and Sexuality After Treatment for Prostate Cancer

The cultural construction of masculinity and our understandings of the ill body are closely tied to male sexuality. In their article "Forever Functional: Sexual Fitness and the Ageing Male Body" (2002), Marshall and Katz begin by exploring the historical shifts in perception and practice around male ageing and sexuality through interviews with men of different ages. In particular, they examine the possibility of sexual potency and functionality existing beyond its conventional affiliation with procreation. Later in the article, Marshall and Katz explore erectile dysfunction as a dramatic and recent health problem and discuss the scientific and pharmacological implications surrounding the "technologization" of male sexuality through drugs like Viagra. The authors argue that masculinity becomes anchored in the erect penis across the lifespan and is a visible indicator of successful living:

> The sexual body here is also a gendered body and an ageing body, and it is in this convergence that we wish to locate our discussion. Evident is a new bodily configuration in the making; arising, on the one hand, from the pharmacological and scientific technologization of male sexuality, and, on the other, from a contemporary politics of life that fosters an ageless ageing while creating, paradoxically, an anxiety-ridden and somatized middle-age. (Marshall & Katz 2002:62).

This article is useful as it shows how masculinity and male sexuality are culturally constructed and centered on the phallocentric symbol of the erect penis and also, contrary to speculation, that the ageing male body is also a sexual body.

In a similar vein, the article by Arrington entitled, " 'I don't want to be an artificial man': Narrative reconstruction of sexuality among prostate cancer survivors" (2003), explores the way prostate cancer survivors construct stories of their illness experiences and the consequences for their sexual identities. To begin the article, Arrington illustrates a striking contrast in the research conducted on breast and prostate cancer survivors: there are a number of studies that analyze the stories of women with breast cancer while no studies have addressed the stories of prostate cancer survivors. According to the author, men diagnosed with prostate cancer either made their sex life a noteworthy motive in the decision-making process about which procedure to undergo, or they were conflicted and framed their sexuality as holding little significance: "[…] prostate cancer survivors seemed trapped between conflicting messages about the significance of sex and sexuality. Either sex comprises the bulk of their identities […] or sex means little to them" (Arrington 2003:50). Being conflicted about the role of sexuality in their lives is a direct result of the cultural construction and social expectations of masculinity in a given context. In addition, men who decided on the surgery and are suffering from erectile dysfunction opted to decline and not pursue any means of arousal (Viagra and Cialis) that would leave them feeling like an "artificial man". Therefore, Arrington makes it clear that the stories of survivors reveal that the prostate cancer experience threatened men's sense of masculinity (independence, virility, potency, and control) and illustrates "[…] that sexuality is a social construction and that sex is open to multiple definitions that can change in the wake of serious illness" (Arrington 2003:55). This article is significant as it demonstrates the benefits of a narrative approach and shows the complex relationship between gender, sexuality, illness, and culture.

Using a similar lens, Potts' article " 'The Essence of the Hard-On': Hegemonic Masculinity and the Cultural Construction of 'Erectile Dysfunction'" (2000), explores the symbol and significance of the phallus in sexual discourse and the economy. As discussed by Marshall and Katz (2002), the "hard-on" symbolizes a successful and healthy life for men and thus, a failure of the penis to become erect "[…] signifies the downfall of this phallic economy as it dictates the sexual identities of both men and women" (Potts 2000:87). Because male sexuality is valorized for being "hard and fast" in the hegemonic masculine framework, a man measures his own success in sex around the penis and therefore limits what counts as enjoyable male sexual experience. While Potts' text is influential and contributes to the discussion on hegemonic masculinity and sexuality, I feel that sexuality, similar to gender, needs to be considered as a set of interactions and relations. While I agree that male sexuality is focused around the erect penis and the act of penetration, Potts seems to ignore that apart from masturbation male sexuality involves an interaction between individuals in an intimate way. Furthermore, the "hard-on" is the symbol of hegemonic masculine sexual identity because it has been culturally constructed as such. In addition, these authors seem to presume that hegemonic masculinity is representative of all men's lives and as a result, lived experience is ignored.

The article by Fergus, Gray, and Fitch entitled "Sexual Dysfunction and the Preservation of Manhood: Experiences of Men with Prostate Cancer" (2002), focuses on the significance of sexual prowess and the erect penis as a symbol of successful male sexuality and how it is problematized by the experience of prostate cancer. Similar to the text by Arrington (2003), the authors begin by outlining the possible side effects of radiation and radical prostatectomy surgery and focus specifically on erectile dysfunction. In particular, Fergus, Gray and Fitch report that men diagnosed with prostate cancer learn that "being sexual" entails:

> […] the expectation that one's sexual organ should function 'on command', with predictability and precision; that sex is a 'serious, task-oriented business' with no room for play or experimentation; that a man's sense of his sexuality rests on tender hooks—having never been 'permanently earned; each time [it] must be reproven'; and lastly, that the ultimate (and perhaps only true) sexual accomplishment is coital penetration. (Fracher & Kimmel 1987 and Zilbergeld 1992, cited in Fergus, Gray and Fitch 2002:305)

Therefore, through a prostate cancer diagnosis, men become more conscious of the social expectations placed upon them concerning their sexuality and in turn, they are forced to negotiate their identity and masculinity based on these cultural norms. Fergus, Gray and Fitch conclude their article by arguing that for both gay and straight men, sexuality was commonly defined through conquest and competition: "[…] through the conquering of sexualized 'others', and/or through a sexually focused one-upmanship with other men" (Fergus, Gray & Fitch 2002:310).

In order to maintain this conquest and competition after a diagnosis with prostate cancer, participants in this study either tried to reinstate their previous level of sexual functioning to the best of modern technology's ability or they were required to alter their expectations and expand their notions of what constitutes acceptable sexual expression

(Fergus, Gray & Fitch 2002). This article is useful as it explores the impact of prostate cancer on male sexuality from both a homosexual and heterosexual perspective and also because it views sexuality as a set of interactions and power relations with others, a significant point that was not addressed in enough depth by Potts (2000).

In the first chapter of the book *Medicalized Masculinities* (2006) entitled, "The Viagra Blues: Embracing or Resisting the Viagra Body", Loe explores the way an illness like prostate cancer that causes erectile dysfunction, causes a kind of "broken body part" for men. She begins her discussion by exploring the work of anthropologist Emily Martin and her research exploring the medical discourse that compares the male body to a disciplined machine. Martin's work sets the stage for the rest of Loe's chapter where she explores the way that male consumers grapple with deficient body parts, the concept of manhood or masculinity, and medical diagnoses. In particular, she outlines the way consumers view Viagra as a way of fixing their "broken body part" and reinforcing the masculinity they **feel** they have lost: "[…] they imagine their bodies as machines, and use Viagra as a tool for fixing their broken masculinity" (Loe 2006:30). This article is valuable because it demonstrates how illness impacts sexuality and ultimately causes masculine identity to be fractured. In addition, it illustrates how perceptions of healthy and ill bodies, male sexuality, and conceptions of manhood are culturally constructed. It does leave a few unanswered questions however: What about men whose masculine identity does not rest on male sexuality or the ability to achieve an erection? While this chapter is useful, it assumes that all men experience and understand manhood and masculinity in the same way. Therefore, as with other texts in this section of the literature review, this chapter relies heavily on theories of hegemonic masculinity and has a tendency to homogenize and depersonalize men’s identity and sexuality.

In a similar vein, the article by Brubaker and Johnson entitled “ ‘Pack a more powerful punch’ and ‘lay the pipe’: erectile enhancement discourse as a body project for masculinity” (2008), explores consumption trends and their relationship with male sexuality and identity. In particular, the authors explore how erectile enhancement products are based on hegemonic conceptions of masculine sexuality that are constructed culturally through medical and popular discourse. Both types of discourse privilege the penis as essential to: “[…] sexual activity and power, and to some extent grant agency to the penis independent of men’s subjective experience or consciousness” (Brubaker & Johnson 2008:134). In this way, sexuality becomes a key site of identity and therefore, when it is put into question and problematized through erectile dysfunction, it needs to be reinforced. Furthermore, Brubaker and Johnson argue that a man’s masculinity is measured by his sexual prowess, performance, and virility. Therefore, if a man is unable to achieve and maintain an erection after a diagnosis with an illness like prostate cancer, his sense of masculinity and identity may be jeopardized. While this article is helpful because it shows how the norms of male sexuality are socially and culturally defined, it falls into a similar trap as many other texts in this section of the review because it makes the assumption that all men negotiate their identity and experience their sexuality and masculinity in the same way. Furthermore, as with articles in this literature review, this article relies too heavily on theory and not enough on fieldwork and the lived experience of men suffering from erectile dysfunction.

Media Construction of Prostate Cancer and Impact of "Celebrity Stories"

The final section of this literature review will focus on how prostate cancer and other types of cancer have been constructed and presented by the media while exploring the impact of celebrity stories on illness experience. While this thesis is concerned with prostate cancer more specifically, the literature on breast and testicular cancer in the media is also important; conceptions of masculinity, femininity, and selfhood may intersect in very different ways depending on the type of cancer however, the role of the media in peoples' lives and how it may influence how they understand their illness experience is worth considering. In particular, due to the rise and development of media fundraising campaigns focused on illness, health, and overall well-being, cancer-related issues are receiving greater exposure. In their article "Gender-specific Cancers: Gender-specific Reporters: Twenty-Four Years of Network TV Coverage" (1999), Corbett and Mori explore media coverage of both men's and women's health issues over the past few decades. In particular, they found that media coverage of women's health issues has increased over the past twenty years and a more recent trend occurred in the late 1980s regarding prominent men and their prostate cancer.

In addition, with the growing coverage of cancer in the media, Corbett and Mori argue that celebrities with diseases like breast and prostate cancer have largely contributed to this trend: "The celebrities with these diseases—and the American public's fascination with celebrities—have established perhaps permanently breast and prostate cancer as topics of discussion by individuals, the medical community, and the media" (Corbett & Mori 1999:399). The authors also discuss the way that the gender of the reporter is specific to the type of cancer being discussed. In particular, male reporters are more likely to report on female- and male-specific cancers. Although this is the trend, the authors do not delve much into why they feel this trend exists. In this sense, the authors could have explored constructions of masculinity and femininity and how they relate to the way different illnesses are presented in the media. While this article is useful because it surveys three decades of media coverage on health-related issues such as breast and prostate cancer and demonstrates the role celebrities have played in increasing print and television coverage of these diseases, it does not explore the impact these findings have on individual viewers and consumers. Their article would have been more thorough if they had examined the impact of celebrity stories on people diagnosed with either breast or prostate cancer—Do celebrity stories influence people's willingness to speak about their illness experience with others? Do they influence the choices people make regarding surgical procedures or therapies?

Another article that explores the role of media coverage of health-related issues is entitled "Survivors on Cancer: The portrayal of survivors in news print" by Kromm and his colleagues. In this article, the authors explore the role of survivors in the media and how it impacts the lives and identities of people diagnosed with cancer through textual analysis. In particular, they argue that news coverage involving survivors provides considerable information to the public about disease for everything from prevention, diagnosis and treatment, prognosis and meaning, and illustrates how cancer and perceptions of disease are culturally constructed and shaped depending on context: "In this way, news helps to shape the social and cultural contexts within which illness and disease are both collectively understood and individually experienced" (Kromm et al. 2007:298).

Kromm et al. argue that cancer survivors serve on the front lines of cancer control advocacy efforts and often engage with the media and therefore have the potential to impact public understanding of the disease. In this sense, survivors "[…] provide a face for the disease through awareness and educational activities that involve media interaction" (Kromm et al. 2007:299). To conclude their article, the authors illustrate that survivors, whether celebrities or not, help to construct an image of a survivor, the expectations of what it means to be a cancer survivor and what life as a survivor should and will entail. While this article is useful because it complements the work of Corbett and Mori (1999) and their research on celebrities and media coverage of health issues, I feel their arguments would have been strengthened had they had explored the implications of gender in cancer screening endorsements and provided case studies and specific examples to support their claims.

In their article "Celebrity Endorsements of Cancer Screening" (2005), Larson et al. used a random-digit dialing survey to examine the extent to which adults of screening age without a history of cancer had seen, heard, or been influenced by celebrity endorsements of screening mammography, prostate-specific antigen (PSA) testing, or colonoscopy in the United States. The authors begin their article by exploring how cancer screening from celebrities are becoming increasingly common and are delivered in one of two ways: "[…] either when celebrities endorse screening tests in news stories related to their own diagnosis of cancer or when celebrities become involved in promotional campaigns for specific cancer screening tests" (Larson et al. 2005:693). While media coverage of celebrity stories are becoming more commonplace, the results of the survey indicate that respondents who had heard such endorsements by celebrities reported that the endorsements did not influence their likelihood of having a test. Therefore, Larson et al. conclude by stating that they see no obvious role for celebrity endorsement of cancer screening (Larson et al. 2005). While this article is practical for my thesis because it explores the impact of celebrity stories and endorsements of different types of screenings (I asked my participants whether they were influenced by celebrity endorsements and stories), I believe that further research should be conducted on how celebrities impact the identities of people already diagnosed with the disease. In addition, it would be worthwhile to explore how constructions of gender play into the celebrity endorsements of screening procedures. For example, how would an endorsement by an athlete like Lance Armstrong impact a man's decision to undergo screenings for cancer? Would they be influenced in the same way if a more feminine male celebrity endorsed it? Also, while it is useful to explore the impact of celebrity endorsements on people *without* a history of cancer, it would be interesting to see whether the results would be different or similar if the sample had been of people *with* a history of cancer in their family.

In her article "A comparison of breast, testicular and prostate cancer in mass print media (1996-2001)" (2004), sociologist Juanne Nancarrow Clarke explores the intersection between disease and identity and argues for the importance of studying the association of disease with personhood and the specifics of stereotyped masculinity and femininity. To begin the article, she explores the role of the media in everyday life and how it informs people about the realms of disease, medicine, death, and illness. In particular, Nancarrow Clarke explores the role of celebrities in the media and argues that along with certain doctors who are specialists in the treatment of cancer (here she focuses her attention on prostate cancer), "[…] the heroes of these stories were often celebrities who had done their part for increasing the visibility of prostate cancer" (Nancarrow Clarke 2004:547).

Furthermore, she argues that by exploring all three types of cancer (breast, testicular, and prostate cancer) and how it is presented in mass print media, one is able to investigate the gendered nature of the disease and how it impacts personal identities and its relationship with women's and men's roles and conceptions of masculinity and femininity. This article is effective because it complements and adds to the rest of the literature in this section of the review by focusing specifically on the intersection between disease and gendered personal identities. Similar to many of these other studies, however, providing narratives or stories of cancer survivors themselves would have strengthened her claims and would have provided more thorough and clear evidence of the gendered nature of disease. Similar to other articles in this literature review, it would have been useful to do more of an intersectional analysis and explore how media coverage, gender, and disease, relate to issues of race, class, ethnicity, and sexuality.

The final article that will be presented in this section is one that demonstrates the overlap between the previous bodies of literature: the cultural construction of illness and the ill body, masculinity theory, male sexuality, and the role of media coverage. In his article "Sporting cancer: struggle language in news reports of people with cancer" (2001), Seale explores newspaper representations of cancer experiences, with a particular interest in the imagery of struggle and the use of military metaphors and connotations. Extending Sontag's arguments in *Illness as Metaphor* (1978) and the studies by Belizzi and Blank (2006, 2007), the author finds that "[…] the language of cancer is dominated by purely military connotations" (Seale 2001:308). The way that military metaphors are adopted in print media suggests that perceptions of the ill body, disease and illness, and appropriate masculine and feminine responses to feeling unwell are culturally constructed.

While this article supports the work of Sontag and other scholars who have explored the relationship between language, suffering, and illness, I feel that it leaves much unanswered. Seale uses "[…] in news reports of people with cancer" in the title of his work and does not explore how men and women might embody and experience their cancer differently. In addition, the type of cancer might be understood and experienced in drastically different ways depending on how it intersects with culturally constructed conceptions of masculinity and femininity and also depending on the side effects and consequences of surgical procedures and therapies. Furthermore, Seale's analysis seemed to lack depth because he did not delve enough into the implications of how struggle language might intersect with gender, class, sexuality, race, and ethnicity, and ultimately how all of these factors influence personal identities and notions of selfhood.

Having surveyed literature from a range of subfields, this literature review illustrates that a substantive amount of research has been conducted on masculinity, illness, and identity. Depending on an author's background, different sets of methodology are used to gain insight into the relationship between gender and illness. Many of these texts however rely so heavily on theory that the lived experience of men is ignored. As a result, this kind of scholarship tends to flatten, homogenize, and depersonalize men's identity and sexuality. In addition, many of these texts tend to ignore the way that illness and identity are impacted factors such as race, ethnicity, sexuality, culture, and social class. In this sense, these texts would have benefited from an intersectional approach to their topics. Through my research, I endeavor to fill these gaps by maintaining a balance between theory and fieldwork. This will enable me to focus on the lived experience of men and illustrate the way that patient care should be specific to the needs of different communities.

Chapter 1--Early Fieldwork: Considering the Culturally Constructed Body

Masculinity and sexuality are so tightly interwoven that, as a researcher, you cannot seek to understand one without considering the other. During my fieldwork in Montréal over the course of the summer and fall months of 2012, I was perplexed by the extent to which the hegemonic masculinity I read about in seminal texts by Connell (2005), Kimmel (2008), Messerschmidt (2005) and others, was enacted. Throughout the five months spent observing, conducting interviews, and reading, I came to realize that an illness like prostate cancer allowed for an opportunity to understand masculinity both conceptually and how it is lived and experienced. While previous research has tended to focus on a more theoretical approach to the study of masculinity, this thesis will balance theory and narratives from the field to understand the lived experience of survivors. The behaviors exhibited by both the participants in my research and the institutions with which I worked and collaborated confirmed the results of previous studies on topics such as: male help-seeking behaviors, masculinity and erectile dysfunction, self-labeling for prostate cancer survivors, etc. In what follows, I will illustrate the obstacles that I faced as a young researcher studying prostate cancer and how these intersected with the way masculinity and illness are culturally constructed and how these in turn have impacted the lives of prostate cancer survivors in Montréal.

When I first began my fieldwork in spring 2012, I contacted the Québec foundation for prostate cancer, ProCure, and they showed an interest in helping to get my fieldwork started. As stated earlier, ProCure was founded in 2003 and its mission is to provide science and humanity with means to help prevent and cure prostate cancer. Its main research is geared at further developing their BioBank, which is a bank of donated biological materials and data on men with prostate cancer as well as those at risk of developing the disease. Therefore, the organization seemed to be concerned about the physical consequences of the disease and the repercussions it has on their identity as men.

As discussed by authors Lorber and Moore in their book, *Gender and the Social Construction of Illness* (2002), it is important to consider all of the significant factors related to "[…] the transformation of physical bodies into social bodies […] [t]he social context is an integral part of any illness" (Lorber & Moore 2002: 6-7). Closely tied to perspectives on the body as both "physical" and "social", then, is the way that gender is theorized and understood in different contexts. Similar to Lorber and Moore (2002), masculinities theorist Connell illustrates that we need to consider the body as a surface or landscape on which a social symbolism is imprinted. In doing so, she argues that we can further understand the processes and relationships through which men and women conduct gendered lives and the "[…] practices through which men and women engage in that place in gender, and the effects of these practices in bodily experience, personality, and culture" (Connell 2005: 71). Until I attended a conference organized by ProCure, I was under the impression that the bodies of survivors and of men diagnosed with prostate cancer were considered physiologically, but also socially in the ways described by both Lorber & Moore (2002) and Connell (2005). While any research on cancer-related issues is important, it seemed as though the social lives of the men were not considered in ProCure's discourse on therapy and treatment options.

