

**THE CONFLICTS OF DECISION-MAKING FOR LOCALIZED PROSTATE CANCER
(LPC) TREATMENTS**

by

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Prostate cancer is the most commonly diagnosed malignancy among US men. Men diagnosed with LPC, or cancer confined to the organ, are presented with many equally efficacious treatment options, such as radical prostatectomy surgery or radiation treatments, all with specific benefits and side effects. Clinicians often, respecting autonomy in decision making, provide information but do not prescribe therapy, leaving treatment decision-making to patients and families. Understanding these factors and conflicts can help clinicians better guide patient treatment decisions. The aims of this study are to: (1) summarize the specific factors men take into consideration when making the LPC treatment decision, and (2) to identify inherent conflicts of this decision-making process. Methodology included a content, conceptual, secondary data analysis of transcribed interviews from primary study of LPC decision-making.³ Concept categories were established through review of literature. Assessment of interview text using previously established translation rules ascertained factors and conflicts in LPC treatment decision process. These were summarized and corroborated with expert review. For the purpose of this study, factors have been categorized into absolute and relative factors. Analysis reveals that several inherent, multifaceted conflicts persist among these men. The conflicts that surfaced during secondary analysis of 31 individual interviews were thematically categorized

into (1) fear of a reduction in quality of life, (2) time urgency, and (3) lack of trust in the physician. Interestingly, if men have had experiences with traumatic family medical histories, especially non-prostate cancer, they were particularly fearful of cancer spread, and some even expressed inaccurate perceptions about prostate cancer treatments. The most prominent conflict appeared to be a lack of trust in the physician and healthcare system, which is categorized further into four subthemes. Many of these conflicts stem from profound past experiences that may require a more comprehensive assessment by clinicians than what is done in a typical doctor visit. Future studies should focus on discovering realistic, cost-effective methods to address patient conflicts and fears. If clinicians wish to individualize care, knowing men heavily rely on personal factors, they must understand the uniqueness of a man's life experience will undoubtedly influence decision-making.

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1.0 INTRODUCTION

Prostate cancer is the most commonly diagnosed neoplasm in men, comprising 29% of all cancers, and is the second leading cause of cancer related deaths.¹ Based on rates from 2003 to 2005, approximately 16% of men (1 in 6) born today, will be diagnosed with cancer of the prostate at some point during their lifetime. When examined by race, the incidence of prostate cancer among African American men compared to other ethnicities is significantly higher. For Caucasian men, the incidence of prostate cancer is 156.7 per 100,000 men; Hispanic men 138 per 100,000 men; Asian and Pacific Islander men 93.8 per 100,000 men; and American Indian and Alaskan Native men 73.3 per 100,000 men. African American men, however, have an incidence rate of prostate cancer diagnosis remarkably greater at 248.5 per 100,000 men. Furthermore, the death rate of prostate cancer for African American men is twice as high compared to the general population.² Overall however, the incidence of diagnosis and mortality rate for men with prostate cancer has been decreasing since the early 1990s.

The majority of prostate cancer cases diagnosed are localized prostate cancer, or cancer confined to the organ. When reviewing trends among US men from 2001 to 2005, only about 4% of those diagnosed have prostate cancer that has already metastasized. The 5-year survival rates for localized prostate cancer and metastatic prostate cancer is 100% and 31.7%, respectively.²

Prostate cancer, unlike any other neoplasm, has a variety of treatment alternatives. There are no randomized trials to support a greater survival rate of any option. Furthermore, there is no clear consensus among the scientific community as to which treatment option is superior. Each option has potential benefits along with specific unpleasant side effects. Some clinicians provide information but do not prescribe therapy, leaving treatment decision-making to patients and families. For a patient with no prior medical knowledge having just received the devastating diagnosis of cancer, decision-making related to LPC treatment can be a daunting task. The patient has to consider all the factors in his life in order to make the best decision.

Traditionally, prostate cancer has been a disease of older men, over 70 years of age, and thus, these men, with typical life expectancies of less than 15 years, will usually pass away from other comorbidities.³ However, the age of diagnosis is progressively declining due to improvement in prostate cancer detection through the widespread use of prostate specific antigen (PSA) screening.⁴ Today, instead of death from other comorbidities, men with prostate cancer experience the long-term side effects of the LPC treatment option they chose, or will die from the cancer itself, if it is not effectively treated.