In early April 2012, I attended a conference at the Ruby Foos Hotel in Montréal entitled "New Developments in Prostate Cancer Treatment" which was organized by ProCure. Once I arrived at the hotel, I walked in and presented myself at the table where a kind woman who I later found out was the master of ceremony handed me a pen, a pamphlet about the organization, an additional illustrated pamphlet about prostate cancer screenings, and a book by urologists Dr. Fred Saad and Dr. Michael McCormack entitled *Understanding Prostate Cancer* (2008). Once I left the table, I was guided into a conference room by another volunteer, which was filled with about sixty seats with an aisle in the middle, facing a small podium and a table with a few chairs. In addition, there was a large screen between the podium and the table at the front of the room onto which a PowerPoint presentation was displayed. As I sat down at the end of a row on the left-hand side, we were informed that this conference would be recorded and could be viewed "live" on their website for any people who were not able to make it that evening to the presentation.

While I sat waiting for the conference presentation to begin, the chairs were filling up around me and I was being looked at by many of the men and women who were attending. The room was filled predominantly with men and their partners, however a few men were there alone. Most of these men and women seemed to be aged forty and over, were white, and seemed to be middle-upper class. A few rows behind me, I noticed four African American men who were the same age as the other attendees. Initially I felt very uncomfortable because it seemed as though I was out of place. While many anthropologists struggle with finding the right moment to take field notes, I felt that this moment might be a good time. I felt this was an appropriate course of action because attendees sitting on either side of me were ready to take notes as well. I took out my copybook and right away, the puzzled gazes and whispers that initially felt ominous dissipated. I had about five or six of the men who initially were puzzled by my presence grow interested and they asked me if I was a medical student. I told them that I was a student in medical anthropology studying the effects of prostate cancer on masculinity and identity and while they were confused about what medical anthropology was, they showed a keen interest in having a young person interested in health issues that affect men who are older. While I was viewed as impressive given my age and the topic I had chosen to undertake for my thesis by the men at this conference, I knew I had to prepare myself for the reality that this social characteristic may also be an obstacle when I entered the field and began conducting interviews; I will address issues related to “age” and other social characteristics in the field in a later chapter.

Promptly at 7pm, the conference presentation began and a urologist began discussing some of the recent literature and controversy concerning the PSA blood test as an accurate screening method for detecting prostate cancer. In particular, the focus was on the way men are sometimes being over-diagnosed with prostate cancer. Quickly however, the discussion shifted to the main topic of the conference, namely, new developments in treatment for prostate cancer. The radical prostatectomy, radiation, and hormone or androgen deprivation therapy were elaborated on at length and the urologist suggested that the pamphlets and book we received upon arrival should be looked at in depth as it complemented much of the presentation. As the presentation was winding down, we had a short break where refreshments like water, tea, coffee, and cookies were served. This gave me the opportunity to intermingle with some of the men who were attending the conference and to speak with some of the members on the board of directors of the organization with whom I had met in March 2012 at the initial meeting. After discussing my research with some of the board of directors who were absent when I first visited the organization, an announcement was made by the master of ceremony, explaining to us that we were going to move into a question and answer period with the urologist and other guest speakers who had shared their illness experiences.

While treatments were discussed at length during the presentation, there was very little attention paid to the impact of side effects like erectile dysfunction, urinary and bowel incontinence, penis shrinkage, the development of breast tissue, etc. When the question and answer period began, I noticed that many of the questions were focused on concerns related to sexuality, particularly erectile dysfunction and urinary incontinence. These questions illustrate possible gaps in the style of public education conferences, in the literature geared at spreading awareness, and in the way that medical professionals interact with their patients pre- and post-diagnosis. In particular, it seemed that there was a contradiction between the objectives of conference organizers and the attendees.

Towards the end of the discussion session, an African American man approached the microphone and explained the way that prostate cancer is understood and experienced in the Caribbean. He stated that in the Caribbean, the rectal exam used in prostate cancer screening is stigmatized and viewed negatively by men because the act of penetrating the anus is considered a homosexual act. After explaining the cultural perspective found in much of the Caribbean, he asked whether there was some way that ProCure could assist him in trying to spread awareness in the African American community in Montréal. He claimed that African American men are more susceptible to being diagnosed with prostate cancer because of higher levels of testosterone and are less likely to undergo screening because of cultural factors (especially the homosexual stigma). Previous studies have confirmed the argument related to the homosexual stigma associated with screening for prostate cancer (Winterich et al. 2009 and Reynolds 2008) and higher levels of testosterone in African American men (Magnus 2004). While each of the questions previously asked were answered to the best of the panel's ability, the concerns of this African American man seemed to be brushed aside, ignored, and not considered. Shortly after asking the question, there was a pause and the master of ceremony thanked everyone for coming and offered the leftover refreshments. Immediately after this occurred, I went and introduced myself to this man who I later interviewed and will be known in this thesis as Jerry. I was astonished by the way that his question was disregarded and when we discussed it later, he mentioned to me that very often his community is ignored: "This is my whole thing…to bring awareness to the community. Like when you saw me the evening of the seminar, I worked and rushed there and was hoping that people would have been more receptive about my requests but unfortunately, you were the only one who followed-up…" (Interview, July 24 2012). While I will focus on the needs of the African American community in a subsequent chapter on the significance of considering diversity in patient care, I have included it here because it was an important early moment in my fieldwork experience because it showed that there were/are, clearly, some taboo subjects in the medical community.

I will first turn to the possible gaps in the style of public education conferences, in the literature geared at spreading awareness, and in the way that medical professionals interact with their patients pre- and post-diagnosis. These will be considered first because I feel that they are integral to understanding masculinity and the cultural construction of illness. When I was attending the ProCure conference, I found that the presentation focused on scientific details like the changes to levels of hormones in the body and the success rate of different treatments. While this is important and I do not mean to undermine the significance of research being conducted to improve existing treatments, it seemed that the men and women attending this conference were interested in how these treatments would affect their lives in both the short- and long-term. In this way, the opportunity for public education on prostate cancer seemed incomplete and could have elaborated on the way that these new developments impact the lived experience of men. In particular, research on prostate cancer in the medical and social sciences and outreach programs seem to omit the lived experience of survivors. This neglect is significant as it highlights a broader and widespread unwillingness to engage with male emotion and vulnerability.

It is also important to consider the possibility that the literature on prostate cancer available to men may not be as complete as it should be. While much scholarly research has focused on the way men self-label following treatments for prostate cancer (Park, Zlateva & Blank 2009) and the way that masculinity is understood after prostatectomy-induced impotence (Oliffe 2005; Oliffe 2009; Wall & Kristjanson 2004; Arrington 2003; Potts 2000 and Fergus et al. 2002) it seems that the literature on prostate cancer provided in texts such as the one handed out at the conference (Saad & McCormack 2008), does not delve enough into the way prostate cancer influences a survivors' life. During an interview with one of my informants named James who is a general practitioner, we discussed the quality of literature available to recently diagnosed men. Instead of relying on the information provided in these pamphlets and books, an acquaintance with whom he plays tennis, who will be known in this thesis as Matthew, provided him with a journal where he documented his experience of prostate cancer. James argued that it was useful reading about another man's experience of the illness because of the detail that was provided: "What was particularly helpful was my tennis friend who had written a diary and provided it for me and I found it extremely helpful for me to read about his experiences…it was very helpful to normalize the circumstances" (Interview, October 5 2012). This excerpt from James' narrative is significant because it highlights that lived experience matters to survivors and is lacking in the literature.

In another interview with a man named Victor and his wife Martha, they described how helpful the literature was that the urologist supplied but argued that he also greatly benefited from hearing about the experiences of others:

> He gave us three options and a book that was really useful…and he said to read the book and think about it…and then come back in two weeks…which is good because you get over the shock you know… Yeah…a friend at the tennis club…I didn't know for a while that he had had it…there is another guy who is a GP who had the surgery the year before and I got a lot of comfort from him.
> (Interview, September 19 2012)

These testimonies suggest that adding a section for stories or entries at the end of pamphlets and books on how other men have experienced the illness and deal with side effects may help men to better understand their own circumstances. By providing the opportunity for these entries, it would shed greater light on the lived experience of survivors while complementing the other information in the pamphlet or book; it would add an understanding of the "social" and "experiential" body to what has already been provided on the "physical" body. In essence, men who have undergone the surgery appear to be equally or more concerned with the way their bodies will adapt to the side effects following treatment than the treatments themselves. Therefore, while these are closely tied, it is imperative to provide equal attention to treatments and how these in turn impact the social and sexual lives of men. In doing so, it would make the resources available more thorough and permit recently diagnosed patients to make an informed decision.

The final gap that will be addressed relates to the relationship between physician and patient. In my interview with physician, James, he argued that very often people do not understand biology very well and thus, part of his job is to educate and provide them with as much information as necessary:

> Almost invariably, the question I get asked: "what will I miss with the prostate?"…Well the prostate produces secretions that go into your semen and most men don't know that…they are not well versed…but that is not surprising because most people don't understand biology very well…probably a function of the educational system…part of my job then is not only psycho-education but actual education. (Interview, October 5 2012)

In this sense, it is important for urologists to provide their patients with thorough information about the prostate gland, its function, what prostate cancer entails, the possible treatments for the level of cancer detected through the PSA on the Gleason scale, and ultimately, the way that these treatments will impact their social and sexual lives in the short- and long-term. On many occasions, while my participants were recounting their narratives, they emphasized the difficulties they faced in terms of erectile dysfunction and incontinence. One informant named Richard seemed to be the most affected by the changes in his libido and sexual potency and emphasized how the doctor seemed less concerned about side effects. This was bothersome to Richard because he felt as though he was not provided with enough information and that his sexual life seemed unimportant to the two urologists with whom he spoke:

> "[My urologist] gave me books to read and he went right through them and so did my wife, she did faster than I did. But I did have certain reservations about the doctor…obviously he is good at what he does but he seems to go over things like impotence or incontinence…and pass right over it. The fact that I could be impotent, which I am now, seemed to just whiz by him. (Interview, July 28 2012)

The role of the urologist in this case was paramount to the patient's well being in the short-term because it seemed to hinder his ability to make an informed decision in confidence. It also impacted Richard in the long-term because he was left without enough information and resources to deal with the changes to his sexuality.

Another example of this gap and of conflicting priorities between patients and physicians is evidenced by James' story concerning orgasm and ejaculation following a laparoscopic prostatectomy. He argues that he faced a completely different kind of obstacle because due his status as a physician, it was assumed that he knew everything necessary about the procedure he had chosen. James argues that it is like a kind of "don't ask, don't tell policy" where if the patient doesn't inquire, the urologist does not seem to cover it:

> Even as a physician, I didn't know if I was going to be able to achieve an orgasm…if anything was going to come out…nobody tells you these things if you don't ask nobody tells you…the answer is that yes you do have an orgasm but you don't ejaculate which is very strange for a lot of men. (Interview, October 5 2012)

These accounts shed light on a blindspot in the medical system and demonstrate the important role of physicians and the significance of presenting both the physiological and social implications of prostate cancer and its treatments.

In the subsections that follow, I will turn my attention to the lived experience of survivors who graciously shared their narratives with me during my fieldwork. I will draw on these narratives to illustrate the importance of considering masculinity, sexuality, and a social body that is culturally constructed in the biomedical discourse on prostate cancer. Therefore, my research will add to the existing literature in the burgeoning fields of medical anthropology and masculinity studies and demonstrate the necessity of reconsidering the literature available to those diagnosed with prostate cancer, public education conferences, the patient-physician relationship, with the ultimate goal of improving the quality of patient care.

Chapter 2--Masculinity in the Narratives of Prostate Cancer Survivors

2.1. Contextualizing Masculinity

I began my thesis with a chapter focusing on the significance of considering a social or culturally constructed body in public education conferences, literature, and in the patient-physician relationship. I decided to do begin my thesis this way because I was struck by the number of men at the conference who were seeking comfort and answers about the changes in their sexual lives following treatments for prostate cancer. While only a few of these men whom I met at the ProCure conference participated in my research, similar concerns were evident in the rich and detailed narratives of other men with whom I spoke. By not providing enough information to prostate cancer survivors about the way their social and sexual lives will be impacted by the different treatments, research has ignored the insecurities and anxieties of these men. In particular, it seems that there is an implicit assumption made by medical professionals that one's masculinity or identity naturally returns to the way it was pre-op/pre-radiation therapy with ease.

In this sense, once the cancer is cured or the prostate removed, it is assumed that one's masculinity is also repaired: "True masculinity is almost always thought to proceed from men's bodies—to be inherent in a male body or to express something about a male body" (Connell 2005:45). This quote from Connell is useful because it highlights the way that masculinity is often viewed as purely biological and not culturally constructed and perhaps most importantly, considered to be unbreakable and invulnerable. There is evidence that healthcare institutions and organizations like ProCure are making great efforts at improving patient care. However, if there is no understanding of how masculinity and sexuality are culturally constructed and central to a man's identity, the needs and concerns of survivors are not being adequately assessed.

Over the course of my five months of fieldwork, I had the opportunity to meet with 13 men for interviews and speak with others in a less formal way about their experience with prostate cancer. On most occasions, I would contact my informants by phone and present myself, explain my research topic in greater depth, and schedule a convenient time for an interview. Apart from my interview with Jerry, an African American man from the island of St-Lucia in the Caribbean, I met with my other informants at their homes as per their request. I would arrive at their homes, introduce myself, and speak for about fifteen minutes with my informant because for many this was the first time I was meeting them and it was my only chance to gain their trust. At this time, I would often be offered tea and other refreshments and we would settle in a comfortable spot in their house, usually at the dining room table or in the living room.

After introducing ourselves, I would present my informant with the informed consent document that I prepared in both English and French depending on their language preference. Together, we would go over the document and if he had any questions, I took the opportunity to clarify and make him feel at ease with the process. Having just completed a thesis proposal where I was required to complete a detailed literature review on theories and topics pertinent to my research topic, I thought about the work of Connell (2005), Kimmel (2008), Reeser (2010), and other scholars as I prepared to begin my interviews with each man. I initially felt that understanding the way sexuality was tied with prostate cancer would be easy because most men would discuss it with me. Throughout this chapter, I will demonstrate how several men shared intimate details about their sexual lives with me and explained the way they felt prostate cancer treatment impacted them. What concerned me, however, was how I would understand and assess masculinity; I felt it would be abstract and intangible. Related to sexuality but not openly discussed, I was surprised by the many ways that survivors enacted masculinity. In this sense, while I feel that I was able to successfully understand the way that identity, masculinity, and sexuality are tied and impacted by the prostate cancer experience, a fundamental part of the topic I set out to understand was the greatest obstacle I was required to overcome as a researcher.

Discussed in depth by Todd Reeser (2010), masculinity is constructed; built up through ideology, domination, practice, language, and other related elements. In this sense, similar to understandings of disease and illness, masculinity is dependent on social context (Shilling 2003; Connell 2005; Kimmel 2008; Reeser 2010; Connell & Messerschmidt 2005; Gray et al. 2002 and Courtenay 2009). Both the roles that men assume to the social expectations of how a man should respond to issues such as illness are closely related to the social expectations placed on men in different circumstances. Courtenay (2009) explores these social expectations that men seek to achieve by outlining the theory of hegemonic masculinity. Drawing on the work of Connell (1995, 2005) and Kimmel (2008) amongst others, Courtenay argues that: "[…] males use health beliefs and behaviors to demonstrate dominant—and hegemonic—masculine ideals that clearly establish them as men. Hegemonic masculinity is the idealized form of masculinity at a given place and time" (Connell 1995; cited in Courtenay 2009:14). In other words, hegemonic masculinity is an ideal that most men strive to uphold. The extent to which these behaviors or values are exhibited allows men to develop a masculine identity as unbreakable and invulnerable.

Masculinity is therefore closely related to the way men view health and help-seeking behaviors. Courtenay (2009) writes extensively about the way that men try to reinforce the cultural norm that men are powerful, stoic, and should not show any sign of weakness:

> In exhibiting or enacting hegemonic ideals with health behaviors, men reinforce strongly held cultural beliefs that men are more powerful and less vulnerable than women; that men's bodies are structurally more efficient than and superior to women's bodies; that asking for help and caring for one's health is feminine; and that the most powerful men among men are those for whom health and safety are irrelevant. (Courtenay 2009:14)

It is important to understand that masculinity is constructed in relation to other masculinities and conceptions of femininity and that these cultural perspectives influence the behavior of men vis-à-vis a range of identity-related issues. I have briefly outlined and contextualized the concept of masculinity, as it is essential to understand how prostate cancer survivors tell their stories both verbally and non-verbally. I will now turn to my fieldwork experience where I encountered some of the behaviors tied to the constructions of masculinity discussed above.

2.2. Body Language

In late June, I finished a long day at work and made my way to Westmount for my second interview with an entrepreneur named Arthur. Over the phone he had given me his address and told me to arrive at his home by 6pm. After walking up the stairs of the large three-storey home where I would be conducting the interview, I rang the doorbell. The live-in nanny for the family greeted me and I was brought into the living room. As I sat down on the couch and took out my notebook, I was told that Arthur would be arriving home from work shortly and that I could wait for him here. Not long after, Arthur walked into the room and sat down, slouched in his chair. He said to me: “Ok, whenever you’re ready, let’s get this over with…” (J. Folco, field notes, June 28 2012). He seemed disinterested in my background and he made it clear that he was confused about why a student in social science would be interested in pursuing such a topic. I provided him with a brief outline of the discipline of anthropology and the subfield that concerned me in particular, medical anthropology.

After five minutes of him asking me questions about anthropology and the research I was conducting, he signed the consent form without reading it and tossed it on the table. The behavior and body language that Arthur exhibited during this initial encounter and his nonchalance regarding the ethical dimension of my project suggests a lack of emotional involvement and is an example of the stoic and powerful masculine ideals discussed by Courtenay (2009). Arthur began to share his narrative and remained slouched in his chair, picking at his fingernails. Discussed in an earlier section on methodology in anthropology, I first suspected that he was uncomfortable given my age. As the narrative went on however, he seemed comfortable discussing issues relating to his sexuality openly which led me to believe that he was behaving in this way to reinforce his manhood. Therefore, the body language that Arthur exhibited was tied to his understanding of masculinity and even though his identity would remain anonymous, I got the feeling that he wanted me to perceive him as a survivor who is strong and without weakness. In particular, his body language seemed to communicate that he was worried about my perception of him. Because there is a social expectation that associates a masculine body with strength, virility, and invulnerability, Arthur reinforced these qualities through his body language. By avoiding any sign of weakness or struggle, Arthur steered clear of any behavior that would undermine his masculine identity.

Embarrassment and Discomfort

Linked with body language, embarrassment and discomfort are cultural conceptions of masculinity that can be demonstrated by my interaction with another informant named Martin. In mid-August, I was scheduled to meet with two men for interviews on the West Island. I completed my first interview with Charles and headed to the second one, which was about a fifteen-minute drive away. Once I arrived at his home, Martin welcomed me into his kitchen and offered me a cup of tea with some biscuits and we spoke about my interests in prostate cancer research and his role at a prostate cancer support group. While he read over the consent form, he emphasized that he did not feel comfortable being recorded and would prefer if it was more of a conversation between the two of us. I told him that I understood and that I would take notes if it was okay and he agreed. Once he began sharing his story, he rarely made eye contact and if there was a pause he appeared uncomfortable. After about ten seconds of silence, I began asking him a question related to his experience and he answered before I was able to finish. While we had spoken for about fifteen minutes before beginning the interview, he gave me the impression that he was uncomfortable. Martin often re-worded the same sentence three or four times and at one point he said to me: “I want to ensure that you get it down accurately…” (J. Folco, field notes, August 18 2012).

Although Martin claimed that he did not care about the perceptions of others, it seemed that he did not want to appear weak in his narrative and thus constantly re-worded his sentences on issues that were about emotion or sexuality. The embarrassment, discomfort, and unease with which he shared his story, coupled with his preoccupation with how his thoughts were expressed, made it clear that he was concerned about both my perception of him and that of others, even after I emphasized that he would remain anonymous. Similar to Courtenay (2009), Kimmel (2008) argues that masculinity is a social product and is influenced by contextual factors. In particular, Kimmel views masculinity as a "homosocial enactment": "We test ourselves, perform heroic feats, take enormous risks, all because we want other men to grant us our manhood […] a relentless test by which we prove to other men, to women, and ultimately to ourselves that we have successfully mastered the part" (Kimmel 2008:214-9). In this sense, a man may be concerned about the perceptions of other men, particularly a young researcher. Therefore, keeping Kimmel's notion of "homosocial enactment" in mind, Martin's behavior can be explained in two ways. On the one hand, he wanted to appear strong and on the other, he was worried about how this behavior that he is struggling to uphold will be perceived by others.

Another example of how body language illustrates a close tie to upholding social expectations related to masculinity can be illustrated by a later interview with a man named Victor. In mid-September, I scheduled an interview with one of my final participants who was referred to me by another informant. Once I had arrived at his condo, I was welcomed and invited into the living room by his both Victor and his wife. While I was speaking with him, his wife Martha asked if she could stay at the kitchen table to do some reading. I did not object as the condo was small and both rooms were joined and separated by a few stairs. Once we had introduced ourselves, I was offered some refreshments and we began looking over the consent form together. Victor was a very different kind of candidate because unlike the others who had undergone treatment years ago, he had had his prostate removed about six weeks prior to the interview. I wanted to ensure that he understood the conditions of his participation and because it was a recent procedure, I made sure he was aware of possible risks such as ruminations or painful memories from his experience. Ethically, it is difficult to determine the amount of time required for a patient to be interviewed following a surgery or treatment for cancer (Kleinman 1988), especially because it varies so much from patient to patient. Therefore, I wanted to be even more cautious about this interview because my primary responsibility as an ethnographer is to ensure the well being of my informants.

After signing the consent form, Victor slouched in his chair in a way similar to how Arthur had done, and did not make eye contact. On one occasion, his wife stepped in because he was not responding; he looked annoyed and made hand movements insinuating that she was “blabbing” and that it was not her place to answer on his behalf:

> Victor: Yes. Well you do find later on that lots of guys are following…they are being monitored for PSA or whatever….Most guys don’t discuss….after a certain age…after 80 they discuss it with close friends…you discuss your ailments…you don’t discuss your ailments when you are with guys my age.
>
> Martha: They never talk about it! But you came back from your tennis club and were shocked about how many men were being monitored or had the surgery…
>
> Victor: Well…guys know I think…uh…
>
> Martha: Well you didn’t know before you had prostate cancer
>
> Victor: But it is not something that guys discuss…
>
> JF: So why do you think that guys don’t want to discuss their issues?
>
> Victor: (long pause)…

> Martha: Men are “macho” and strong and they don’t want to…they don’t talk about themselves like women do…
>
> Victor: (Hand movements like he is annoyed that she is talking)…
>
> (long pause)
>
> Victor: I know that it is a fact that you can have a sore knee but you aren’t going to discuss prostate cancer.

This particular exchange between the three of us demonstrates two important issues. First, it illustrates the way that body language or non-verbal communication is tied to masculinity; showing disinterest or nonchalance, I argue, is a way for men to reinforce strength and not weakness. In this sense, if they had displayed attentiveness, these three men may have been showing a sign of weakness or that they are too emotionally connected to their illness experience.

The second important issue that is raised by this exchange is what is being said. Victor explains that men do not like discussing issues related to their health with other men. When I ask why he feels that way, there is a pause and his wife Martha steps in. Martha states: “Men are “macho” and strong and they don’t want to…they don’t talk about themselves like women do…” (Interview, September 19 2012). Following this comment by Martha, Victor looks annoyed and begins making hand movements to indicate that he is not fond of his partner jumping into the discussion and confirming the findings of research on male help-seeking behaviors (Chapple & Ziebland 2002 and Hegelson & Lepore 1997). If Victor had agreed with his wife’s comment, he would be agreeing that masculinity plays a significant role in how men discuss issues pertaining to their health. As Connell (2005) argues, masculinity needs to be understood as “[…] a place in gender relations, the practices through which men and women engage in that place in gender, and the effects of these practices in bodily experience, personality, and culture" (Connell 2005:71). Therefore, it seems that by ignoring the discourse related to being "macho" and the comments brought up by his wife, Victor is reinforcing his identity as a man by illustrating that he has a greater understanding of men's behavior. In addition, this behavior illustrates a feeling of embarrassment by Victor because the conversation focused on bodily fragility, which would explain why he downplayed the discussion by making it seem unimportant.

As historian Nancy Partner has put it, people often both highlight and suppress when sharing their narrative in order to sustain a coherent identity:

> Constituting and maintaining the integrated sense of self over time is the work of narrative at the level of the individual mind, involving acts of highlighting and suppression to sustain coherent identity, the work of memory and forgetting, the hermeneutics of experience. Narratives of collective power and narratives of individual integrity are bound together at their roots since both can be theorized in terms of serial sequencing, foregrounding and suppression, selection of motifs of meaning, the assignment of agency, and, finally, causal responsibility. (Partner 2009:99)

While Partner's work focuses on the link between personal identity and national identity in former Yugoslavia, Israel, and Palestine among others, I feel that it can be applied to the narratives of prostate cancer survivors as well. Men often appeared uncomfortable and embarrassed when they discussed their struggles with erectile dysfunction and urinary incontinence. At times, these feelings seemed to be associated with moments of silence or hesitation concerning this subject. These side effects challenge the social expectation that men should be strong, invulnerable, virile, hard, and contained beings (Potts 2000, Arrington 2003, Marshall 2006 & Grosz 1994). Therefore, to maintain a coherent hegemonic masculine identity and not appear weak, men suppress or hesitate when discussing their struggles and highlight or reinforce their progress in recovery. In this way, similar to Partner's argument about national and personal identity, the narratives of prostate cancer survivors involve highlighting and suppression to maintain a seemingly seamless masculine identity as they discuss the lived experience and impact surgery has on their sexual lives.

2.3. Silence

As I reflected further on the interviews I had conducted in the field, I felt that I did not have as much data as I imagined I would. I reviewed the notes I took during the interviews and listened to how each man recounted his illness experience however, I understood that data could be both tangible and intangible. Lisa Stevenson (2009) focuses on this balance between different forms of data in her work on Inuit suicide. She discusses a fieldwork experience where one of her informants, a young boy named Paul, reflected on the death of his uncle and recounted how his sister used to say that his uncle came back to life as a raven: " 'My sister used to say that my uncle came back to life as a raven, and that raven is living behind our house' " (Stevenson 2009:55). While the raven is still living behind the house, it is uncertain whether this raven is really Paul's dead uncle. Even if the raven is still there and present, there is a degree of uncertainty about its meaning, and Stevenson spends the rest of her chapter discussing that which is not neatly resolved or understood in fieldwork:

> I will reflect on the status of the raven in fieldwork and how we come to relate to it as a figure of a kind of productive and even hopeful uncertainty, one that stubbornly remains (*it's still there*) even as it refuses to be neatly resolved. I want to think, then, about the possibility in fieldwork of listening for hesitation—listening for that which persistently disrupts the security of what is known for sure. Doing so entails taking uncertainty as a legitimate ethnographic object. (Stevenson 2009:56)

In the context of my research on prostate cancer, the silence that I faced when trying to keep the conversation flowing for longer than forty-five minutes to an hour will be the “raven” and uncertainty of my fieldwork.

The difficulty of making uncertainty or silence a legitimate ethnographic object however is that your evidence as a researcher is not tangible. I began looking through online journals and books about a possible link between masculinity and silence. I find it ironic that only a limited number of studies focus directly on the relationship between silence and masculinity. This might be explained, at least in part, by the fact that studies involving masculinity rely too heavily on theory and not enough on the lived experience of men. There is however, a plethora of work published on the way that hegemonic masculinity silences women and other gender identities through the normalization of masculinity in institutions (Kronsell 2006; Connell 1995; Ferguson 1993; Hearn & Parkin 2001 and Pateman 1988). As I reflected on the possible meaning of these silences however, I was puzzled on how to interpret them because such limited scholarship had previously explored this connection. I will use Stevenson’s perspective, which posits that we need to allow ourselves to be shaken as ethnographers and displaced from the familiar: “[Fieldwork] becomes a practice of the self in which, in the interest of understanding another, we allow ourselves to be shaken, displaced from our customary dispositions and beliefs […]” (Stevenson 2009:56). Therefore, my research will fill the gap left by past research because I will consider the silences, uncertainties and hesitations ignored by other scholars and relate them to the lived experience of men.

Silence or ignoring particular questions during interviews was closely tied to sexuality and the side effects of treatments for prostate cancer and will be discussed in the subsequent section. I want to turn now to a moment in my fieldwork that was difficult because of silence, where as an ethnographer, I was shaken and displaced from the familiar. This moment was just as important to understanding the implications of prostate cancer on the identity of its survivors as the interview itself. Similar to Stevenson, when I acknowledged the doubt or uncertainty exhibited in the behavior of my informants, a new kind of relationship developed between us, one that seemed to dissolve the professional distance between the ethnographer and the informant (Stevenson 2009).

Dismissal

In early July, I drove to Rosemont, an area northeast of downtown Montréal, for an interview with Robert. Robert is sixty-nine years old and was treated for prostate cancer with radiation therapy in 2000 and 2001. After many years of receiving treatments, malignant cancer cells had been detected again and he is currently looking into other possible options. As I arrived at his house and introduced myself, he said "hello" and guided me to the kitchen table without saying a word. To fill the silence, I began discussing my background as a student and the project I was undertaking. After presenting myself, I asked Robert general questions about his life and after a number of long pauses and moments of hesitation, he answered them with short responses. I grew worried about the interview itself, afraid that the silence would persist. Shortly thereafter, we moved to the consent form and we looked it over together. I asked him if he had any questions concerning his participation in my research and he said that he felt comfortable.

While I was initially worried about how Robert would share his narrative given the initial silence that I faced upon arriving at his home, he turned out to be a terrific storyteller. Over the course of the next forty minutes, he recounted his experience with prostate cancer in great detail. As the narrative began to slow, I asked some questions that I had prepared (see Appendix). When he had finished answering the questions to the best of his ability, the same kind of silence returned that was present when I first arrived. I thanked him for participating in my research, he immediately stood up and began walking to the door, leaving me in the kitchen to collect my things and meet him at the entrance:

> Robert: I try not to think about my prostate cancer…not because I don't want to accept it but because I have a lot of personal projects and have a good life and I want to take advantage of that. At first, yes, I didn't handle it well, but I think I am doing well now… I am doing better.
>
> (Long pause)
>
> JF: Okay, I think we have covered everything.
>
> Robert: Thank you.
>
> JF: Yes, thank you for having shared your story with me.
>
> (Robert immediately stands up)

The beginning and end of this experience are just as important as the interview itself because they illustrate that silence is a significant ethnographic object that must not be overlooked. The silence can be interpreted in many different ways: this behavior could be linked to codes/norms of masculinity that discourage men from sharing details relating to their emotional lives (Kimmel 2008), could have been caused by the environment in which the interview took place (Bailey 2007), or could have been linked to the social characteristics of the researcher (Bailey 2007). Determining the exact meaning of the silence itself is not what is at stake. Instead, it is important to understand the place of silence in my fieldwork experience. As Stevenson (2009) argues that acknowledging doubt or uncertainty, "[…] implicates [the anthropologist and informant] in a mutual project of discovering the world" (Stevenson 2009:56). By recognizing the silence, I took it seriously and considered its analytical implication in our encounter. While sharing his narrative appeared easy, the silence reinforced the reality that prostate cancer is a deeply emotional experience and an illness that affects parts of the body that people do not publicly discuss (Hegelson & Lepore 1997). I walked out the door of his house and Robert grabbed my shoulder and said: “Thank you for listening to my story, it wasn’t easy to recount but I know you care…Thank you” (J. Folco, field notes, July 5 2012). By acknowledging Robert’s silences and pauses, as well as his final comment as I left his house, we embarked on a journey of mutual understanding and reflection—one that permitted us both to understand the way prostate cancer has and continues to impact his life.

My fieldwork experiences with Robert, Martin, and Victor illustrate the complexity of conducting research on a topic as personal as prostate cancer. In addition, body language and silence are imperative to understand conceptions of masculinity and how it is related to this illness. For Martin, he was concerned about the possible perceptions of other men who may read the research even if he was made aware that his anonymity would be guaranteed. Fearing the perceptions of others is strongly tied to how masculinity is culturally constructed, particularly as regards Kimmel’s notion of the “homosocial enactment” whereby a man’s identity is reinforced by the approval of other men and women. For Victor, the combination of his body language, apparent nonchalance, and ignoring the discussion about masculinity and prostate cancer clearly demonstrates his attempts at reasserting his manhood. This particular encounter illustrates the arguments made by Connell (2005) and Reeser (2010) about understanding masculinity in relation to women and other gendered identities. By ignoring his wife’s attempts to explain the reasons for male help-seeking behaviors, Victor wanted to reinforce that he knows and understands masculinity better than a woman ever could or, perhaps, that there was nothing worth understanding at all.

The final fieldwork experience with Richard illustrates a different display of masculinity. The silence that surrounded me as I entered and left his home, and my acknowledgement of it, enabled Richard and I to embark on the discovery of how prostate cancer impacted his life. By accepting his hesitation and uncertainty about how to interact with me as an ethnographer, I accepted his struggle to maintain an image of strength and virility when faced with such a difficult part of his past. In this sense, Richard felt that I understood and cared about both his story and his life by accepting the hesitations that were embedded in his narrative and validating the concerns that caused these hesitations.

These three examples demonstrate how dominant norms of masculinity impact the perspectives and values of men, the language they employ, and behaviors such as body language and silence particularly when discussing a topic, like illness, which has the potential to make them feel weak or vulnerable. Part of what makes silence so difficult to discuss in the context of research on masculinity and prostate cancer is the irony that there is a silence around silence in scholarship on related topics. While this thesis is only one example of how silence is related to the experiential narratives of men who have survived an illness, future research needs to treat uncertainties and hesitations as legitimate ethnographic objects and not dismiss them as irrelevant (Stevenson 2009).

Chapter 3--Sexuality and the Prostate Cancer Experience

3.1. The Penis, Masculinity, and Sexuality

Now that masculinity has been contextualized as culturally constructed and we have explored its connection to body language and silence, I will turn to the way it is tied to male sexuality. As Reeser (2010), Connell (2005) and Beynon (2002) argue, hegemonic masculinity is the idealized form of masculinity in a given time and place. While different social expectations are associated with every gendered identity, masculinity is linked with strength, sexual virility, and power. In this sense, male sexuality is linked to masculinity because certain norms are prescribed and must be maintained for a man to achieve a socially accepted masculine identity: “In the context of sexuality and intimate relationships, hegemonic masculinity prescribes that proper sexual activity must be initiated by a man and involve the insertion of the penis into the female partner’s bodily orifice” (Oliffe 2005:2250). While this particular conception of male sexuality is problematic because of its heteronormative character, it associates the act of heterosexually-oriented penetration as the primary way of engaging in sexual relations. Further, it assumes that men are the only ones with a sex drive and ignores that women may feel sexually aroused and want to initiate intimate relations with their partners. Nevertheless, it is clear that if a man is unable to perform the act of penetration, his masculinity is put into question.

If penetration is linked to definitions of masculinity, the erect penis is fundamental to successfully accomplishing this act. In their article “ ‘Pack a more powerful punch’ and ‘lay the pipe’: erectile enhancement discourse as a body project for masculinity” (2008), Brubacker and Johnson explore the centrality of the penis in medical and popular discourse. In particular, they focus on the role of sexual enhancement drugs like Viagra and Cialis in the lives of men with sexual dysfunction. The obsession with the erect penis and phallocentrism more generally is linked to the social expectations associated with a hegemonic masculine identity:

> Of particular relevance to the topic of erectile dysfunction are hegemonic conceptions of masculine sexuality as constructed through medical and popular discourse. Both types of discourse privilege the penis as essential to sexual activity and power, and to some extent grant agency to the penis independent of a man's subjective experience or consciousness. (Brubaker & Johnson 2002:134)

In this sense, a man's sexual performance is measured through the penis, which in turn determines one's level of masculinity. Following a radical prostatectomy surgery for prostate cancer or radiation treatment where the main side effects are a lowered libido, erectile dysfunction, and urinary and/or bowel incontinence (Bokhour et al. 2001 and Saad & McCormack 2008), a man's sexual potency is impacted. This change in libido or the development of erectile dysfunction may cause a man severe psychosocial distress and feelings of emasculation because it challenges his sense of masculinity, fundamental to his personal identity (Brubaker & Johnson 2002; Clark et al. 2003; Hegelson & Lepore 1997; Kiss & Merryn 2001; Oliffe 1995; Potts 2000; Oliffe 2005 and Marshall 2006).

In his article " 'I don't want to be an artificial man': Narrative reconstruction of sexuality among prostate cancer survivors" (2003), Arrington explores the ways that prostate cancer survivors constructed stories of their illness experiences and the consequences for their sexual identities. He argues that many survivors he interviewed stated that sex was a noteworthy motive in their decision-making when choosing particular treatments:

> Some punctuated erectile dysfunction as the end of their sex lives, placing a lower value on sex than they had before the diagnosis. Others reframed the onset of

> prostate cancer as an opportunity to experience their sexual selves in other ways, affirming the value of sex, but defining it in a broader sense than they had before. (Arrington 2003:35).

For these men, the changes to their sexual lives were significant, requiring them to adapt their social and sexual lives to fit their new circumstances to ultimately maintain their sense of masculinity: "[…] failure to perform sexually can challenge the fundamentals of masculinity, and make heterosexual men believe that they are not 'real men'" (Oliffe 2005:2250).

To deal with these changes in sexuality, many prostate cancer survivors turn to performance enhancing drugs to cope with the side effects of treatments for prostate cancer. In this way, the struggle to maintain and reinforce one's sense of masculinity becomes part of a culture of consumption. This focus on drugs to reinforce a manhood that may have been lost implicates men in what Brubaker and Johnson call a "postmodern body project" whereby men become defined through their consumption. Because masculinity is defined and understood in relation to and especially against femininity and other gendered identities (Connell 2005; Kimmel 2008 and Reeser 2010), men become obsessed with sexual potency and virility. Therefore, as Brubaker & Johnson argue: "The discourse of erectile enhancement constructs masculinity around the centrality of the penis. The penis is the site and source of male power and must be used to define masculinity in opposition to femininity" (Brubaker & Johnson 2002:138).

In the next subsection of this chapter, I will explore how the survivors I worked alongside dealt with the changes to the sexual lives following treatments for prostate cancer. As I will demonstrate, many of the men whom I interviewed shared similar views to the men from Arrington's article; the impact on sexuality was central to decisions about treatments. While the following section explores the experiences and obstacles of my informants, these narratives are meant to illustrate how prostate cancer is an individual experience. While the perspectives I will share may coincide and echo the results from others studies, I am not attempting to make generalizations about how men's sexuality is impacted by different treatments. Instead, I hope to shed light on the diversity of experience when an individual confronts an illness and share some of the ways that they have learned to cope with the changes to their lives. As medical anthropologist Gay Becker argues in her book *Disrupted Lives: How People Create Meaning in a Chaotic World* (1997), our role as anthropologists is to understand how the continuity of people's lives are impacted by unexpected circumstances and how they are adapted to. Therefore, similar to Becker (1997), I seek to understand the role of a disruption like prostate cancer in the lives of survivors and explore the way they make sense of it.