Berry³ identifies factors that men may consider when making their treatment decision such as age, health status or the presence of comorbidities, work status, and family and marital status. While knowledge of *factors* men consider is well established,^{5,6} men also may face certain *conflicts* that can make the treatment decision-making process difficult. Conflicts can create fear or apprehension, potentially causing a standstill in the decision-making process. Factors and conflicts that contribute to a decision are very individualized to each man. In some cases, a factor that, without difficulty, contributes to one man's decision may present as a conflict for another man. One example of this may be the consideration of side effects of each

treatment and how it affects a man's quality of life. Some men are certain urinary incontinence is not a desired side effect, causing them to choose radiation therapy. Other men may be unsure which effects they are willing to live with, creating a halt in their decision-making process.

Because factors and conflicts appear to be closely related, this study will address both. The aims of this study are to: (1) summarize the specific factors men take into consideration when making the LPC treatment decision through a review of the literature, and (2) to identify inherent conflicts of this decision-making process through a secondary data analysis of transcribed interviews from a primary study of LPC decision-making.³

Clinicians must become skilled at assisting men in identifying factors to aid them in their decision-making process. Clinician responsibility is equally important in recognizing and resolving the conflicts men face during this process in order to decrease anxiety and increase satisfaction. Studies have shown that when men experience more conflicts, or "factors that contribute to uncertainty", the satisfaction with their treatment decision is lower. Furthermore, if men have low decisional conflict, they were more likely to report a desire for a high level of participation with their physician in making the treatment decision.⁷

Patients' conflicts must be identified, and clinicians must become capable of understanding the individual's factors that contribute to their treatment decision. This may lead to a better individualized treatment plan and, expectantly, with more satisfying results for these men.

2.0 REVIEW OF THE LITERATURE

2.1 PROSTATE CANCER OVERVIEW

Prostate cancer presents as either localized or metastatic. Localized prostate cancer is defined as cancer confined to the organ. When the cancer extends past the borders of the prostate gland, it is labeled metastatic prostate cancer and spread may progress to adjacent structures including the seminal vesicles, the lymph nodes and throughout various anatomical structures, particularly bones. Prostate cancer is staged T1 through T4 which categorizes the cancer into localized or metastatic (Table 2.1). Assessment of the extent of cancer involvement is the best predictor of prognosis, especially when curative treatment is best offered to patients with localized disease.⁸ For the purpose of this study, we will only focus on localized prostate cancer (LPC). Table 2.1 summarizes the cancer stages.

Table 2.1: Cancer stages ⁹

Stage	Description
T1	The tumor is not palpable but identified by needle biopsy
T2	The tumor is palpable but confined to the prostate; may be in one or both lobes
T3	The tumor is palpable and extends beyond the prostate; may involve seminal vesicles
T4	The tumor is palpable and is fixed or invades adjacent structures

The majority of men with prostate cancer have no clinical symptoms; their cancer is typically detected through routine blood testing of prostate specific antigen (PSA) levels, digital rectal exams (DRE) and further recommended biopsies based on those results. However, of those who do experience symptoms, localized disease can cause hematuria or urinary obstruction. Cancer that spreads outside the organ may result in lower extremity edema from regional lymphatic obstruction or pain from bone metastasis. Unpleasant urinary tract symptoms resulting from non-cancerous benign prostatic hyperplasia (BPH) may be similar to those found in prostate cancer and are common in older men. While the presence of BPH creates a rise in PSA levels, it does not increase the risk of developing prostate cancer.¹⁰

Prostate specific antigen (PSA) testing through blood tests is increasingly being used for screening and early detection of prostate cancer in middle-aged to older men. PSA is a protein found in the blood of all men and may be produced by both benign and malignant prostate cancer cells. However, PSA is not cancer specific and small amounts are normally leaked into circulation with usual concentrations less than 4 ng/ml. Increased concentrations of PSA have been associated with certain non-cancer disorders or interventions, including BPH, prostatitis, vigorous massage or exercise, or biopsy of the prostate.^{8, 10} After cancer diagnosis, the PSA level is used to monitor the disease and examine for cancer relapse after treatment.