3.2. Let's Talk Sex

When I first began my fieldwork, I was worried about the way that survivors would share their stories; the details they would include and those they would omit. I was concerned about whether survivors would be willing to share personal stories about how side effects affected their social and sexual lives. In particular, I started to question whether anthropological methodology was appropriate for such a topic and how my informants would react to the interview setting. While I discussed some of the reasons why anthropological methodology is problematic for research on prostate cancer in an earlier chapter, I would like to draw attention to male sexuality in the narratives of survivors. To my surprise, many informants discussed intimate details concerning their sexual lives and the way that prostate cancer treatments have affected them. While the degree of detail tended to depend on the age of the informant, every narrative that was shared included details about the side effects that impact their sexual lives.

The first informant I had the pleasure of meeting for an interview was named Thomas and he was a retired Sûreté de Québec police officer in his late fifties. He was diagnosed in 2009 at the age of fifty-six with prostate cancer following a high PSA of 10.9 on the Gleason scale. As we began to discuss the options that were made available to him for treatment, he emphasized that he was worried about the side effect of erectile dysfunction. This was difficult to hear for Thomas who explained to me that since his retirement, his sex life is better than when he was in his forties:

> After the second blood test that came back with a PSA reading of 10.9, we decided to move to the biopsy, which revealed prostate cancer at a T2 level. The cancer seemed to be well contained and my doctor provided me with the possible procedures I could undertake with their possible side effects: radical prostatectomy, brachytherapy, and radiotherapy. My urologist suggested that I get a second opinion from another doctor but when you trust someone and are confident in their decisions, you feel comfortable with their input and advice. So, healthy and 56 years old, the radical prostatectomy seemed the best option. My urologist told me it would be the best option for me and felt I would have a routine recovery from it, however, he did warn me about the possible erectile dysfunction that was a common side effect in 50-60 % of men and that's what is difficult…the side effect of incontinence is not pleasant but one can live with it. Erectile dysfunction however....at 59 years old…I am more active sexually than at 40 years old. When I was in my forties, when you go to bed you are exhausted and you want to sleep. Now, I am retired and more in shape than at 40 years old. My wife is also retired now and works part-time and so we have more time for sex now. (Interview, June 28 2012)

As he began to describe the intensity of his sexual life prior to his diagnosis with prostate cancer, he emphasized that sex was still an important part of his life. In retrospect, I feel that my age as a researcher may have influenced Thomas' remarks about his sex life.

While my age may have impacted our interaction, research has illustrated that sexuality remains significant in the lives of many aging men. In her article "The New

Virility: Viagra, Male Ageing, and Sexual Function" (2006), Marshall explores the misconception that aging was equated with emasculation. In particular, she discusses the way that no illness is more painful to the male ego and psyche than sexual impotence, regardless of the age. Contrary to the medical and moral authorities of the late 19th and early 20th centuries, Marshall argues that aging is not a process of "de-sexualization", but rather, there is increasing evidence of older men turning to performance enhancing drugs to improve their sex lives (Marshall 2006). Therefore, it seemed that Thomas felt that a researcher in his early twenties should be at the peak of his sexuality and therefore, he felt the need to reinforce the intensity of his intimate relations to both: reassert his manhood and clear up any misconceptions I may have about sexuality and the aging male body. By emphasizing this detail in his narrative, Thomas demonstrates that while urinary incontinence is an unpleasant side effect, erectile dysfunction would be a more difficult obstacle to overcome.

While Thomas had a radical prostatectomy, blood tests six months following the surgery indicated a higher PSA than usual and he began radiation and hormone therapy. Struggling with the psychological distress of the radical prostatectomy, he now had to deal with the additional side effects of another set of treatments. According to his urologist, radiation and hormone therapy patients usually struggle with a loss of libido because it lowers levels of testosterone, which might slow the recovery of erectile dysfunction:

> Because I did hormone therapy and radiotherapy, I was told by my doctor that the erectile dysfunction process would be longer and therefore, to not get frustrated with myself. I scheduled visits with my radio oncologist and urologist every six months, each at three-month intervals. (Interview, June 28 2012)

Despite the warning from his doctor, he emphasized the frustrations he faced with erectile dysfunction and a loss of libido through the metaphor of a steakhouse. Thomas explained to me that when he was younger, he would be easily aroused and had a very active sex life with his wife. Following the radical prostatectomy and hormone treatments, his libido fell so dramatically that no matter what his wife did; he did not feel interested in sex. He stated:

> I did not feel like it however because hormone therapy lowers the level of testosterone in your body on therefore, it took a while for me to get back my libido. I would always say to my friends that I felt as though I would go into a steakhouse and see everybody eating and just not be hungry.
> (Interview, June 28 2012)

While erectile dysfunction poses a threat to a man's sense of masculinity, not having a sex drive at all is additionally a powerful assault to the male ego. In addition, the metaphor Thomas uses of the steakhouse and the connection between consuming meat and achieving sexual satisfaction is highly significant. As discussed by Sobal (2005), consuming meat is highly gendered in Western society and has often been considered a masculine act. Therefore, the use of this metaphor when discussing his sex drive illustrated the degree to which his masculinity was affected by erectile dysfunction. In this sense, not wanting a steak in a steakhouse was linked to a lack of libido when his wife initiated sex and challenged the social expectations of virility and potency.

As Bokhour et al. (2001) argues, sexuality remains a pervasive part of a man's life despite erectile dysfunction because men are sexual beings. If a loss of libido is added to a man's list of side effects however, his masculinity is further assaulted and requires redefinition. While both of these obstacles were closely connected for Thomas because they affected his sexual potency, he describes learning to be intimate in another way and adapting his sexual life to his circumstances:

> My wife and I began sexual activity again through caressing and cuddling. We knew that we couldn't get discouraged because even with Cialis, my libido was not as it was. I would say that now, we have a very active sex life. Sometimes I get discouraged and wonder if it will come back to the way it was at some point. I would say that most of all, it seemed to affect my sense of pride. My doctor told me that I need to actively re-stimulate myself like someone undergoing physiotherapy and that it could take a while. There are some evenings when I would have a sex drive (because my libido came back eventually) and I would tell my wife and we would create a nice ambiance and atmosphere… and then I was unable to achieve an erection. This as you can imagine, became extremely frustrating. It was difficult in the moment but it was even more difficult days or weeks later to have the confidence to try again. (Interview, June 28 2012)

Therefore, while it was frustrating for Thomas he learned to adapt his sexual life to the side effects of his treatment and he began asserting his masculinity in a different way. While Brubaker and Johnson (2008) argue about the centrality of the erection in male sexuality and the significant role it plays in asserting a man's sense of manhood, Thomas describes cuddling and caressing as an initial first step. In this sense, the role of the erect penis in his sexual encounters played a less significant role than it had prior to his surgery. Because little scholarship on prostate cancer focuses on how men adapt their sexuality to side effects, my research on survivors illustrates how important it is to examine the specificities of this particular aspect of the prostate cancer experience.

While cuddling and caressing was described by Thomas as an early adaptation to erectile dysfunction and loss of libido, he describes the intensity with which his sexual potency returned about twenty-five months after his surgery:

> I would say that after the surgery, it took 25 months for the sex drive and erections to come back…and when it came back, it came back quickly. Within a month and a half, with Cialis we felt a difference. Then after a while, we tried without Cialis and it was okay. So we tried to work on it regularly without Cialis and today, I have a more intense sexual activity. Without ejaculation, I am able to

> experience a more intense orgasm and because I can control myself more. When you have not had sex in a while and you are aroused, you tend to have premature ejaculations...but now without any ejaculation, I would say and my wife would probably agree, that we have more intense sex. I can orgasm for a longer length of time. (Interview, June 28 2012)

As this excerpt demonstrates, being able to achieve an erection enabled Thomas and his wife to return to similar sexual relations that they enjoyed before his surgery for prostate cancer. In addition, his experience contradicts commonsense assumptions about the connection between ejaculation and virility. In other words, while Thomas' sex life went back to the way it was on many levels, it was also non-normative in that it was non-ejaculatory, and this, rather being experienced as a problem, led to more pleasure in Thomas' intimate life.

While Thomas was able to successfully recover from the side effects of his treatment, another informant named Richard did not have the same success. Richard is sixty-eight years old and underwent a similar radical prostatectomy surgery as Thomas. When he saw blood in his urine, he booked an appointment to see his urologist. Upon arriving at his appointment, the doctor conducted different tests, one of them being the PSA or prostate specific antigen test for prostate cancer. The test results came back with a PSA of 0.5 the first time and six months later, it had climbed to 2.8 on the Gleason scale. A few weeks later, Richard's urologist conducted a biopsy and out of ten samples, two were cancerous. At this moment of the narrative, he emphasized how difficult it was for him to hear the word "cancer":

> I went to get a biopsy…out of ten samples with the biopsy, two were cancerous…so he called me in and said that I had cancer….I think I was there alone when he said that and I think I turned white…I have cancer? Cancer… the word is scary…. (pause)…and he told me that he would have to operate on me… So, he gave me books to read and he went right through them and so did my wife, she did faster than I did. But I did have certain reservations about the

> doctor…obviously he is good at what he does but he seems to go over things like impotence or incontinence…and pass right over it. The fact that I could be impotent, which I am now, seemed to just whiz by him. (Interview, July 28 2012)

Richard felt an additional level of discomfort and anxiety at this meeting with his urologist because of the fear that this operation would leave him impotent. While Thomas and other informants spoke of the comfort that they received from their doctors during the meetings where they were informed they had cancer and provided with the possible treatments, Richard explains that he felt uneasy toward his urologist. This unease came primarily from the silence around the experiential implications of the surgery. This is significant because silence not only permeated my discussion with informants but is also found in the medical discourse between patient and urologist around different procedures for prostate cancer. It would be a fruitful avenue of future study to explore the way that medical practitioners are taught to interact with patients regarding health issues and surgeries that are closely tied to sexual functioning.

In particular, he states that his urologist seemed more concerned about the procedure and the financial implications for his practice:

> I have a [feeling] that they were not only looking after me but also looking after themselves in a money sort of way. I don't know if they have to keep the operating rooms open 24/hrs a day but I got that impression that every time they do an operation, they get paid so much…whether it is true or not I don't know, it was just a [feeling]. I have been dealing with people for over 35 years, I was a salesman on the road for tons of companies and I sensed that I didn't give these doctors 100% credibility but I thought that nonetheless, it seems like it was just to perform another operation. (Interview, July 28 2012)

As I discussed in the opening chapter, the role of the physician is fundamental for ensuring a high quality of care for their patients. As my informant James who is a general practitioner discusses over the course of his narrative, one of the most important parts of his job is educating the patient and the public about their bodies and biology. In the physician-patient relationship however, there is a shared responsibility with respect to well being.

Despite his doubts and stress about the possibility of impotence, Richard went through with the surgery and was operated on in January 2012. While Thomas was able to adapt to the obstacles related to erectile dysfunction, Richard was struggling both physically and psychologically. As he began discussing the changes to his sexuality, Richard showed signs that he may not have thought enough about the side effects of the treatment before making a decision:

> Having no erections or have chances that you will still live? I said: I don't know… I needed to discuss this with myself. When you grow up and always have erections, it is something that just happens and it is a pleasure to have an erection and to make love…but not anymore…son of a bitch…I don't feel good about that, I hope it is going to turn around but I have certain qualms about it that it won't…. (pause…) And that is how I feel about it… (Interview, July 28 2012)

Similar to survivors from Arrington's research (2003), sex seemed to be a note-worthy motive when choosing a treatment for prostate cancer. For Richard however, he feels that he made a decision too quickly without weighing the possible risks. He made this decision because there is no public discussion of what these side effects mean for men. If more literature outlining the lived experience of survivors were available to men pre-op, they would be able to make a more informed decision. These feelings may be due, however, to the amount of time that had elapsed since his surgery; he was operated on in January 2012 and our interview was in the end of July 2012.

The only other informant who was interviewed so shortly after a surgery was Victor who was more confident in his decision but reported similar frustrations and side effects:

> Victor: I know it is a slow moving thing but I wanted…at that point you just want it dealt with. So, my urologist used the robot and I was in the hospital for two days and the first two weeks were not great but umm…really the recovery period after a month…I was pretty good and ummm…now after five weeks, I am almost…I have some residual problems but not very much…
>
> Martha: I don't think that they are problems; I just think that it is too early for everything to work as it should…
>
> JF: Yes, for sure.
>
> Victor: You know…plumbing stuff…
>
> (Interview, September 19 2012)

As Victor demonstrates, he is confident that he made the right decision by opting for the radical prostatectomy despite some of the residual side effects he faces on a daily basis. Therefore, Victor's experience contrasts with Richard's because he trusted both his urologist and the procedure. As a result, Victor has exhibited a greater level of well being than Richard following the surgery. As Clark et al. (2003) argue in their article "Patients' Perceptions of Quality of Life After Treatment for Early Prostate Cancer", psychosocial well being is associated with feeling confident about one's decision. Victor's greater confidence in his decision may have been due to the presence of a supportive partner that helped him deal with the emotional labor of the experience. It is difficult however to fully discern the role of the partner in the lives of prostate cancer survivors. Therefore, as I discuss in a later chapter, it would be worthwhile to consider the role of the partner in how survivors deal with the emotional and physical changes to the body after surgery.

The fact that both of these experiences are so different is significant because it illustrates the way that the prostate cancer experience is individualized. Following the dissatisfaction that Richard felt towards his urologist's approach, he continued to discuss the struggle he faces with erectile dysfunction and states that he feels like he is living without a goal:

> I feel like I am living without a goal…it makes me feel like something is not finished…I have a friend across the street and he had his prostate removed and I had a conversation with him and I wasn't asking him about whether he was impotent or not…and right away he thought I was…and he told me he was fine. I mean they took out his prostate and he is okay? He can have an erection? I don't think he is telling me the truth… (Interview, July 28 2012)

This excerpt demonstrates the way that in many cases, masculinity and identity are defined through a man's ability to perform sexually (Connell 2005; Reeser 2010; Potts 2000 and Oliffe 2005). Also, this discussion between Richard and his neighbor is significant because he knew his friend was lying. Lying is another form of silence, one that dismisses the reality and struggle he was facing sexually. In doing so, his neighbor was able to reinforce his masculinity by erasing any sign of weakness and vulnerability. This encounter however made Richard uncomfortable because he turned to a friend who shared common struggles and was left feeling troubled and frustrated. Therefore, providing care to a patient recovering from prostate cancer is not only physical but also social and psychological:

> All treatment may present a threat to a man's understanding of himself as an autonomous, functioning male. This is particularly important in the context of treatments that render him helpless for a time (as in the case of recovery from surgery) or affect his energy level or the way his body looks and feels. (Ofman 1995:1951)

The changes to a man's sexuality not only challenge his conception of masculinity, but it also destabilizes his sense of identity. Therefore, because masculinity is understood in a personal and individual way, erectile dysfunction is a challenge for survivors of prostate cancer because of its implications for their sexual lives.

While sexuality and masculinity are closely entwined it would naïve to assume that all men view their sex lives and erections as the most important part of their lives. Over the course of my fieldwork, I interviewed three men who were aged sixty-five and older who placed other priorities such as family and a happy marriage with their partners over their sexuality. They will be identified in this thesis as: Robert, Mark, and James. The experiences of these three men demonstrate a different way of understanding and asserting one's masculinity; their roles as husbands and fathers seemed to take precedence over their sexual exploits. For example, Robert emphasized that he is in a relationship where sex is not an integral part of their lives because they are an older couple. Instead, he focused on physical activity as the primary way of asserting his masculinity:

> Hormone therapy is one of the treatments that concern many men because it impacts masculinity. It impacts it because you feel nothing any more…you have no sense of libido, no sex drive, no ejaculation (dry ejaculation), but a better orgasm apparently…Well my wife and I are an older couple so we didn't have an intense sex life…it's over…. Anyways, now my cancer has come back and I have continued the hormone treatments now and I will have to for the rest of my life. This however means that my sex life and drive is over […] I do have a lot of my masculinity though that is still there….while I may not be active sexually, I am most certainly someone who travels and goes hiking and does physical activity…so my masculinity is still there, it still exists for me.
> (Interview, July 5 2012)

Although Robert frames exercise as more significant than sexuality for his sense of masculinity, he also emphasized that the side effects from his radiation and hormone therapy continued to impact his level of energy. Therefore, because Robert prioritized what defined his masculinity differently from other informants like Thomas and Richard, his identity was impacted differently by the prostate cancer experience.

Another informant who shared his narrative with me is Mark, an eighty-one year old retired engineer. Having been diagnosed in his late seventies with prostate cancer, he provides a very different experience of prostate cancer. Mark lives with a wife who suffers from a heart condition and mental illness and emphasized in his narrative that his focus post-hormone therapy is centered on taking care of her:

> We are going to be great grandparents in a few months…something I never imagined. We have a very athletic sixteen year-old who is doing beautifully in school and everything. So there is a richer appreciation of their lives…getting married, having a baby…so there is certainly an attitudinal shift but not a role change. My role is dictated here by wife's health. Without getting into the medical history of my wife but she has had a lot of medical problems and it has been going on for thirty-five years so that is my role…and I am here for her. I have been volunteering at many different organizations and it has been very rewarding which involves travel within Canada and there is the occasional meeting in Europe from time to time. I enjoyed every bit of it but now I have a new role, in the next few years we are going to depend on each other and try and stay here in this apartment…and when our health deteriorates, we need to leave. In the meantime, I am here for her and will do whatever is required and that is where the focus is. (Interview, July 28 2012)

This contrast in attitude from other informants is most likely due to Mark's age and the fact that his wife has a mental illness and other health conditions. In his case, sexuality is not even considered because other, more important parts of his life like family and caring for his wife take precedence. In this sense, the way that Mark asserts his masculinity or sense of manhood is by being present as a grand-father and husband; his role in the family is more important to his sense of identity than his ability to perform sexually. Like Robert, Mark can be seen to be substituting other typically masculine traits such as athleticism and the role of protector for sex.

A similar example to Mark is one of the last informants I had the privilege of sitting down with for an interview; his name is James. As I have discussed elsewhere in this thesis, James is a general practitioner who has been practicing for close to forty years. When he began discussing his prostate cancer experience, he openly discussed some of the complications that he has had to deal with following his radical prostatectomy. When discussing the difficulty he has engaging in intercourse due to erectile dysfunction, he emphasized that it is not worth the effort. Instead, he argues that sexuality was usually initiated by him pre-surgery and that his relationship with his wife is more intellectual than anything else:

> We have been married for forty years and in our sexual relationship it was essentially me who initiated most of the time anyways…I have not asked her but I think she is just disinterested at this point…we have never been that physically affectionate…not in public and not really in private either….so we had a very rich sexual life prior…frequency I think is immaterial but there was enough to make us both satisfied…today I would say the same without the intimacy, our relationship is more intellectual than anything else and I don't think it is likely to change. (Interview, October 5 2012)

Despite similar side effects and issues with erectile dysfunction, James states he is kept busy as a physician, which distracts him from some of the psychological distress that he has had to deal with. What is more, the intellectual relationship with his wife is more significant to him than sexual intimacy. Therefore, perhaps his social and "gendered" capital as a doctor functions as a substitute for his sexuality the way that sports and the protector role do for other informants.

These examples drawn from the narratives of prostate cancer survivors demonstrate how each man's experience is dependent on a host of factors such as age, the amount of time elapsed since treatment, life circumstances, etc. It is impossible then to generate broad generalizations about the way that prostate cancer treatments shape men's identities. While sexuality is closely tied to masculinity and identity, prostate cancer treatments and side effects are handled in an individual way and may influence a man's conception of masculinity differently. In this sense, my research shows that there are a variety of responses and coping mechanisms that survivors use to deal with the side effects of their surgery. This creates obstacles for patient care because each man's needs may be specific to the way that the side effects of prostate cancer are understood and fit into their lives. In particular, it demonstrates that more open discussion on men's lived experiences is needed to respond adequately to this patient population. While some of these narratives support the findings of previous studies, it demonstrates the diversity of prostate cancer experience and the importance of considering other factors beyond sexuality when trying to understand the way that masculinities are conceptualized and lived.

3.3. Liminality and Sexuality

Influenced by the work of Belgian anthropologist Arnold van Gennep, Victor Turner developed the concept of liminality when examining rites of passage. During Turner's fieldwork among the Ndembu of Zambia in the late 1960s, he explored life cycle rituals and argues that each life cycle has three phases: separation, transition, and reintegration (Turner 1969; cited in Miller et al. 2010:293). In the initial phase of "separation", the person undergoing the ritual is separated physically, socially, and symbolically from normal life. An example of this phase is when a baby is baptized in the Catholic faith; the child is put into a white gown and transitions into another phase of the life cycle. The second phase described by Turner is the transition or "liminal" phase where the person is no longer their previous status but is not yet a member of the next stage (Turner 1969; cited in Miller et al. 2010:294). This particular phase involves the person learning the specialized skills that will equip them for their new status. The final stage of the life cycle that Turner describes is labeled "reintegration". This last stage occurs when the initiate emerges and is welcomed by the community and adopts their new status in society.

While Turner's concept of liminality has been associated with rites of passage cross-culturally, I feel that it can also be applied to the prostate cancer experience. When a urologist diagnoses a patient with prostate cancer, he is forced to choose from a range of treatments, namely: radical prostatectomy, radiation, and hormone therapy. The act of choosing a treatment and undergoing it is similar to Turner's phase of "separation". During this phase, the patient is separated physically and psychologically from society because they now feel like "ill" subjects and are admitted to a hospital for treatment with side effects that may impact their masculinity and identity. In the second phase, called "transition" or "liminality", the patient returns to home or is discharged from the medical institution. In this phase, survivors are in an in-between space; they are no longer living the same life they had prior to treatment and have not yet adapted to their new set of circumstances. For some patients, the transition into the final stage occurs rapidly whereas others remain in a liminal space for a longer period of time, struggling with their sexuality and side effects like erectile dysfunction and urinary incontinence.

Once the man has accepted the side effects of his treatment and his new life circumstances, some begin adapting their social and sexual selves and move into the final stage called "reintegration". While Turner's concept of liminality is useful because it explores the different phases that an individual or group undergoes when transitioning from one life stage to another, it is unclear what factors determine when the next phase has been reached for prostate cancer survivors. Therefore, for the purposes of my research on prostate cancer, Turner's phases will be used to illustrate how some men have adapted their sexual lives to the side effects of prostate cancer treatments and have begun reintegrating themselves and moving on. For others however, doubts about whether they chose the appropriate treatment coupled with the inability to accept how side effects have impacted their lives leaves some men in a liminal space between the reality they once knew and the uncertainty of the future. The lack of public discussion about these hardships certainly compounds these feelings of liminality.

For Charles, who underwent a radical prostatectomy following a diagnosis with prostate cancer in 2003, he has and continues to struggle with erectile dysfunction. A year following his surgery, Charles' urologist detected cancer cells and he was put on intermittent hormone therapy. As he explains in his narrative, learning to adapt to the side effects of his treatments has been frustrating for both him and his partner Meryl:

> So, it has been nine years now and I am still struggling with it because Meryl is very affectionate and a touchy-feely kind of a person. I never was but she taught me. As a result of my disability, you know…you kind of feel that you don't want to start something that you can't finish…so even as much as a hug or a caress…you think oh jeez, I hope that this doesn't go further because I won't be able to perform. She keeps reassuring me…but I feel that I am depriving her. So, that is a very real issue and I am still struggling with that…very much so. Ummm, now…obviously sex isn't the end of the world and before the surgery we talked about it and she said that my health was more important than anything else and that sex at our age isn't that important anymore…but as a matter of fact, it is. So, are on hormone therapy, your libido is zero, like zero (emphasis added)…no interest. So, it requires a real interest on my part to be affectionate and I am not…and I recognize that…and so that is a major major problem. The other problem associated with it too is that some men are incontinent or have problems with incontinence…I did for a period of time and well it's normal. You work at it and you do your exercises and whatnot and you work at it and it was fine…for a long, long time, and then about a year ago, I started dribbling. Especially when you are tired…you know…and the other thing I found too is that when I gave her a hug, I tended to dribble…even before…even when I was fine…normally…so mentally…it goes through your mind. You get affectionate with each other…and what if I dribble…I mean it's…it's just not what a man should do.
> (Interview, August 18 2012)

Because sex is still important to Charles and his partner Meryl, both of them are struggling with the consequences of the side effects. In particular, both erectile dysfunction and urinary incontinence (which will be discussed in more depth in the following section) are difficult to accept because both of these inhibit intimacy and the sexual relations that they were used to. In this sense, Charles seems to be in a liminal space of transition where he is unable to return to his previous life and is having difficulty adapting to the constraints on his sexuality because of treatments.

In addition, Charles frames his erectile dysfunction as a “disability” which illustrates the depth of his concern. By framing it as such, he is able to take the pressure off himself to perform sexually. In doing so, Charles illustrates that it is not his fault and places the blame on the consequences of surgery. This excerpt also demonstrates this informant’s preoccupation with being seen as virile in later life. Similar to my other informant Thomas, Charles emphasized the inaccurate assumption that aging entails the loss of libido. This may have been due to my age as a researcher and his way of reinforcing his masculinity and virility. He may have assumed that I had read texts that would have suggested this connection before beginning my fieldwork and wanted to reinforce reality, whether it was truthful or fictitious. This is significant because he wanted to alter my perception of him by highlighting that he still has a sex drive and that the inability to perform is beyond his control.

Similar to Charles, Richard discussed the way that he struggled with erectile dysfunction by emphasizing the integral role of sexuality in his conception of masculinity:

> I figured that if I didn’t have any erections up until now, I wouldn’t have any erections until God knows when. And, a friend of mine. I talked to a friend of

> mine and he said: what is better? Having no erections or have chances that you will still live? I said: I don't know… I needed to discuss this with myself. When you grow up and always have erections, it is something that just happens and it is a pleasure to have an erection and to make love…but not anymore…son of a bitch…I don't feel good about that, I hope it is going to turn around but I have certain qualms about it that it won't... (pause…) […] I feel like I am living without a goal…it makes me feel like something is not finished…
> (Interview, July 28 2012)

While I conducted my interview with Richard sooner after surgery than I had with Charles, he exhibits anger and a similar difficulty accepting his current circumstances. In this sense, while Charles' experience was drastically different, particularly because he had both a radical prostatectomy and hormone treatment, Richard seems to be in a similar liminal space between his prior life and adapting or reintegrating. What is particularly significant about this excerpt however is Richard's hesitation between undergoing surgery and being able to achieve an erection. This hesitation is telling because it illustrates the pressure men feel from the social expectations associated with masculine behavior. If men are contemplating between life and the ability to achieve an erection, perhaps men are victims of the very masculinity discourse they try to uphold (this will be discussed in a later section entitled "A Space in Between").

In sharp contrast to Charles and Richard, Thomas and Matthew both discussed the frustrations associated with side effects but placed greater emphasis on the ways that they adapted their lives to fit their current obstacles. About a year after hormone treatment, Thomas's urologist suggested that he begin to re-stimulate himself sexually. He was prescribed performance-enhancing drugs like Viagra and Cialis and while his sex life did not return to the way it was pre-surgery, he states that together with his wife they learned to adapt and be intimate in new ways:

> After a year of therapy, he suggested I start to stimulate myself and so I took Viagra…I did not like it. I felt dizzy, had headaches and rashes. Every time I took Viagra, the next morning I would wake up the next day and feel like I had five glasses of whiskey. Cialis on the other hand was a great success. My wife and I began sexual activity again through caressing and cuddling. We knew that we couldn't get discouraged because even with Cialis, my libido was not as it was. I would say that now, we have a very active sex life. (Interview, June 28 2012)

Therefore, for Thomas, the use of prescription drugs enabled him to adapt to the side effects of his treatments, shifting from Turner's stage of liminality and transition to the final stage of adaptation and reintegration.

Similar to Thomas, Matthew, a retired computer science professor, describes the way that both he and his partner adapted their sexual lives to the erectile dysfunction and loss of libido. While he states that his sex life is not where he would want it to be, Matthew emphasizes that it is acceptable and not the most important aspect of his life:

> Yeah at that point I had a female friend and we adjusted our sex life subsequently to the change in my behavior. She left the scene about a year ago. Since then I have been with another woman and she too has adjusted. So to some degree I have a sex life…while it may not be to the extent that one would want it to be…it passes. (Interview, August 20 2012)

Being an avid tennis player, engaging in physical activity and volunteering for a prostate cancer support group occupies most of his time, which distracts him from some of the obstacles he continues to face. Similar to Mark who is caring for his wife with mental illness and James whose job as a physician occupies most of his time, it is clear that sexuality is not always the most important part of the lives of these men. Like other informants, Mark substitutes sex with other fulfilling masculine activities such as being the breadwinner, through the protector role, and being an athlete. Therefore, it can be argued that Matthew is similar to Thomas because he has begun adapting and has moved from the phase of liminality to reintegration. In this sense, Mark and James have moved on to the reintegration phase because they have different priorities that have distracted them and allowed them to move forward.

As these narratives illustrate, prostate cancer is an individualized experience that is understood and adapted to in diverse ways depending on cultural context and factors such as social class, age, race, ethnicity, and sexual orientation or other gendered identities. Because sexuality and masculinity are so tightly interwoven, it is imperative that they be considered alongside the factors mentioned above when trying to determine the way that the experience of such an illness impacts identity. In this subsection, Victor Turner's concept of liminality (Turner 1969; cited in Miller et al. 2010) was used as a framework to study the way survivors understand and live with the side effects of treatments for prostate cancer. While it is difficult to assess at which point a survivor moves from one phase to the next or to which extent they have accepted their current circumstances, I feel that Turner's concept demonstrates a diversity of prostate cancer experience and the different ways that masculinity and identity are negotiated.

3.4. Other Side Effects

Thus far, I have focused on the way that the sexuality of prostate cancer survivors is impacted by the side effects of treatments. Many men have placed erectile dysfunction as what most significantly affected their lives, and in turn have emphasized that their illness experience forced them to adapt their intimacy and sexual lives to their circumstances. While many previous studies have focused on the way hegemonic masculinity is defined through the penis and the act of penetration (Oliffe 2005; Potts 2000; Arrington 2003; Fergus et al. 2002 and Loe 2006), few studies have examined other side effects such as urinary incontinence. These authors argue that masculinity and a man's identity is defined primarily by his ability to engage in sexual relations with an erect, infallible penis. The stories of my informants however have shown, that while sexuality continues to be a defining factor for the identity of some men, others place greater emphasis on the relations with their families and partners, physical activity, and work. For the men whose experience is the latter, they have negotiated their sense of self worth and conception of masculinity based on other factors, which illustrates that it is problematic to reduce men to their sexualities.

As Charles and Victor describe in their narratives, urinary incontinence was experienced as a side effect that is just as problematic as erectile dysfunction. Charles explains how despite the exercises used to strengthen the muscles that control his bladder; he still struggled with dribbling and urine loss. Similarly, Victor describes how he struggled with incontinence, particularly when he returned to playing tennis a few months following his surgery. He discusses how wearing a diaper or a pad was uncomfortable but that none of his friends knew about it because it was hidden beneath his shorts. Victor did allude however to how wearing a diaper is a emasculating, particularly because it is infantilizing. As these excerpt demonstrate, Charles and Victor interpreted incontinence as an equal assault on their sense of manhood as erectile dysfunction.

This particular experience demonstrates how masculinity is defined as and determined by the control a man has over his body. If his body is leaky and thus no longer bounded, solid, and under control, it throws off a man's sense of masculinity:

> The nature of men's experience with prostate cancer makes it particularly well suited to revealing the linkages between health and illness and masculinity. Becoming ill, in and of itself, is a threat to hegemonic masculinity, in that is implies weakness and lack of control over one's body. (Gray et al. 2002:45)

To complement the work of Gray et al., I will turn to the work of feminist cultural theorist Elizabeth Grosz and her focus on bodily control, fluids, and gender. In her book entitled *Volatile Bodies: Toward a Corporeal Feminism* (1994), Grosz explores how solidity and a contained body are associated with masculinity while fluidity and leakage are associated with femininity. While men's bodies leak through the ejaculation of semen, this form of fluidity is viewed as powerful because it holds the possibility to fertilize and produce an object through "extended corporeality":

> Seminal fluid is understood primarily as what it makes, what it achieves, a causal agent and thus a thing, a solid: its fluidity, its potential seepage, the element in it that is uncontrollable, its spread, its formlessness, is perpetually displaced in discourse onto its properties, its capacity to fertilize, to father, to produce an object. Man sees that his 'function' is to create, and own, at a (temporal and spatial) distance, and thus to extend bodily interests beyond the male body's skin through its proprietorial role, its 'extended corporeality' […]. (Grosz 1994:199)

In sharp contrast, any liquid that flows from a woman's body is viewed as unclean, particularly menstrual blood and urine, and thus does not hold the same level of power as a male body. Therefore, similar to Martin (1991), the functioning of the male body is framed as active while the female body is perceived as passive.

In this sense, if a man is unable to control his urine and leaks, his body loses the characteristics of solidity and containment and is viewed as feminine. Grosz argues that a man's urinary incontinence is viewed in a similar way as erectile dysfunction. She argues that a hard and erect penis is linked to solidity and masculinity while a flaccid penis is associated with fluidity, dysfunction, and femininity (Grosz 1994). Because the male body takes on the function of model or ideal type of body, when a man is unable to achieve an erection or control the flow of his urine, his identity as a man is challenged.

Therefore, while few studies explore the lived experience of prostate cancer survivors, the implication of urinary incontinence on the identity of men is ignored. As my research demonstrates, to gain a fuller understanding of how surgery for prostate cancer affects the lives of men, it is imperative that all side effects are considered as they too impact a man's gendered self.

To support the argument made by Gray et al. (2002) and Grosz (1994), I turn to an interview with an informant and his wife. During my interview with Victor and his wife Martha, I asked a question about why it is that men find it difficult adapting to a side effect like urinary incontinence and Martha stated that it is because they are forced to wear a pad or a diaper:

> Martha: One of the things we were talking about before the surgery and I think it is what you want…it was the issue of the diapers/pad…that you were really worried about…
>
> Victor: Yeah.
>
> Martha: For a woman, pads are not a big deal…you know it is not an issue for a woman…but it is a big issue for a man to do this.
>
> Victor: So, the first time I transitioned didn't need a diaper…just the pad…it was a relatively big deal…like I said…each week now…it is getting better…
>
> (Interview, September 15 2012)

In this sense, masculinity is impacted by urinary incontinence but in a different way than erectile dysfunction. This is perhaps because men no longer have control of their bodies following treatment for prostate cancer and are forced to wear a pad or diaper, which for them signifies weakness and vulnerability instead of strength and control. Nonetheless, similar to Charles, Victor seemed very compelled to reassure me that he is getting better which illustrates their concern with being perceived as strong.

The experiences of men who are troubled by the effects of urinary incontinence demonstrate the necessity of considering masculinity as a complex concept based on a set of culturally constructed social expectations that range beyond erectile dysfunction. In order to understand the way that prostate cancer impacts identity and conceptions of manhood, it is imperative to look beyond the male body as a sexual body. Instead, a more thorough and expanded analysis of the social construction of the male body is required. While I do not intend on undermining the significance of sexuality in the definition of masculinity and hegemonic masculinity, the narratives of Charles and Victor demonstrate the importance of exploring how other side effects fit into the realities and embodied experiences of survivors.

3.5. A Space in Between

Before entering the field, I read the diverse perspectives on masculinity in the work of Connell (2005), Kimmel (2008), and Synnott (2009). While Connell and Kimmel take a pro-feminist stance when defining masculinity by focusing on its implications for patriarchy and inequality, Synnott provides a conflicting perspective by arguing that men are victimized by the manhood they try to uphold. In this final section of the chapter, I will illustrate how the narratives of prostate cancer survivors provide a different discourse on masculinity, one that validates arguments made by Connell, Kimmel, *and* Synnott. Before I illustrate how men are both victims and responsible for the maintenance of patriarchy, I will briefly outline each perspective.

In the second edition of her book *Masculinities* (2005), Connell explores masculinity and hegemonic masculinity theory and demonstrates the way it is carried out in everyday life through sets of actions, behaviors, and in the relationships between men and between men and women. She begins her book by juxtaposing essentialist/biological explanations of masculinity with theories of social constructivism that view masculinity as more of a cultural product. While Connell presents both perspectives on masculinity, she adopts a framework more aligned with the latter, one that views masculinity and the body as socially defined. To understand how masculinity is enacted in everyday life, Connell argues that we need to explore the processes and relationships through which men and women live gendered lives. In addition, she argues that in order to understand gender, we must go beyond it and see how it relates to and intersects with class, race, and global inequality. Therefore, according to Connell, an intersectional analysis is imperative to fully uncover the enmeshed relationship between social factors and relations at work in the gender order at both a micro- and macro-level.

Connell outlines and fleshes out the complexities of hegemonic masculinity theory and how this type of masculinity shapes the acts and behaviors of men and their relationships with others. She uses the concept of “hegemonic masculinity” to demonstrate how this approach to gender relations is one which legitimizes patriarchy and guarantees the dominant position of men and the subordination of women. In particular, Connell illustrates that the behaviors men adopt in their relationships with other men and women plays into the “patriarchal dividend”, which enables them to gain “[…] honour, prestige and the right to command” (Connell 2005:82). Similar to Connell, sociologist Michael Kimmel views masculinity as being constantly in flux and being redefined by men’s relationships with both other men, and with women. In particular, he argues that masculinity is a product of “homosocial enactment”, which means that masculinity is performed by men for men (Kimmel 2008:214).

In his book, *Rethinking Men: Heroes, Villains and Victims* (2009), Synnott criticizes these two theorists by arguing that men are both hegemonic and in crisis and that these are not mutually exclusive categories. He presents the “patriarchal tax” to contrast with Connell’s “patriarchal dividend” and illustrates that masculinity is not based on a set of rigid categories but rather, a continuum. In addition, he presents an alternative perspective, which views men as victims instead of power-hungry villains (Synnott 2009). While these three theorists present valid arguments and useful perspectives for researching masculinity and illness, I believe that all three rely too heavily on theory and ignore the lived experience of men. In the following paragraphs, I will explore how the data I collected in the field must be considered using all the three perspectives discussed above to fully understand the nuanced relationship between gender, illness, and identity.

In the narratives of the prostate cancer survivors I interviewed, some described how side effects like erectile dysfunction impacted their gendered identities because it affected their sexual potency and virility, two fundamental factors that define masculinity and, by extension, hegemonic masculinity. By framing erectile dysfunction as an integral part of their lives and as essential for them to assert their manhood, informants Thomas, Richard and Victor placed sexuality and the erect penis at the heart of their identity. In doing so, it illustrates that sexuality and the act of penetration is key to masculinity and identity, which continues to reinforce its legitimacy and contributes to the maintenance of patriarchy. In this sense, many of the narratives described the frustrations that survivors faced and the obstacles they needed to overcome. While the sexual act itself may not be performed, the patriarchal discourse persists because men continue to strive for values of sexual potency and virility that are defining elements of hegemonic masculinity:

> Failure of the penis to become erect signifies the downfall of this phallic economy as it dictates the sexual identities of both men and women […] Not surprisingly, then, in the more powerful, traditional patriarchal discourses—those that dictate commonsense notions of ‘normal’ and ‘abnormal’ human sexual response—such as medicine and sexology, the erect penis symbolizes ‘healthy’ male sexuality. (Potts 2000: 87-89)

In this way, by striving for these values associated with hegemonic masculinity, men are able to profit from a patriarchal dividend, a kind of honor or prestige that is granted to them by other men through homosocial enactment (Kimmel 2008).