Digital Rectal Examination (DRE) is routinely done by the trained clinician to assess for indurations or nodules on the prostate. Its accuracy is user dependent and has poor reproducibility even among trained clinicians. Though valuable when the patient's age, family history of prostate cancer and PSA concentration are taken into account, many men with prostate cancer detected by this technique will typically have disease outside the gland at diagnosis. Only about 3-6% of exams produce abnormal results that raise suspicion for cancer.¹⁰

If the results of the PSA test and/or DRE are abnormal, the next stage in diagnosis is a biopsy for tissue samples, usually with ultrasound guidance.⁸ If the samples are found to have cancerous cells, they are graded by the pathologist and are presented to the clinician and patient as a Gleason Score.

The Gleason Score is an estimation of the tumor differentiation determined by comparing biopsy samples to five established histologic patterns. The Gleason Score is the sum of two numbers: (1) the primary grade representing the majority of the tumor (>50%) is scored according to the most common pattern, and (2) the secondary grade representing <50% of the tumor is scored according to the second most common pattern as determined by the pathologist.⁹ An increase in the score signifies an increase in tumor aggressiveness and a poorer prognosis. Although the Gleason Score contributes towards determining pathological extent of the disease, its setbacks include subjectivity, and it requires accurate interpretation by the pathologist.¹¹

While there are many treatment options available for men with LPC, the most common include watchful waiting, radical prostatectomy surgery, external beam radiation therapy, brachytherapy, androgen deprivation therapy, and cryotherapy. Because of the lack of randomized trials, the optimal treatment is not known, and preferred choices and recommendations vary widely. All treatment options carry varying risks of complications and short-term and long-term side effects relating to urinary, bowel and sexual dysfunction. Specific complications associated with each treatment option are discussed below. Individual priorities are a factor in treatment decision. Patients must weigh their values between quantity of life and cancer eradication, with quality of life and the side effects they are or are not willing to live with.¹⁰

Watchful waiting is an active plan to postpone intervention while following the patient regularly by monitoring PSA levels, changes in DRE, repeat biopsies or waiting for symptoms to develop. Later interventions, whether curative or palliative, may be necessary depending on the patient's preference, symptoms and clinical findings.^{8, 10} Older men or men with significant comorbidities, who have a life expectancy less than 10 years, with low PSA and Gleason Score, may tend to choose watchful waiting. Because of the relatively indolent nature of prostate cancer, this is done to avoid side effects or a decrease in quality of life caused by treatment, with the expectation that the prostate cancer may not cause morbidity during their lifetime.¹²

The surgical intervention, radical prostatectomy, involves removing the prostate, seminal vesicles, ampulla of vas, and possibly some pelvic lymph nodes, usually through a lower abdominal incision or through the perineum.^{8, 10} This surgery can be done laparoscopically or with robotic assistance, and attempts to preserve nerves for erectile function. Advantageous characteristics of radical prostatectomy include the possibility of complete elimination of the cancer, providing it is localized, and it is generally well tolerated. However, urinary, bowel, and sexual dysfunction are side effects most strongly associated with this procedure. Long term urinary incontinence, urethral stricture, bladder neck contracture, and bowel and erectile dysfunction are all associated with radical prostatectomy and may significantly decrease a man's quality of life.¹⁰

With External Beam Radiation Therapy (EBRT), multiple doses of radiation from an external source are applied to the prostate over several weeks. Potential benefits include possibly eliminating the cancer without exposing the patient to operative risks, such as bleeding, adverse affects from anesthesia, and death. Conversely, it does not remove the gland and is not guaranteed to cure the disease. EBRT requires 5 to 8 weeks of daily outpatient therapy. Side

effects associated with EBRT include treatment related death, incontinence, proctitis, diarrhea, cystitis, erectile dysfunction, urethral stricture, bladder neck contracture, and bleeding. EBRT is also contraindicated for those with inflammatory bowel disease because of the risk of bowel injury.¹⁰

Brachytherapy includes the permanent implantation of approximately 80 to 120 radioactive seeds into the prostate gland. This procedure may eliminate the cancer, avoids the operative risk, and is done in a single, outpatient session. However, it does not remove the prostate gland and its side effects include urinary retention, incontinence, impotence, cystitis or urethritis, and proctitis. This is contraindicated in men with prior transurethral resection of the prostate (TURP).¹⁰ Though brachytherapy is becoming a more popular treatment for LPC, there are yet to be any long-term randomized clinical trials comparing brachytherapy to radical prostatectomy.