While the experiences of prostate cancer survivors support the pro-feminist arguments made by Connell (2005) and Kimmel (2008), men are also victimized by this very same set of behaviors. By being unable to achieve an erection or by suffering from urinary incontinence, many survivors feel as though they cannot exhibit the values of sexual potency, virility, and strength that are associated with socially accepted conceptions of male sexuality and masculinity. Not being able to have the same sex life and libido they may have enjoyed prior to treatments for prostate cancer, these men suffer from psychological distress. This psychological stress and anxiety, which is caused by being unable to display sexual potency and virility and unable to perform a highly penetrative and infallible sexuality, victimizes men. In this sense, the very discourse that allows for the maintenance of patriarchy and allows them to benefit from a patriarchal dividend (Connell 2005) simultaneously victimizes them and impacts their psychosocial well being when they are unable to satisfy its requirements and meet its demands. Therefore, my research highlights the importance of taking all three of these approaches into consideration. In particular, it demonstrates the diversity of experience among survivors and sheds light on how they negotiate identity and understand their lived reality.

Chapter 4--Acknowledging Difference

4.1. Why Difference?

Early in my fieldwork, I attended a conference organized by ProCure, the Québec foundation for prostate cancer awareness and research. As I described in the opening chapter, I was astonished by the reaction of the panel when one of my informants Jerry, an African American man, asked about how he could spread awareness to his community. He stated that in the Caribbean, there is a stigma associated with prostate cancer, particularly the rectal exam. When the panel did not respond to his comment and the master of ceremony abruptly ended the question and answer period, Jerry returned to his seat and grabbed his jacket. The reaction of the panel made me uneasy, particularly because a urologist was one of the panelists. I began asking myself a series of questions: Did they understand the comment or question being asked by Jerry? If they did, why did they sit confused and unable to answer? If they did not, why did they not ask for it to be rephrased? As I returned home that evening, I continued to be perplexed by the behavior of the panelists and the master of ceremony, all of whom work closely with the ProCure organization.

As I arrived home, I spent the following hour typing “prostate cancer”, “Montreal”, “support group”, and “African American community” into a search engine. Apart from research being conducted in the UK concerning higher rates of prostate cancer in black men and awareness programs being organized in Toronto addressing the black community and screening for prostate cancer, I found no support groups in Montréal that exclusively addressed the needs of this community. As I typed “African

American/Black community" and "support group" into the search engines of websites for organizations like Hope and Cope, ProCure and the West Island Prostate Cancer Support Group, I was unable to find a set of resources that addressed the needs of Montreal's Black community apart of course from the awareness Jerry is spreading. In addition, I searched for the resources available for gay men suffering from prostate cancer and even fewer results were displayed. I managed to find a gay support group in San Francisco but nothing in Montreal; I assume this is because of the large population of gay men living in that city. Montreal however has a large gay population and is culturally diverse. Therefore, why is it that both of these populations lack visibility and the access to resources that they need? My work suggests that this is because research has tended to focus more on the physiological changes to the body and less on the lived experience of men with different cultural and sexual identities.

In the subsections that follow, I will outline the reason why diversity needs to be considered when providing better patient care for those with prostate cancer because I do not want to reproduce the very limitations found in previous research that I discuss in my literature review. As I demonstrated in the previous chapters on masculinity and sexuality, the behaviors of men suffering from the side effects of treatment for prostate cancer are understood differently because the experience is an individual one and is dependent on a host of factors such as social class, age, race, ethnicity, cultural background, sexual orientation etc. This supports the research of Connell (2005) who argues that masculinity should be considered using an intersectional approach, one that considers the range of contextual factors and social characteristics. The diverse experiences of survivors illustrate the fact that illness, like masculinity and conceptions of sexuality, are culturally constructed and contextual: “[Medical anthropologists] recognize that the culture within which a patient is operating influences the illness experience” (Lupton 1994:13). Therefore, in addition to impacting the way that illness is understood, a patient’s cultural background can also influence the way they perceive it has impacted their masculinity and identity. By assuming that men from diverse cultural backgrounds understand the prostate cancer illness and the screening procedures in a similar way, men run a greater risk of being affected by the disease because awareness programs and public education conferences are not oriented in a way that addresses their needs and preconceptions. Also, it also implicitly assumes that the only men who matter are straight, white, middle-upper class men.

An additional social factor that can impact the prostate cancer experience is sexual orientation. While both homosexual and heterosexual men may share the same cultural background, they will experience prostate cancer differently because masculinity is not a concept that applies in the same way to all men. Instead, there exists a plurality of masculinities and identities that need to be considered, which often stand in opposition to the hegemonic ideal (Connell 2005; Connell and Messerschmidt 2005 and Reeser 2010). For each type of masculinity, there is a conception of sexuality that is associated with it: i.e. the values and norms that are viewed as socially acceptable for this particular identity. By not having a separate set of resources for gay men, it is assumed that they share the same understanding of masculinity as heterosexual men, experience sexuality in a similar way, and therefore share the same identity which erases the gay reality. As I will demonstrate however in the following section on prostate cancer and the gay community, it is imperative that a plurality of masculinities be considered when providing care for survivors of prostate cancer and greater emphasis be put on researching the effects of treatments on the sexual health of gay men. Being cured from prostate cancer does not only involve a PSA of zero and a lack of symptoms, it also entails ensuring the psychosocial well being of survivors by providing them with the resources specific to their social and sexual identities: “[…] understanding the diversity of experiences with cancer adds to our broader comprehension of cancer treatment and outcomes themselves, and provides opportunities to develop more sophisticated theoretical and treatment models for all people” (Blank 2005:2593).

4.2. Prostate Cancer and the Gay Community

Despite the plethora of literature on cancer that focuses on a range of social factors such as race, ethnicity, age, and socioeconomic status, there has been little attention paid to the lived experience of the gay, lesbian, bisexual, and transgender (GLBT) community. Due to both the continuity and variation in prostate cancer experience evidenced by the narratives of the survivors with whom I worked, it is important that information about this illness and its effects be as richly textured and varied as the range of men in our society (Blank 2005:2593). Research by Saad and McCormack (2008), ProCure, and other scholars claim that one in seven men will be diagnosed with prostate cancer over the course of their life. In this sense, homosexual men in committed relationships are twice as likely to be affected by prostate cancer within the couple.

In addition, very little attention has been paid to the range of factors that can influence homosexual and heterosexual men differently. For example, in his article “Gay Men and Prostate Cancer: Invisible Diversity” (2005), Blank argues that gay men are affected differently by the illness experience, and he focuses on the impact of side effects on their sexuality, their social relationships, and relations with the medical community. To begin, gay men are faced with heterosexual normativity and a disregard for other sexual identities when considering the side effects of treatments for prostate cancer. As Oliffe (2005) demonstrates, a man's sense of masculinity is almost always defined by their sexual conquest of women, predominantly their ability to achieve an erection and engage in intercourse involving penetrating the female vagina: "[…] hegemonic masculinity prescribes that proper sexual activity must be initiated by a man and involve the insertion of the penis into the female partner's bodily orifice" (Oliffe 2005: 2250). A plurality of sexual identities is ignored from the dominant discourse of masculinity, leaving any man who does not define his manhood through the act of penetration with a woman out of the picture.

For a gay couple, the side effects of treatments for prostate cancer impacts their sexual lives differently than a heterosexual couple. For example, a gay man who is exclusively anally receptive may be less concerned about side effects impacting erectile dysfunction than both heterosexual and homosexual men who are penetrators. In this sense, the anally receptive gay man will most likely show a greater concern about the possible impact of radiation treatments on bowel function and rectal irritation (Blank 2005:2594). Therefore, because of the significant differences in sexual acts for homosexual couples, prostate cancer will impact their masculinities and identities in a different way. This diversity in lived experience illustrates the necessity of providing care and resources for gay men that are specific to their needs instead of assuming that the illness experience impacts all men in the same way.

In addition to the way side effects impact the sexual lives of gay men, Blank (2005) discusses the way social support systems differ for heterosexual and homosexual men. In many cases, gay men are less likely to have a long-term, monogamous, relationship. Therefore, while they may have support from their friends and family, many gay men do not have the extensive support that heterosexual men do in the weeks and months following the treatment (Blank 2005). This lack of social support for some men may lead to greater levels of psychological distress and higher rates of depression. Therefore, the fact that there are barely any resources available for gay men in Montreal, places added stress on survivors that is detrimental to both their identities and overall well being. If gay men have different relationship patterns than heterosexual men, the medical system needs to provide care to help these men adapt both physically and socially to their lives post-treatment.

The final factor that Blank (2005) presents in his article is the added anxiety associated with homophobia in medical institutions and having to deal with urologists and oncologists who are mainly heterosexually oriented. Without a concrete understanding of the sexual behavior and identities of gay men, there is a fear amongst the gay community that urologists may let their personal biases influence their approach to patient care and cause them to be less cautious when performing surgery (Blank 2005: 2594). Another concern is associated with the lack of research on gay men with prostate cancer. If medical practitioners are not educated about the plurality of masculinities and sexualities and that each of these is impacted differently from side effects, perhaps homosexual and heterosexual men will be treated the same with the assumption that their understanding and experience of the disease is similar. If this occurs, then patients with different sexual and gender orientations will not be receiving adequate care that addresses the issues pertinent to the lives.

By examining how prostate cancer impacts the sexual lives of gay men differently from their heterosexual counterparts, understanding how support systems may differ and depend on gendered identities, and by outlining some of the anxieties faced by the gay community with respect to care, it is clear that our medical system in Québec has some important issues to address. Support groups and safe spaces specific to gay men and their needs must be made available to those survivors who require it and efforts made to sensitize existing support resources and groups to the diversity of needs in men facing prostate cancer (Blank 2005). By taking each of these factors into consideration, the healthcare system can work together with the gay community to be more inclusive by paying greater attention to sexual diversity.

4.3. Prostate Cancer and African American Men

Similar to the gay community, greater attention should be given to the cultural factors that may hinder African American men from being screened for prostate cancer. Men construct their sense of masculinity based on socio-historical settings, their cultural background and their relations with both other men and women. In this sense, as Reeser (2010) argues: “The male body functions as a kind of tabula rasa or inscriptive surface for masculinity and for culture, and discourse is inscribed on that matter, asserting its power through inscription and reinscription” (Reeser 2010:91). While conceptions of masculinity and identity are social products, understandings of illness and how it is experienced are similarly culturally constructed. Therefore, the culture in which we grow up teaches us how to perceive and interpret the many changes in the body that can occur over time (Helman 2007:19). In this way, it is important to acknowledge cultural diversity when caring for men with prostate cancer because they will have different understandings of the illness experience and its effects on the body.

Research in both the United Kingdom and the United States has shown that out of all the populations of men affected by prostate cancer, the African American community displays the lowest screening rates (Sanchez et al. 2007; Rajbabu et al. 2007; Magnus 2004; Reynolds 2008 and Winterich et al. 2008). This decision-making behavior is driven by the cultural conception of many African American men that the digital rectal exams (DREs) are a violation of their manhood. In particular, these men fear rectal penetration and associate such exams with homosexuality: "The screening procedure was described as 'not macho'. Several participants believed that getting a DRE implies homosexuality, and African American men in general did not want to be identified as 'that type of guy'" (Sanchez et al. 2007:377). Therefore, as Helman (2007) discusses in her book *Culture, health, and illness*, the cultural background and a host of other factors contribute to the way an individual interprets and understands illness:

> Cultural background has an important influence on many aspects of people's lives, including their beliefs, behavior, perceptions, emotions, language, religion, rituals, family structure, diet, dress, body image, concepts of space and time, and attitudes to illness, pain, and other forms of misfortune—all of which may have important implications for health and health care. (Helman 2007:3)

While cultural background plays a central role in how people define and understand disease, other factors such as access to health care, socioeconomic status, fear, inadequate knowledge about prostate cancer, and preconceptions about medical institutions and practitioners can certainly influence a man's attitude concerning screenings for prostate cancer.

Over the course of my fieldwork, I was fortunate to have had the opportunity to interview two African American men; one who had prostate cancer ten years ago and the other has not been diagnosed, but is trying to create awareness programs for the African American community here in Montreal. For a man to be active in outreach programs and interested in prostate cancer research **who** has not been diagnosed illustrates the severity of this illness in the African American community. While the personal experiences of both men and the studies discussed in this chapter cannot be used to make broad generalizations about how all African American men feel about screening methods, they will demonstrate the necessity of considering cross-cultural understandings of disease when providing patient care. During an interview with my informant Jerry who I met at the ProCure conference in April 2012, he discussed the challenges he faces when trying to create awareness programs and public education conferences for men living in Montréal's Caribbean diaspora. He argues that there is a stigma associated with prostate cancer, particularly the rectal exam. He explains:

> It's a "macho thing"…it is to most of the guys, an invasion of their privacy because all of us are very homophobic from the Caribbean…and looking at it from that perspective…I think it is the hardest thing to sell. But you don't have to do it that way….you can have blood tests…but the reason I have the rectal exam is because the doctor has a better feel of the prostate and compare it…the blood test may show results…it is not an invasion of privacy…I am going to be blunt with you…you guys like to fuck girls up the ass but you don't want someone to stick their finger up your ass for your own good….you know…so excuse my language but sometimes you need to be blunt with these guys…but I think the biggest stigma is the rectal part of it…if someone could explain it to them in general terms because they don't know much about the prostate but the stigma is this….the invasion of their privacy…they don't mind the privacy but not the rectal part…they don't see it as something major but it is killing many of my friends. (Interview, July 14 2012)

As this excerpt demonstrates, many men from the Caribbean maintain and perceive certain parts of their bodies as private and essential to how they negotiate their heterosexual identities. While prostate cancer is an illness that affects parts of the body that people do not publicly discuss (Hegelson & Lepore 1997), Jerry's friends also illustrate a perspective that associates anal penetration with homosexuality. As a result, these men are reticent about undergoing screening for prostate cancer because of the way that illness and the body is culturally perceived in their community.

My second interviewee named Ben is an African American from the United States living in Montréal. He has many close friends who live elsewhere in North America and in the Caribbean with whom he spoke when he was first diagnosed with prostate cancer in 2002. Like Jerry, many of Ben's African American friends from the Caribbean articulated similar feelings about the screening process, particularly the discomfort associated with the rectal exam:

> It is definitely a "no no" to have someone sticking their hand up their rectum. They really…they are so, I don't know what the word is…they are so against that. They feel that you have to be gay to…and I try to explain to them that it has nothing whatsoever to do with that. Even my own brother down in Florida thinks the same way. You know… I say no it is nothing like that, they are just going up to feel the prostate can see if it is hard or soft or if it is creating any problems…I don't know why it is so taboo with them. I think it is a lack of education. I don't think that there is enough information. It should be a lot more on TV or somewhere advertising it, making people aware of what kind of tests there are and why you have these tests. (Interview, October 15 2012)

Therefore, both Jerry and Ben's experience highlight the importance of implementing awareness programs that are culturally sensitive and do not mobilize a homophobic discourse. These programs need to have two purposes: to spread awareness to the African

American community about the importance of undergoing screening on a regular basis and to de-stigmatize the link between these screening procedures and homophobia.

The influence of the Roman Catholic Church has most certainly played a significant role in shaping the cultural attitude of homophobia in the Caribbean with respect to prostate cancer screening procedures (Corrales & Pecheny 2010). Because masculinity is culturally constructed and determined by socio-historical factors, Christianity in the Caribbean remains highly influential and shapes the identities and attitudes of men. As Kimmel (2008) discusses, masculinity is often constructed in opposition to homosexuality and this is due to fears of being perceived as gay: "Homophobia is a central organizing principle of our cultural definition of manhood. Homophobia is more than the irrational fear of gay men, more than the fear that we might be perceived as gay" (Kimmel 2008:214). Because a Roman Catholic doctrine that emphasizes heteronormativity is still prevalent in many Caribbean societies, conceptions of masculinity are constructed around the belief that certain actions such as anal penetration and same-sex relations should be avoided and stigmatized:

> It would indeed be an understatement, from both a historical and a contemporary perspective, to say that Caribbean culture has been unkind to men and women who engage in same-sex practices and relationships. This is obvious in the policing of bodily practices, institutionalizing of hegemonic laws, acts of violence, compulsory heterosexist practices and other borders […]. (Crichlow 2004: 214)

Because heteronormativity permeates Caribbean culture, many African American men view the screening process for prostate cancer as a violation of their manhood, are not tested, and as a result, face higher risks of mortality from this illness.

Therefore, because religion is an integral part of Caribbean society, it has the potential to help de-stigmatize these screening practices. By illustrating the benefits of these procedures for the health and well being of men in the community, the Church can demonstrate that the link between homosexuality and screening practices is a misconception. For this to be possible however, religious leaders in the Caribbean would need education about prostate cancer and its implications for masculinity and identity. In addition, the Church would need to acknowledge that there are cultural barriers, particularly homophobia, that impedes men from undergoing screening. By doing so, the awareness programs organized by religious leaders would need to consider the effect of Christian discourse and work at dissembling the power structures such as heteronormativity that influence men's perceptions and attitudes vis-à-vis prostate cancer. While the Church has the potential to de-stigmatize the screening process by breaking down homophobic attitudes, other institutional forces would be required as well. These include but are not limited to: the media, the healthcare system, the education system in general and the specific training for nurses and urologists.

While the perspectives from my fieldwork and other research (Sanchez et al. 2007; Rajbabu et al. 2007; Magnus 2004; Reynolds 2008 and Winterich et al. 2008) illustrate the tension between an African American man's sense of masculinity and screening for prostate cancer, it is important to acknowledge that these views do not necessarily apply to all men from this racial group. In addition, it is important to note that diversity can exist within the Caribbean itself and among diasporas living across the world and therefore, the terms "African American" and "Caribbean" should not be used as overarching labels that encompass the perspectives and experiences of all men concerning prostate cancer. For example, previous research on African American men and prostate cancer (Reynolds 2008, Sanchez et al. 2007, Magnus 2004 & Winterich et al. 2008) ignores the reality that there are gay African American men. Therefore, creating awareness programs that are not homophobic and recognize the diversity within the African American community is imperative to provide care specific to their needs. As I suggest earlier, the Church has the potential to help de-stigmatize the misconception that links the screening process for prostate cancer with homosexuality by demonstrating the benefits of these procedures for the health and well being of men.

4.4. Implications for Patient Care

As I have demonstrated in my discussion about gay and African American men and the prostate cancer experience, it is imperative that cultural and sexual diversity be taken into consideration when preparing public education conferences and awareness campaigns. In particular, it cannot be assumed that all men share the same lived experienced and conception of masculinity and sexuality. To address this issue, educational institutions need to sensitize medical professionals about the effect of cultural background and variations in gender and sexual identities. An awareness of these issues will help ensure that patients receive care specific to their needs, which will enable them to make informed decisions about treatments and screening procedures. In addition, efforts need to be made at adapting the literature distributed to men about prostate cancer by ensuring that it is inclusive, i.e.: addressing how the side effects of treatment can impact men differently depending on their sexual preference. Finally, post-therapy resources need to be made available to men with diverse sexual and cultural identities and address issues that are relevant to their community's understandings of prostate cancer and the lived experience of individual men.