The androgen, testosterone, in men has been known to be a contributing cause of prostate cancer. Androgen deprivation therapy, through oral or injected drugs (eg. Finasteride) or through surgical removal of the testicles, can be used to lower or block circulating androgens. Its potential benefits include avoiding the risk of prostatectomy or radiation therapy and it usually lowers PSA levels by slowing cancer progression. The primary risk factors associated with this therapy is it does not remove the cancer. Furthermore, androgen therapy may cause gynecomastia, impotence, diarrhea, osteoporosis, lost libido, hot flashes and “androgen deprivation syndrome”, which includes symptoms of depression, memory difficulties, and fatigue.¹⁰

Cryotherapy includes destruction of the cancerous cells through rapid freezing and thawing using transrectal guided placement of probes, and the injection of freezing and thawing

gases. Its benefits include possible elimination of the cancer, and it is completed in a single outpatient session. Risks include incomplete eradication of the cancer because the gland was not removed, and side effects include impotence, incontinence, scrotal edema, pelvic pain, sloughed urethral tissue, prostatic abscess, and urethrorectal fistula.¹⁰

2.2 DECISION-MAKING METHODS

Before examining the specific factors men take into consideration for decision-making, it is worthy to consider the methods men use to make their decision. A study by Steginga and colleagues describe non-systematic and systematic processes used by men when progressing through LPC treatment decision-making.¹³ Non-systematic processing is explained through heuristics, or an informal method of decision-making using a set of rules, particularly used to quickly come to a solution that is reasonably close to the best possible option. Behaviors using the heuristic model include deferral of decision-making responsibility to the doctor, previous experience and memories, and lay beliefs about cancer treatment and causes. Systematic processing is defined as the consideration of medical information, such as treatment side-effects, and the significance of clinical aspects of their cancer (stage and grade) when making a treatment decision.¹³ It is assumed that systematic processing is superior to non-systematic processing, and its use by patients is preferred by most clinicians. However, an astounding 91% of men in the study conducted by Steginga and colleagues reported using non-systematic processes in their decision making.¹³ In most qualitative studies addressing factors in LPC treatment decision-making, the research participants were all approached with similar statements or questions. Participants were usually asked to describe their treatment decision-making process, what factors

they had considered, and how they chose their treatment. Also, men were asked what aspects had been helpful or unhelpful in making their decision, and concerns that surfaced.^{3, 13, 14}

2.3 FACTORS

Analysis of the medical literature reveals a myriad of individualized factors that influence treatment decision-making in men with prostate cancer. A study by Berry and colleagues at the University of Seattle titled, “Treatment decision-making by men with localized prostate cancer: the influence of personal factors,” specifically studied such global factors.³ The purpose of Berry’s study was to “systematically document meaningful and relevant aspects of treatment decision-making reported by men with localized prostate cancer.”³ The study results, presented in greater depth in Section 5: Discussion, concluded with several themes and aspects describing men’s decision making experience, including nine personal factors, the influential other, and a core process of “making the best choice for me.” Personal factors identified were age; what I do; priorities; health status; personality; lifestyle; experiences; philosophy; and ethnicity.³

In order to define the process of decision making in further detail, this study includes the consideration of treatment decision factors. These factors are defined as something the decision-maker takes into consideration that contributes to or has an influence on the treatment decision. Certain factors can be helpful in making the treatment decision, while other factors can create conflicts and barriers for the individual. Conflicts are defined as a state of uncertainty or distress, thus, impeding the decision-making process unless a resolution or compromise is made in a timely manner. These can result from fear of negative outcomes or incompatibility of needs and desires. Even so, conflicts are not uniformly barriers. For example, the possibility of

impotence may be a barrier to decision-making for a man who is sexually active, but not necessarily so for men who are not.

In order to better characterize these unique and personal factors, they were categorized into *absolute factors* and *relative factors* (Figure 2.1). Absolute factors that affect decision-making are present at the time of diagnosis and are essentially fixed throughout the course of the decision-making process. These factors include (1) demographics, (2) LPC disease characteristics, and (3) current health status. Relative factors, however, occur and affect decision-making after the LPC diagnosis has been presented to the patient. These factors are grouped into (1) information they obtain, seek, and value, and (2) consideration of quality of life versus cancer eradication.

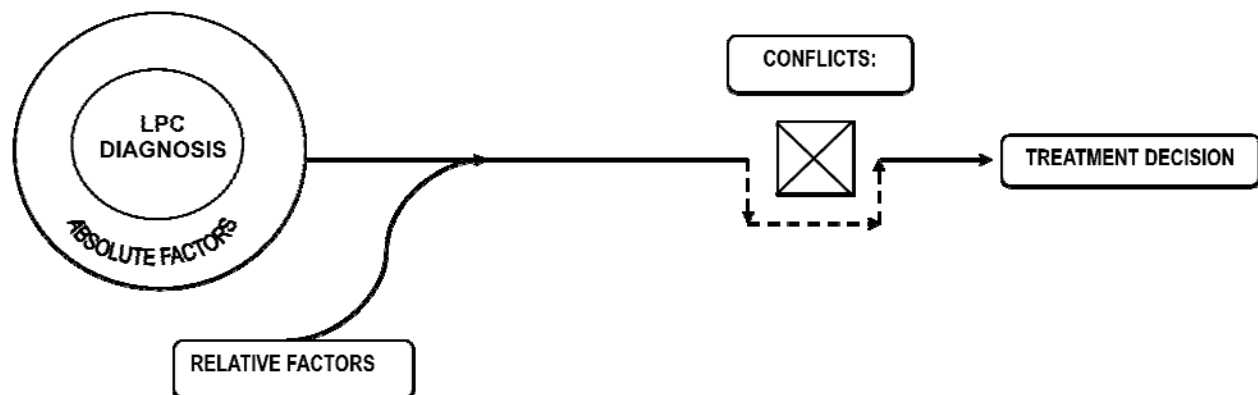


Figure 2.1: The decision-making process. The patient, represented by the inner sphere, considers individualized absolute and relative factors when making a treatment decision. These factors may create conflict requiring resolution before a treatment decision can be made.

2.3.1 Absolute Factors

An absolute factor existing at the time of diagnosis is the demographic characteristics of a man, which play an important role in treatment decision-making. Characteristics found in literature that appear to have the largest role are age and life expectancy, ethnicity, work status, family status, and marital status. In some cases, a man's demographic standing may change (i.e. change of employment status, death of a spouse, etc.), but for most, demographics are essentially fixed for the course of the decision-making process.

Age and life expectancy are factors largely used by clinicians in LPC treatment recommendations. A patient is expected to live an additional ten to fifteen years if he is perceived as "young" and/or presents with few to no comorbidities. In this case, physicians typically recommend aggressively treating the LPC with surgical or radiation options. However, if the patient is not expected to live past ten years, physicians usually recommend watchful waiting anticipating the patient will pass away from unrelated diseases, and would rather the patient not experience decreased quality of life from LPC treatment side effects.¹⁵

Conversely, longevity has been steadily increasing, and some researchers have theorized that "perceptions about age may inadvertently result in 'undertreatment' of elderly oncology patients."¹⁵ How a patient factors age into their treatment decision is not always consistent with clinicians. Furthermore, personal preferences vary widely when considering a patient's family and marital status, which appears to play a large role in treatment decisions. For men forty to fifty years of age, the value of quality of life usually supersedes the possibility of extending life, especially if they have a spouse and value sexual function. The opposite appears to be true for individuals over fifty years of age, who are concerned about longevity, primarily if they have young children that require a decade or more of parental support. However, when older men

have fulfilled life goals, such as familial responsibilities of raising children, they tend to focus again on quality of life, particularly if their spouse is still living.¹⁶