Chapter 5--Doing Anthropology at Home

Since the 1960s, there has been a shift in anthropology about what is considered a legitimate site to conduct fieldwork. Over the course of the last decade, the discipline has seen an increase in multi-sited ethnography (Hannerz 2003), the use of the Internet as a space of social interaction with sets of values and norms, and anthropology being conducted "at home" (Peirano 2008). This last development, anthropology "at home", marked a significant moment in the discipline. As students of anthropology, we read ethnographies by Margaret Mead, Ruth Benedict, Claude Lévi-Strauss, and Napoleon Chagnon among others, where fieldwork was conducted in locations seen by Westerners as exotic. Even when we discuss our studies as students in the discipline, the general public has this stereotypical image of the anthropologist adorning a grass skirt and war paint, and floating towards an island in the Pacific in a canoe. Therefore, the thought of anthropology being conducted in a familiar space has caused much reflection on the discipline's methodology and what is considered legitimate: " 'Home' and 'abroad' continued to be distinctive sites, but by denouncing exoticism, there was a sense that a metamorphosis was taking place and ethnographers were moving past anthropology toward experimentation and cultural studies" (Peirano 1998:111).

Anthropologists began asking themselves whether they could actually engage in fieldwork on topics relevant to their own society. By living in the society that they intend to study, there was a concern that there would not be enough physical space to reflect on their experiences. In addition, as Amit demonstrates in her chapter entitled "Constructing the field", the melding of personal and professional roles in ethnographic fieldwork makes it difficult to compartmentalize (Amit 2000). Because of the nature of anthropological methodology, which entails living with the population one is working with, it is sometimes difficult to set personal issues and fieldwork apart. Doing anthropology at “home” has had a significant influence on the subfield of medical anthropology, particularly because it was founded on the basis of understanding illness and healing practices cross-culturally (Van Dongen & Fainzang 2010). Initially, medical anthropologists focused so much on illness and disease in other cultural settings that they ignored a range of issues in their own medical system. Therefore, in the last two decades, this subfield has witnessed a change and the gaze has shifted to critically assessing Western biomedicine.

Because anthropology has always been concerned with “otherness”, the prospect of doing anthropology at home problematizes the previously fixed “we-other” dualism (Hadolt 1998). As a result, Hadolt argues that anthropologists are therefore engaging in research with informants who share the same cultural background as them. While this may be true in some contexts, Montréal’s multicultural fabric means that engaging in fieldwork often entails working alongside people of different sexual orientations, ethnicities, and cultural backgrounds. Furthermore, while the anthropologist might live in the society he/she decides to study, there can exist a variety of perspectives on issues and distinct identities. In my case, because prostate cancer is so individualized and understood differently depending on the informant, engaging in fieldwork in my home city of Montréal enabled me to gather a diverse array of perspectives. In addition, because I am familiar with Québec’s medical system and the services provided to prostate cancer patients, I was able to reflect critically on the resources available to men with diverse gender, sexual, and cultural identities. As a result, I discovered that certain services and resources are lacking for both the GLBT and African American population.

Anthropologists as early as Malinowski and Evans-Pritchard have reported culture shock when arriving in the field. In their ethnographies, they share their reflections about their initial encounters and the embarrassment that comes from not properly adhering to social norms and values. This added stress of the unfamiliar can affect a researcher’s mental and physical health and can impact their relations in the field and the data they collect (Irwin 2007). While anthropologists undertaking fieldwork at “home” will most likely avoid this kind of issue, they face a series of other obstacles that may be difficult to overcome. As Amit (2000) argues, compartmentalization in fieldwork and the separation of personal and professional engagements is a difficult task because occasionally one bleeds into the other. In this sense, it is imperative to organize and structure your time in the field by balancing both personal and professional responsibilities.

While I was conducting my fieldwork over the course of summer 2012, I worked forty-hours a week and was one of the primary caregivers of my grandmother. Very often, when I would come home from work, I would be physically exhausted and found it difficult to motivate myself to do readings, transcribe interviews, and look over field notes. In addition, because I worked during the day, most of my interviews were conducted with my informants in the evenings and on weekends. It was difficult to stay positive at times and find the energy to meet with my informants but I learned to compartmentalize and not let a difficult day at work impact my interactions in the field. In addition to working long hours, I had other responsibilities with my family that were important and needed to be thrown into the balance. In this sense, while conducting anthropology at “home” enabled me to be comfortable with my surroundings and have the support of my family and friends, balancing and compartmentalizing each of my commitments remained a challenge.

In sum, anthropology has witnessed a shift in the last few decades with respect to defining the field and what constitutes legitimate anthropology. In particular, such changes have caused the academy to reevaluate the discipline’s methodological and epistemological foundations: Can we be critical of the society in which we live? What does anthropology at “home” mean for conceptions of otherness and the “we-other” dualism? What reflections are required for a researcher who is conducting fieldwork in his/her own community? While the number of legitimate fieldwork sites is growing, each one has a set of positive elements and obstacles. As I have indicated, through my experience studying prostate cancer and its effects the masculinity and identity of survivors in Montréal, finding a balance between personal affairs and professional commitments is a struggle for anthropologists doing fieldwork at “home”. While compartmentalization is key, other skills such as time management, organization, self-motivation, and stress management are essential to maintaining a healthy lifestyle as a researcher and help to deal with other responsibilities.

Chapter 6--Future Considerations for Research

This thesis has focused on the relationship between masculinity, illness, and selfhood through the narratives of prostate cancer survivors. While data collected in the field illustrates the complex relationship between masculinity, sexuality, and the treatments for this illness, there are issues that have not been included in this research that deserve further attention. As I examined in Chapter 4: “Acknowledging Difference”, it is important to consider both cultural and sexual diversity and how prostate cancer is experienced differently. In particular, there should be greater attention paid to the way prostate cancer is understood and lived depending on the cultural background of the patient and/or their gender and sexual identities. In doing so, medical institutions can aim to make care for survivors specific to the needs of different communities and work to sensitize medical professionals and existing support groups about being more inclusive.

In addition, research should pay particular attention to the perspectives of the urologists and nurses who care for prostate cancer patients. It would be worthwhile to see how a medical practitioner understands the institutional framework they are a part of and what can be improved to better care for the needs of survivors. As medical anthropologists, we often critically assess the biomedical model from our perspectives as social scientists—it would be interesting to see how a physician who works within this model would contribute to this body of literature. Also, research has tended to focus less on the role of caregivers and more on the well being of patients and the consequences of different procedures. However, my interview with Victor and his wife Martha illustrated the importance of exploring the involvement of the caregiver in the illness experience because she handled a great deal of the couple’s emotional labor. It would also be important to study the implications of gender for care outside the home and how prostate cancer survivors engage with both male and female nurses and urologists considering the private and personal nature of this illness.

Finally, through an interview with one of my informants Victor, I have discovered that barely any attention has been paid to the partners of survivors. In particular, it would be important to study the effect of prostate cancer on the lives of spouses or partners who are usually the primary caregivers for these men when they are first released from the hospital. Exploring the implications of different treatments on the sexuality and psychosocial well being of both the survivor and their partner may shed light on the experience of this illness. In addition, different resources should be extended to partners because prostate cancer impacts the sexual lives of both people in a relationship and may have a different impact psychologically depending on the role that is assumed: survivor and caregiver.

Conclusion

The narratives of the prostate cancer survivors with whom I collaborated during my five months of fieldwork in Montréal have shed light on how closely the illness experience is tied to masculinity, sexuality, and conceptions of selfhood. As medical anthropologist Gay Becker argues in her book *Disrupted Lives: How People Create Meaning in a Chaotic World* (1997), the use of the narrative method empowers informants by allowing them to structure their stories around moments in their experience that were most significant for them: "Narratives, the stories that people tell about themselves, reflect people's experience, as they see it and as they wish to have others see it" (Becker 1997:25). While the stories of prostate cancer survivors were often rich in detail about lived experience, it is important to acknowledge that their stories are constructed—some moments may have been omitted and others emphasized. My presence as a researcher and my background may have influenced the way that survivors told their stories and therefore it is important that the fieldwork encounter be viewed as an interaction.

Coupled with the intimate details some informants shared, it was important that I analyze the silences, uncertainties, and hesitations embedded within the ethnographic encounter (Stevenson 2009). These moments illustrated how masculinity can be enacted through language and other behaviors that are both integral to understanding how prostate cancer impacts the individual. In particular, I have explored the way that uncertainties or hesitations may be linked with the age gap between researcher and informant, which may have left some participants uncomfortable disclosing both personal and private details. Furthermore, nonchalance before, during, and after the interviews may be indicative that the participant did not want to appear weak or emotionally attached to his experience and used this behavior to assert his strength and masculinity. Therefore, as these fieldwork encounters demonstrate, prostate cancer impacts a man's sense of manhood and this can be reflected just as much through language as non-verbal communication.

For many of my informants however, the narrative method enabled them to share personal details about the impacts of side effects on their lives. For some, sexuality played a central role in defining their masculinity and identity. Dealing with erectile dysfunction caused distress in their lives and many struggled to adapt their sexuality to their new circumstances. Other informants illustrated how their roles as fathers and husbands, their jobs, or physical activities like tennis, biking, and running, distracted them from the side effects. For them, other responsibilities were prioritized instead of sexuality and therefore, they asserted their manhood in a different way. This diversity in experience illustrates how problematic it is to define men as purely sexual beings and demonstrates the significance of viewing prostate cancer as an individual experience.

For informants whose lives were severely impacted by the side effect of erectile dysfunction, Turner's concept of liminality (Turner 1969; cited in Miller et al. 2010) was used as a framework to study the way survivors understand and live with the side effects of treatments for prostate cancer. While it is difficult to assess at which point a survivor moves from one phase to the next or to which extent they have accepted their current circumstances, I feel that Turner's concept demonstrates a diversity of prostate cancer experience and the different ways that masculinity and identity are negotiated. In particular, men who have difficulty adapting their sexual lives to the effects of erectile dysfunction remain in a liminal space between their pre-op and post-op selves. For other men who have turned to cuddling and caressing or performance enhancing drugs such as Cialis or Viagra, they seem to have adapted to their post-op self and negotiated a masculine identity.

Because masculinity and understandings of illness are culturally constructed, it is imperative that cultural background and sexual orientation be considered when offering resources to men with prostate cancer. Due to the way sexual acts differ for homosexual men, side effects may affect them differently. As Blank (2005) discusses, for a man who is anally receptive, he may be less concerned about erectile dysfunction than a homosexual and heterosexual man who engages in penetration and instead, more troubled by bowel and rectal irritation following radiation treatments. For African American men with cultural roots in the Caribbean, it is important to consider the cultural stigma associating the rectal exam for prostate cancer screening with homosexuality. Therefore, in order to spread awareness to these men about the importance of screening procedures, it is important that public education conferences and literature be more culturally sensitive and consider some of the factors that shape their perceptions. For example, as my informants Jerry and Ben suggest, having a local hero become a spokesperson and sharing his experience may help men overcome this cultural stigma and see the importance about being tested. As these two cases illustrate, in order to improve patient care, it is paramount that cultural and sexual diversity be taken into account to make resources more inclusive and specific to the needs of different communities.

Finally, being an anthropologist at “home” posed some difficulties, particularly with respect to balancing personal and professional commitments. While I may not have faced the culture shock that some of my colleagues may have encountered upon entering the field, I struggled with other issues. In particular, changes in the discipline and the growing trend of research being conducted at “home” forced me to compartmentalize my different responsibilities and not have one impact the other. Therefore, juggling work, research, and family played a central role in my fieldwork experience which at times put a strain on my relationships in the field. Time constraints with participants were due to both personal and professional engagements and the nature of the topic. Negotiating limited time in the field and a topic related to a personal and private experience made fieldwork on prostate cancer a challenge, particularly participant observation. As research and awareness on prostate cancer grows, there will be more public events available for researchers to attend and a greater number of men may feel comfortable sharing their stories. Together, these factors will make the field on this topic more accessible in the future.

Despite the obstacles that I faced gaining access to the field, the difficulties I had to overcome when faced with silences, hesitations, and uncertainties, and a range of other behaviors related to masculinity, this research demonstrates the complex relationship between illness, gender, and selfhood. In particular, the narratives of the survivors with whom I worked illustrate how prostate cancer is an individualized and personal experience. It is impossible based on my sample or any other, to make broad generalizations about the way this illness is understood and lived. Depending on a range of factors such as age, sexual orientation, and cultural background, men are impacted by the side effects of treatments differently. For some, sexuality was paramount to their identities as men whereas for others exercise, family lives, and work were more important priorities. Due to these different understandings of the same illness, future research ought to consider the needs of survivors with different cultural, sexual, and gender identities. In doing so, it will sensitize medical professionals to diversity, make resources more inclusive and specific to the needs of patients, and broaden the academic discourse on masculinity by moving beyond work on erectile dysfunction.

References

Amit, V. 2000. “Introduction”. In *Constructing the Field: Ethnographic Fieldwork in the Contemporary World*, Vered Amit (Ed.). New York: Routledge.

Arrington, M. I. 2003. “ ‘I Don’t Want To Be An Artificial Man’: Narrative Reconstruction of Sexuality Among Prostate Cancer Survivors”. *Sexuality & Culture*, pp.30-58.

Bailey, C. A. 2007. *A Guide to Qualitative Field Research* (2nd Edition). Thousand Oaks, California: Pine Forge Press.

Becker, G. 1997. *Disrupted Lives: How People Create Meaning in a Chaotic World*. Berkeley: University of California Press.

Belizzi, K. M. & Blank, T. O. 2007. “Cancer-related identity and positive effects in survivors of prostate cancer. *Journal of Cancer Survivorship: Research and Practice, 1*(1):44-48.

Belizzi, K. M. & Blank, T. O. 2006. “After Prostate Cancer: Predictors of Well-Being Among Long-Term Prostate Cancer Survivors”. *American Cancer Society*, 106: 2128-2135.

Blank, T. O. 2005. “Gay Men and Prostate Cancer: Invisible Diversity”. *Journal of Clinical Oncology, 23*(12): 2593-2596.

Bokhour, B. G. et al. 2001. “Sexuality after Treatment for Early Prostate Cancer: Explaining the Meaning of ‘Erectile Dysfunction’”. *Journal of General Internal Medicine, 16*(10):649-655.

Broom, A. 2004. “Prostate Cancer and Masculinity in Australian Society: A Case of Stolen Identity?”. *International Journal of Men’s Health 3*(2):73-91.

Brubaker, S. J. & Johnson, J. A. 2008. “‘Pack a more powerful punch’ and ‘lay the pipe’: erectile enhancement discourse as a body project for masculinity”. *Journal of Gender Studies, 17*(2):131-146.

Chapple, A. & Ziebland, S. 2002. “Prostate cancer: embodied experience and perceptions of masculinity”. *Sociology of Health and Illness, 24*(6):820-841.

Charmaz, K. 1994. “Identity Dilemmas of Chronically Ill Men”. *The Sociology Quarterly*, 35(2):269-288.

Clark, J. A. et al. 2003. “Patients’ Perceptions of Quality of Life After Treatment for Early Prostate Cancer”. *Journal of Clinical Oncology 21*(20):3777-3784.

Connell, R.W. 2005. *Masculinities*. Cambridge, UK: Polity Press.

Connell, R. W. & Messerschmidt, J. W. 2005. “Hegemonic Masculinity: Rethinking the Concept”. *Gender and Society 19*(6):829-859.

Corrales, J. & Pecheny, M. 2010. “Introduction: The Comparative Politics of Sexuality in Latin America”. In *The Politics of Sexuality in Latin America: A Reader on Gay, Lesbian, Bisexual and Transgender Rights*, Javier Corrales and Mario Pecheny (Eds). Pittsburgh: University of Pittsburgh Press.

Corbett, J. B. & Mori, M. 1999. “Medicine, Media, and Celebrities: News Coverage of Breast Cancer, 1960-1995”. *Journalism and Mass Communication Quarterly*, 76(2):229-249.

Corbett, J. B. & Mori, M. 1999. “Gender-specific Cancers: Gender-specific Reporters: Twenty-Four Years of Network TV Coverage”. *Science Communication*, 20: 395-408.

Courtenay, W. “Theorizing masculinity and men’s health”. In, Alex Broom and Philip Tovey (Eds.), *Men’s Health: Body, Identity and Social Context,* 2009, West Sussex, UK:Wiley-Blackwell Publishing. Pp.9-32.

Crichlow, W. E. A. 2004. “History, (Re)Memory, Testimony and Biomythography: Charting a Buller Man’s Trinidadian Past”. In *Interrogating Carribean Masculinities: Theoretical and Empirical Analyses*, Rhoda E. Reddock (Ed.). Kingston: The University of West Indies Press.

Esplen, M.J. Section 5, Chapter 1: “Distress, Body Image, Sexuality and Self-Identity and Implications for Treatment”. In, Laurie Elit (Ed.), *Women and Cancer*, 2007, New York: Nova Science Publishing, Inc. Pp. 181-202.

Fergus, K.D., Gray, R.E. & Fitch, M.L. 2002. “Sexual Dysfunction and the Preservation of Manhood: Experiences of Men with Prostate Cancer. *Journal of Health Psychology*, 7(3):303-316.

Ferguson, A. 2000. Article 13: “Making a Name for Yourself: Transgressive Acts and Gender Performance”. In Kimmel M. S. & Messner, M. A. (Eds.), *Men’s Lives* Sixth Edition). Boston: Pearson Education Inc.

Ferguson, K. E. 1993. The Man Question: Visions of Subjectivity in Feminist Theory. Berkeley: University of California Press.

Foucault, M. 1978. *The History of Sexuality Volume 1: An Introduction*. Vintage Books Edition, March 1990. New York: Vintage Books.

Gerschick, T. J. & Miller, A. S. 1994. Article 29: "Coming to Terms: Masculinity and Physical Disability". In Kimmel, M. S. & Messner, M. A. (Eds.), *Men's Lives* (Sixth Edition). Boston: Pearson Education Inc.

Goffman, E. 1974. Frame analysis: An essay on the organization of experience. Cambridge, MA: Harvard University.

Good, G. E. & Wood, P. K. 1995. "Male Gender Role Conflict, Depression, and Help-Seeking: Do College Men Face Double Jeopardy?". *Journal of Counseling and Development* 74(1): 70-75.

Gray, R. E. et al. 2002. "Hegemonic Masculinity and the Experience of Prostate Cancer: A Narrative Approach". *Journal of Aging and Identity, 7*(1):43-62.

Grosz, E. 1994. *Volatile Bodies: Toward a Corporeal Feminism*. Indianapolis: Indiana University Press.

Hadolt, B. 1998. "Locating difference: A medical anthropology 'at home'?". *Anthropology & Medicine 5*(3): 311-323.

Hannerz, U. 2003. "Being there… and there… and there!: Reflections on Multi-Site Ethnography". *Ethnography 4*(2): 201-216.

Hay, C. 2008. "Reading Sensations: Understanding the Process of Defining 'Fine' from 'Sick'". *Transcultural Psychiatry* 45(2): 198-229.

Hearn, J. & Parkin, W. 2001. Gender, Sexuality and Violence in Organizations. London, Thousand Oaks, and New Dehli: Sage Publications.

Hegelson, V. S. & Lepore, S. J. 1997. "Men's Adjustment to Prostate Cancer: The Role of Agency and Unmitigated Agency". *Sex Roles, 37*(3/4):251-267.

Helman, C. G. 2007. *Culture, health, and illness*. 5th Ed. London : Hodder Arnold ; New York, NY : Distributed in the U.S.A. by Oxford University Press.

Hodgson, N. Section 2, Chapter 1: "Surgical Management of Breast Cancer". In, Laurie Elit (Ed.), *Women and Cancer*, 2007, New York: Nova Science Publishers, Inc. Pp. 51-58.

Irwin, R. 2007. "Culture shock: negotiating feelings in the field". *Anthropology Matters Journal 9*(1): 1-11.

Kimmel, M. S. 2008. "Masculinity as Homophobia: Fear, Shame and Silence in the Construction of Gender Identity". In A. L. Ferber, K. Holcomb & T. Wentling (Eds.), *Sex, Gender, and Sexuality: The New Basics* (pp.58-71). Oxford: Oxford University Press.

Kirmayer, L. 1992. "The Body's Insistence on Meaning: Metaphor as Presentation and Representation in Illness Experience". *Medical Anthropology Quarterly* 6:323-46.

Kiss, A. & Meryn, S. 2001. "Effect of Sex and Gender On Psychosocial Aspects of Prostate and Breast Cancer". *British Medical Journal, 323*(7320):1055-1058.

Kromm, E. E. et al. 2007. "Survivors on Cancer: The portrayal of survivors in news print". *Journal of Cancer Survivors*, 1:298-305.

Kronsell, A. 2006. "Methods for studying silences: Gender analysis in institutions of hegemonic masculinity". In *Feminist Methodologies for International Relations*. Ackerly, B. A., Stern, M. & True, J. (Eds.). New York: Cambridge University Press.

Lamont, J. Section 5, Chapter 3: "Sexuality and Cancer". In, Laurie Elit (Ed.), *Women and Cancer*, 2007, New York: Nova Science Publishing, Inc. Pp. 227-234.

Larson, R. L. et al. 2005. "Celebrity Endorsements of Cancer Screening". *Journal of the National Cancer Institute*, 97(9):693-695.

Loe, M. Chapter 1: "The Viagra Blues: Embracing or Resisting the Viagra Body". In, Dana Rosenfeld and Christopher A. Faircloth (Eds.), *Medicalized Masculinities*, 2006, Philadelphia: Temple University Press. Pp.21-44.

Lorber, J. & Moore, L. J. 2002. *Gender and the Social Construction of Illness*. Walnut Creek, California: Altamira Press.

Lupton, D. 1994. *Medicine as culture: illness, disease and the body in western societies*. Thousand Oaks, CA: Sage Publications.

Magnus, M. 2004. "Prostate Cancer and Knowledge Among Multiethnic Black Men". *Journal of the National Medical Association, 96*(5): 650-656.

Marshall, B. L. 2006. "The New Virility: Viagra, Male Aging and Sexual Function". *Sexualities*, 9(3):345-362.

Marshall, B. L. & Katz, S. 2002. "Forever Functional: Sexual Fitness and the Ageing Male Body". *Body & Society*, 8(4):43-70.

Martin, E. 1991. "The Egg and the Sperm: How Science has Constructed a Romance Based on Stereotypical Male-Female Roles. *Signs*:485-501.

Middleton, P. 1992. *The Inward Gaze: Masculinity and subjectivity in modern culture*. New York: Routledge.

Mirandé, A. 1997. Article 3: " 'Macho': Contemporary Conceptions". In Kimmel, M. S. & Messner, M. A. (Eds.), 2004, *Men's Lives* (Sixth Edition). Boston: Pearson Education Inc.

Morris, D. B. (1996). About Suffering: Voice, Genre, and Moral Community. In Kleinman, A., Das, V., & Lock, M. (eds.), *Social Suffering* (pp.25-47). Berkeley: University of California Press.

Nancarrow Clarke, J. 2004. "A comparison of breast, testicular and prostate cancer in mass print media (1996-2001). *Social Science & Medicine*, 59:541-551.

Newman, L. 2001. "Panel Examines Impact of Public Figures on Cancer Awareness." *Journal of the National Cancer Institute*, 93(1):8-9.

O'Brien R., Hunt, K. & Hart, G. 2005. " 'It's caveman stuff, but that is to a certain extent how guys still operate': men's accounts of masculinity and help seeking". *Social Science & Medicine* 61:503-516.

O'Brien, R., Hart, G. J. & Hunt, K. 2007. " 'Standing Out from the Herd": Men Renegotiating Masculinity in Relation to Their Experience of Illness". *International Journal of Men's Health 6*(3):178-200.

Ofman, U. S. 1995. "Sexual Quality of Life in Men with Prostate Cancer". *Cancer Supplement, 75*(7):1949-1953.

Oliffe, J.L. "Positioning prostate cancer as the problematic third testicle." In, Alex Broom and Philip Tovey (Eds.), *Men's Health: Body, Identity and Social Context,* 2009, West Sussex, UK: Wiley-Blackwell Publishing. Pp.33-62.

Oliffe, J. & Mróz, L. 2005. "Men interviewing men about health and illness: ten lessons learned". *Journal of Men's Health and Gender 2*(2): 257-260.

Park, C. L., Zlateva, I. & Blank, T. O. 2009. "Self-Identity After Cancer: 'Survivor', 'Victim', 'Patient', and 'Person with Cancer'". *Journal of General Internal Medicine 24*(2):430-435.

Parsons, T. 1951. *The Social System*. New York: The Free Press.

Pateman, C. 1988. *The Sexual Contract*. Stanford: Stanford University Press.

Partner, N. "Narrative Persistence: The Post-Postmodern Life of Narrative Theory". In *Re-Figuring Hayden White*. Frank Ankersmit, Ewa Domanska and Hans Kellner (Eds.). Stanford: Stanford University Press. Pp. 81-104.

Potts, A. 2000. " 'The Essence of the Hard On': Hegemonic Masculinity and the Cultural Construction of 'Erectile Dysfunction'". *Men and Masculinities*, 3(1), 85-103.

Petersen, A. “Future research agenda in men’s health”. In, Alex Broom and Philip Tovey (Eds.), *Men’s Health: Body, Identity and Social Context*, 2009, West Sussex, UK: Wiley-Blackwell Publishing. Pp.202-214.

Peirano, M. G. S. 1998. “When Anthropology is at Home: The Different Contexts of a Single Discipline. *Annual Review of Anthropology,* 27:105-128.

Rajbabu, K. et al. 2007. “Racial origin is associated with poor awareness of prostate cancer in UK men, but can be increased by simple information”. *Prostate Cancer and Prostatic Diseases, 10*:256-260.

Reeser, T. W. 2010. *Masculinities in Theory: An Introduction*. West Sussex, UK: Wiley-Blackwell.

Reynolds, D. 2008. “Prostate Cancer Screening in African American Men: Barriers and Methods for Improvement”. *American Journal of Men’s Health, 2*(2):172-177.

Ransohoff, D. F. et al. 2002. “Why Is Prostate Cancer Screening So Common When the Evidence Is So Uncertain? A System without Negative Feedback”. *American Journal of Medicine*, 113:663-667.

Ribeiro, G. L. & Escobar, A. (Eds.). 2006. “Preface”. In *World Anthropologies: Disciplinary Transformations Within Systems of Power*. Oxford: Berg Publishing.

Rosenfeld, D. & Faircloth, C.A. Introduction: “Medicalized Masculinities: The Missing Link?”. In Dana Rosenfeld and Christopher A. Faircloth (Eds.), *Medicalized Masculinities*, 2006, Philadelphia: Temple University Press. Pp.1-20.

Rutherford, J. 1992. *Men’s Silences: Predicaments in Masculinity*. New York: Routledge.

Saad, F. & McCormack, M. 2008. *Understanding Prostate Cancer*. Québec: Les Éditions Santé.

Sabo, D. 1998. Article 25: “Masculinities and Men’s Health: Moving Towards Post-Superman Era Prevention”. In Kimmel, M. S. & Messner, M. A. (Eds.), *Men’s Lives* (Sixth Edition). Boston: Pearson Education Inc.

Sanchez, M. A. et al. 2007. “Factors Influencing Prostate Cancer Screening Decisions Among African American Men”. *Ethnicity & Disease, 17*: 374-380.

Seale, C. 2001. “Sporting cancer: struggle language in news reports of people with cancer”. *Sociology of Health & Illness*, 23(3):308-329.

Shilling, C. 2003. *The Body and Social Theory*. London: Sage Publications.

Sontag, S. 1978. *Illness as Metaphor*. New York: The New York Review of Books.

Sobal, J. 2005. "Men, Meat, and Marriage: Models of Masculinity". *Food and Foodways 13*(1-2): 135-158.

Stevenson, L. 2009. "The Suicidal Wound and Fieldwork among Canadian Inuit". In *Being There: The Fieldwork Encounter and the Making of Truth*. Borneman, J. and Hammoudi, A. (Eds.). Berkeley: University of California Press.

Synnott, Anthony. 2009. *Re-Thinking Men: Heroes, Villains and Victims*. Surrey, England: Ashgate Publishing Limited.

Taguchi, Yosh. 2003. *Private Parts: An Owner's Guide to the Male Anatomy*. Plattsburgh, NY: McLelland & Stewart Ltd.

Van Dongen, E. & Fainzang, S. 2010. "Editorial: Medical anthropology at home: Creating distance". *Medical Anthropology Unit, University of Amsterdam*.

Wall, D. & Kristjanson, L. 2005. "Men, culture and hegemonic masculinity: understanding the experience of prostate cancer". *Nursing Inquiry 12*(2): 87-97.

Wilkerson, J. M., Ross, M. W. & Brooks, A. K. 2009. "Social Constructions Influencing Sociosexual Identity Development of Collegiate Gay and Bisexual Men". *Journal of NSRC, 6*(2): 71-87.

Winterich, J. A. et al. 2009. "Masculinity and the Body: How African American and White Men Experience Cancer Screening Exams Involving the Rectum". *American Journal of Men's Health, 3*(4): 300-9.

Young, A. 1982. "The Anthropologies of Illness and Sickness". *Annual Review of Anthropology*, 11:257-285.

Appendix

Permission to Collaborate with ProCure

Hi Mr. Folco,

I was very pleased to receive your E-mail. It's always interesting to find new students working on prostate cancer projects. We could help you in your interview process of patients, since we have at Procure a list of volunteer men who already had prostatectomy and would accept to share with you their personal experience with prostate cancer. I have to say however, that a significant number of our patients are French. So I need to know if you can speak or at least understand well French, since this might decrease the number of patients available in your project.

I could take some time during your research project to meet with you and give you a scientific point of view of prostate cancer: I am not a doctor but I know pretty well about the disease, the different types of treatments and the research on-going on prostate cancer.

As you could imagine also, ProCure has tremendous needs on volunteer work: we need a Webmaster-experienced person, some persons to assist in various tasks during the events throughout the year, others to help in translation of documents from English to French and the inverse, as well as in the distribution of materials and ProCure documentation to various cycling and motorcycling stores, as well as to private clinics, CLSCs and pharmacies around Montreal. So, as you can see, you could be very helpful to Procure if you have some hours available and this type of work could be very useful for you as in introduction to your research project.

Don't hesitate to communicate with me whenever you are ready for either volunteer work or your research project and I will be more than happy to help.

Have a good day,

Ginette McKercher

Ginette McKercher
Coordonnatrice, Biobanque Procure
1320, boul. Graham, bureau 110,
Ville Mont-Royal (QUÉ) H3P 3C8
Cell:(514)928-1322
ginette.mckercher@procure.ca

Permission to Collaborate with the West Island Prostate Cancer Support Group

Hi Joseph:

We are going to contact our members and make an appeal for volunteers to get in touch with you.

Our Group is relatively inactive during the summer so we have no scheduled meetings that you could attend prior to September.

We wish you all the best with your thesis.

Best Regards,

Fred Crombie

Dear PCCN - MWI members and interested parties,

I am forwarding a request by Concordia University Master's candidate Joseph Folco for help regarding his thesis on prostate cancer as outlined below. If you are interested in assisting him (an interview) in this effort, please email him at josephfolco@hotmail.com.

Monty Newborn
Fred Crombie
Steering Committee Members
Prostate Cancer Canada Network - Montreal West Island

French Consent Form

UNIVERSITÉ
Concordia
UNIVERSITY

CONSENTEMENT DU PARTICIPANT AU PROJET DE RECHERCHE : « Une crise de l'identité masculine? » À la croisée du genre, de la maladie et de l'individualité à travers les récits de survivants du cancer de la prostate.

Je comprends que je participe à un projet de recherche entrepris par Joseph Folco, un élève à la maîtrise en anthropologie sociale et culturelle du département de sociologie et d'anthropologie de l'université Concordia.

Personne ressource : numéro de téléphone : 514-668-3106
courrier électronique : josephfolco@hotmail.com

A. OBJECTIF

Je suis conscient que l'objectif de la recherche est d'explorer la façon dont le cancer de la prostate influence les concepts de la masculinité et de l'identité chez les survivants de cette maladie.

B. PROCÉDURES

La recherche à laquelle vous participez comporte une entrevue. Cette dernière est semi structurée; cela signifie que les questions de l'entrevue serviront uniquement de guide pour une discussion. Avec votre permission, cette entrevue sera également enregistrée et ne sera utilisée qu'à des fins professionnelles et dans le cadre de cette recherche. Lors du projet, l'enregistrement sera gardé en lieu sécuritaire et une fois le projet terminé, la copie de l'enregistrement sera détruite. Afin de préserver votre anonymat à titre de participant, vous devrez choisir un pseudonyme (un nom fictif), qui sera utilisé durant toute la durée du projet.

C. RISQUES ET AVANTAGES

En participant à cette entrevue, vous contribuerez à un projet qui vise à approfondir les recherches sur le cancer de la prostate et accroître la sensibilisation en lien avec cette maladie. Cela permettra à l'association caritative du Québec pour le cancer de la prostate, Procure, ainsi qu'aux chercheurs en sciences sociales et aux professionnels de la santé à mieux comprendre l'impact social et sur la vie personnelle des hommes atteints de cette maladie. Toutefois, en participant à cette recherche, il est possible que le fait d'évoquer votre expérience avec la maladie réveille des souvenirs douloureux et de ce fait, considérez-vous libre de vous retirer du projet à tout moment.

D. CONDITIONS DE PARTICIPATION

- Je comprends que je suis libre de me retirer du projet et d'annuler mon consentement à tout moment, sans conséquence.
- Je comprends que je participe à ce projet de façon entièrement CONFIDENTIELLE (par exemple, le chercheur aura accès à mes renseignements, mais ne pourra divulguer mon identité.)
- Je comprends que les renseignements recueillis pour ce projet de recherche peuvent être publiés.

J'AI LU AVEC ATTENTION LES RENSEIGNEMENTS CI-HAUT ET JE COMPRENDS BIEN LES CONDITIONS DE CETTE ENTENTE. JE CONSENS LIBREMENT ET VOLONTAIREMENT À PARTICIPER À CE PROJET DE RECHERCHE.

NOM (lettres détachées) ____

SIGNATURE ____

Si, à tout moment, vous avez des questions concernant le projet de recherche, veuillez communiquer avec le directeur de recherche :
Dr. Marc Lafrance, Professeur de sociologie, Université Concordia.
Tél. : 514-848-2424, poste 2142
Courrier électronique : mlafranc@alcor.concordia.ca

Si, à tout moment, vous avez des questions sur vos droits de participant dans le cadre de ce projet de recherche, veuillez communiquer avec le département d'éthique de la recherche au (514) 848.2424 poste 7481 ou à l'adresse électronique ethics@alcor.concordia.ca

English Consent Form

Université Concordia University

CONSENT TO PARTICIPATE IN: " 'A Crisis of Masculinity?': The Intersection of Gender, Illness, and Selfhood in the Illness Narratives of Prostate Cancer Survivors".

I understand that I have been asked to participate in a program of research being conducted by Joseph Folco, Masters Student of Social and Cultural Anthropology at the Department of Sociology and Anthropology of Concordia University.

Contact Information: Telephone: 514-668-3106
Email: josephfolco@hotmail.com

A. PURPOSE

I have been informed that the purpose of the research is to explore the way the experience of prostate cancer influences a survivor's conception of masculinity and identity.

B. PROCEDURES

The research in which you have volunteered to participate will involve an interview. This interview will be semi-structured, meaning, that a set of questions will only be used to guide the discussion. If you give me permission, this interview will be recorded and will only be used for the purposes of this project. The recording will be kept in a secure location, and once the research has been completed, the copy of the recording will be destroyed. In order to protect your anonymity and confidentiality as a participant, you will be asked to choose a pseudonym (fictive name) that will be used in the research instead of your name.

C. RISKS AND BENEFITS

By participating in this interview, you will be contributing to a project that is geared at furthering research and awareness about prostate cancer and will enable the Québec charity for prostate cancer, ProCure, as well as social scientists and medical professionals, to better understand the personal and social impact of this disease. By participating however, it is possible that recounting an illness experience may arouse painful emotions and memories of the past and therefore, you are free to withdraw your participation in this research at any time.

D. CONDITIONS OF PARTICIPATION

- I understand that I am free to withdraw my consent and discontinue my participation at anytime without negative consequences.

- I understand that my participation in this study is CONFIDENTIAL (i.e., the researcher will know, but will not disclose my identity).

- I understand that the data from this study may be published.

I HAVE CAREFULLY STUDIED THE ABOVE AND UNDERSTAND THIS AGREEMENT.
I FREELY CONSENT AND VOLUNTARILY AGREE TO PARTICIPATE IN THIS STUDY.

NAME (please print) ____

SIGNATURE ____

If at any time you have questions about the proposed research, please contact the study's Principal Investigator:
Dr. Marc Lafrance, Professor of Sociology, Concordia University.
Tel: 514-848-2424, Extension # 2142
Email: mlafranc@alcor.concordia.ca

If at any time you have questions about your rights as a research participant, please contact the Research Ethics and Compliance.848.2424 ex. 7481 ethics@alcor.concordia.ca

French Interview Questions

Ayant survécu au cancer de la prostate, comment vous identifiez-vous? En tant que « survivant », « conquérant » ou « victime »?

Quelles activités et quels rôles étaient importants pour vous avant de recevoir un diagnostic de cancer de la prostate?

Sentez-vous que vous étiez en mesure de poursuivre ses activités et de tenir ses rôles après votre opération ou thérapie? Sinon, quelles difficultés vous en empêchaient?

Quelles procédures avez-vous entamées après avoir été diagnostiqué? Prostatectomie radicale? Curiethérapie? Attente sous surveillance ou autre?

Quel facteur a influencé votre décision de choisir une procédure spécifique plutôt qu'une autre?

Après avoir reçu un diagnostic de cancer de la prostate, étiez-vous inquiet de la perception que d'autres hommes ou femmes auraient de vous? Si oui, cette inquiétude en lien avec la perception des autres a-t-elle influencé votre décision d'entamer une procédure spécifique plutôt qu'une autre?

Étiez-vous à l'aise de parler du diagnostic et de la procédure avec d'autres hommes ou femmes?

D'autres hommes ont-ils partagé leur expérience du cancer de la prostate avec vous?

Sentez-vous que vous avez été influencé par les histoires et les expériences médiatisées de personnes célèbres? Le cas échéant, de quelle façon avez-vous été influencé?

English Interview Questions

Having had prostate cancer, how would you self-identify? As a prostate cancer “survivor”, “conqueror”, or “victim”?

Which roles and activities were important to you before being diagnosed with prostate cancer?

Do you feel you were able to return to these roles and activities after your surgery or therapy? If not, what difficulties have obstructed you from doing so?

Which procedure did you decide to undertake once diagnosed? Radical prostatectomy, brachytherapy, watchful waiting, or other?

What impacted your decision to choose one procedure over the other?

After your diagnosis with prostate cancer, were you worried about other men’s perception of you? Of women’s? If yes, do you feel that the concern about these perceptions of others influenced your decision to choose one procedure over another?

Did you feel comfortable speaking about your diagnosis and procedure with other men? With women?

Have other men spoken with you about their experience of prostate cancer?

Do you feel you were impacted by the stories and experiences of celebrities made public? If so, in which way?