Another demographic characteristic, ethnicity, is largely lacking in LPC research, but may be an absolute factor considered in decision-making. African Americans are statistically shown to present more often with prostate cancer, have more aggressive disease, and have higher mortality rates than their Caucasian counterparts. Despite this information, this group seemingly receives less aggressive therapy. A study by Demark-Wahnefried and colleagues found that treatment options discussed by physicians vary by patient race, with African Americans being presented with fewer options.¹⁷ Furthermore, how African American men factor ethnicity into treatment decision is not well documented. African Americans who do participate in trials concerning decision-making factors show they follow similar decision-making processes as other men, usually viewing age as a stronger factor than ethnicity.¹⁶

Spouses frequently take initiative in seeking out additional information for the patient. Although their goals for therapy are similar to the patient's, their preferences may be slightly different. The significance of quality of life and side effects appear to be minimal for spouses, especially the importance of sexual function. Spouses tend to value the total eradication of cancer as most imperative, which may be inconsistent with what the patient considers most important.⁶ Some studies have shown patients report feeling considerable pressure from their family members to aggressively treat their cancer.^{14, 18} However, the degree to which spouses influence the final treatment decision is unclear.

Disease characteristics, such as the LPC tumor stage, grade, and PSA levels are of utmost consideration by the clinician when recommending a treatment decision. Clinical characteristics are not as greatly considered by the patients as compared to other personal factors. This may be

due to a poor understanding of medical terminology or biology. However, some patients do factor this information into their treatment decision. The clinical characteristics of prostate cancer considered to be most important by men with prostate cancer in making a treatment decision include the stage of their cancer (59%) and the low overall mortality rate associated with prostate cancer (45%). Of slightly lower incidence is the consideration of prostate grade (Gleason score) (20%) and PSA level (21%) in their decision-making.¹³

The presence of significant comorbidities is important to clinicians to determine the life expectancy of a patient with LPC. The most common comorbidities considered tend to be hypertension, arthritis and musculoskeletal conditions, heart disease, urinary conditions and gastrointestinal disease. In a study by Marr and colleagues, men with comorbidities tended to be “older, single and overweight, have lower incomes and less education, and be on Medicare or other non-private insurance than those without comorbid illness.”¹⁹ They discovered patients who had zero to two comorbidities were most commonly treated with radical prostatectomy. In patients with three or more comorbidities, surgery was much less common. At six or more comorbidities, hormonal therapy and watchful waiting comprised almost half of the treatment plans. This trend of treatment recommendations made by clinicians most likely results from the desire for good surgical candidates. A history of stroke or heart disease is associated with significant perioperative risk due to decreased functionality of major organs. These two groups in particular may be poor candidates for any surgery.¹⁹ Interestingly, however, a patient’s perception about their comorbidities may give them less apprehension about choosing the surgical option. In a study by Berry and colleagues, men who have gone through surgery in their past, particularly major surgical procedures such as heart surgery, are much more willing to go through with surgery and have less anxiety than those who have never had major surgery.³

Those who have few to no comorbidities tend to have more apprehension about surgery and tend to choose “less aggressive” treatments, such as brachytherapy.³

2.3.2 Relative Factors

Men strongly consider the absolute factors already present at the time of their LPC diagnosis, such as demographics, disease characteristics and health status. Relative factors, however, occur *after* the LPC diagnosis has been presented to the patient. These factors can be particularly influential if they occur during a vulnerable period before a definitive treatment decision has been made. Relative factors may contribute to the decision, or may impede the process by becoming a conflict and causing distress. These factors are categorized into (1) the information men obtain, seek, and value, and (2) men’s consideration of quality of life versus cancer eradication.

Many studies report high rates of information-seeking behavior about prostate cancer after their diagnosis. Although men may report needing a great deal of information, the extent to which patients comprehensively or systematically process this information is limited.¹³ Information sources, other than a physician, are most commonly sought from the following: the internet; non-medical persons, particularly friends and family; published written material; the media and celebrities; and anecdotes from others with cancer, whether prostate or non-prostate in nature.¹³

Many men and their significant others actively collect as much information about the disease and its treatment options as possible. Men often seek others who have prostate cancer to, first, determine how they decided on a treatment option, and, second, review the consequences of that decision. In Berry’s study, 41 of 44 participants described hearing about or speaking with

other men who had prostate cancer. This person is described as the influential other, or “an individual whose illness experience and/or story had explicit influence on the participant’s treatment decision.”³ Men describe influential others as people who have similar demographic characteristics, primarily age or disease characteristics.

Patients who reported seeking out others with prostate cancer asked about that person’s individual experience and relate it to their own. Often the people they spoke to had prostate cancers with very different clinical characteristics, such as advanced disease compared to their own localized disease. Denberg and colleagues states “anecdotes exerted strong sway over patients’ feelings about their own prostate cancer, treatment preferences...primarily because patients viewed prostate cancer as a uniform entity, unaware of differences in prognosis based on tumor stage and grade.”²⁰ For some, hearing anecdotes supported or justified their already chosen decision to have a particular treatment option. Patients valued others’ experiences much more than reported population-based risk information.²⁰

In the study by Steginga and colleagues, 47% of men described their treatment based on others’ experience with cancer, whether positive or negative. Often these examples were of people who had other cancers, such as breast cancer, where its clinical relevance compared to prostate cancer is low. Through these examples, men exposed an inaccurate understanding of various cancer treatments, particularly chemotherapy and radiation therapy. These men described unpleasant experiences of people they knew, who did not have prostate cancer, as a reason for having excluded radiation therapy.¹³ Another reason for patients ruling out radiation as a therapeutic option is the presence of inaccurate perceptions which arose before LPC diagnosis. Examples of these perceptions were radiation would cause severe skin damage; it would cause other cancers; it would limit further options if it were to fail; and it was uncertain

compared to surgery which was more often associated with cure. Patients' desires to avoid such side effects were produced from stories of radiation used in non-prostate cancers, or in other non-health related uses, such as its use of death and destruction in World War II.⁵

Apart from these information sources, some of questionable validity, men still do place high value on the information provide by his urologist. Interestingly, perceptions arise that clinicians who specialize in the treatment of prostate cancer, primarily urologist and radiation oncologist, are biased to their specialties and will more likely recommend a treatment in their specialty. A study by Fowler and colleagues support this theory and concluded, "while urologists and radiation oncologists do agree on a variety of issues regarding detection and treatment of prostate cancer, specialists overwhelmingly recommend the therapy that they themselves deliver."²¹ More significant is the extent in which patients use physicians' recommendations when making their treatment decision. Most clinicians treating patients with prostate cancer will make recommendations, but will leave the ultimate decision to the patient. Studies report that most men (96.2%) report their primary urologist is a *source* of information for decision-making.²² 64.9% of patients recognized their urologist as a major influencing factor, but very few men indicate that their choice of treatment was based *primarily* on their physicians' preference (6.1%).²²

Relative factors that present during the decision-making process largely consist of prioritizing quality of life and quantity of life. Clearly, patients with cancer desire a treatment option that offers cancer eradication with a low side-effect profile. However, because there remains a lack of consensus among medical professionals as to which treatment option is superior, men often must prioritize which of the two is most important, cancer eradication or quality of life. It is still uncertain how these men balance the trade-offs of survival benefit of a

treatment with its morbidity. As discussed previously, men and their families report spending a considerable amount of time researching the efficacy of each treatment option using a multitude of resources.⁶ A study by Hall and colleagues reported that 64.5% of men indicated they chose a treatment on the basis of evidence that it was the best option to cure their cancer, while 24.8% of men selected a treatment with the best-side effect profile.²² On the other hand, Zeliadt and colleagues completed a database search of decision making in LPC which produced sixty-nine related articles.⁶ This review summarized that cancer eradication remains the patients' primary concern in treatment decision. However, there is a wide variation in the statistic of men that rank this as their top priority factor. Some studies report that only 26% of patients selected treatment on the basis of evidence that it was the best procedure to cure their cancer, whereas other studies report the number of patients who value this as high as 98% of prostatectomy patients and 50% of brachytherapy patients.⁶ This shows there is considerable deviation in how men interpret information available about cancer control efficacy. Other studies have found that men with perceived "good general health" appeared to place a higher value on quantity of life, whereas those already suffering from "poor general health" placed a higher value on quality of life.²³ Generally speaking, it is clear cancer eradication is an important issue for nearly all men.

Equally important for many men is how treatment may impact their quality of life through possible side effects – the primary effects including impotence, bowel incontinence, urinary incontinence, and urinary retention. Studied extensively, reports indicate that more than 800 articles are available in literature concerning prostate cancer treatments and quality of life. Preferences are extremely individualized and the reported results of these preferences also vary widely. Incontinence appears to have great influence on treatment decision in over half of prostate cases; impotence is typically less important, with fewer than 20% of men reporting it as

their top three attributes important to their decision.⁶ Other studies have found that the preservation of sexual function was more important among younger individuals below sixty years-old compared to those over seventy-five years-old. Again, information is limited regarding how the methods men use to balance side effects when making their treatment decision.⁶

2.4 SUMMARY

The majority of men diagnosed with LPC have no clinical symptoms and their cancer is detected and diagnosed with blood PSA levels, DRE and biopsy. Their cancer is then typically graded and categorized into a Gleason score and tumor stage. A variety of treatment options are then presented to the patient, the most common including radical prostatectomy, brachytherapy, external beam radiation therapy, watchful waiting, androgen deprivation therapy and cryotherapy. There is no clear consensus among clinicians as to which treatment option is superior, and, because recommendations vary widely, men must make their decision in a setting of uncertainty. A man's ability to process clinical information, such as disease characteristics, may be limited, and more often men begin to consider individual personal factors relevant to their life.

A search of medical literature reveals a multitude of personal factors considered by men when making treatment decisions about early stage prostate cancer treatments. Improved understanding of decision-making can be guided by further categorizing treatment decision making into absolute factors and relative factors. Absolute factors are present at the time of diagnosis, and include demographics, LPC disease characteristics, and current health status. Relative factors occur after LPC diagnosis, and include the information men seek, and the

consideration of quality of life versus cancer eradication. Both absolute and relative factors hold the potential for creating conflict in the decision-making process. The factors that may present as conflicts are unique to each man. Understanding, not only factors, but the absolute and relative factors that create conflict in treatment decision-making will help clinicians to better assist men with these difficult decisions.

3.0 METHODS OF DATA COLLECTION

This study is a secondary analysis of data from thirty-one individual interviews collected by Donna L. Berry, PhD, RN and her research team at the University of Seattle (PRO08050045). The original study article, “Treatment decision-making by men with localized prostate cancer: the influence of personal factors,” contains methods of data collection and demographic information about all study participants.³ The research done by Berry also includes transcripts from five focus groups; however, that data is not included in this secondary analysis study which is focused only on the individual interviews.

The overarching purpose was to better understand conflicts that may be inherent in the decision making process among men with localized prostate cancer.

The specific aims include:

- 1) Delineate absolute and relative factors inherent in the treatment decision making for early stage prostate cancer.
- 2) Identify conflicts in the absolute and relative factors inherent in the treatment decision making process for early stage prostate cancer.

Institutional Review Board (IRB) approval was obtained under exempt status from the University of Pittsburgh to conduct this secondary data analysis study (IRB # PRO08050045). All thirty-one transcripts were extensively reviewed and highlighted. Relevant factors that created conflicts were noted in each interview. Analysis data, along with exemplar quotes, were

organized into tables by the author and a second expert reviewer experienced in qualitative data analysis. Thematic categorization was performed and final results were corroborated by expert review.

4.0 RESULTS

The sample used in this study comprised of thirty-one men. Demographic information for these participants is summarized in Table 1 of the original study article by Berry and colleagues (Note: Table 1 also includes demographic data from focus group participants not included in this secondary analysis study).³ The absolute and relative factors previously described in literature are clearly prominent in these interviews. The conflicts that persisted among these transcripts as a result of various absolute and relative factors demonstrated how certain experiences impeded the man's decision-making process. For some men, the presence of conflicts created distress and difficulty in choosing a treatment option. For others, their treatment decision was made without these complex dilemmas. Themes of conflict among the thirty-one interviews were (1) a fear of a reduction in quality of life, (2) time urgency, and (3) a lack of trust in the physician.

4.1 FEAR OF REDUCTION IN QUALITY OF LIFE

A fear of a reduction in quality of life is a relative factor that becomes a conflict after diagnosis has been made (Figure 4.1). Men are exposed to mass amounts of information about treatment options and their associated benefits and side effects. Some may have difficulty sorting through this overload of knowledge, and some become apprehensive about the prospect of choosing what side effects were the least disagreeable for their case.

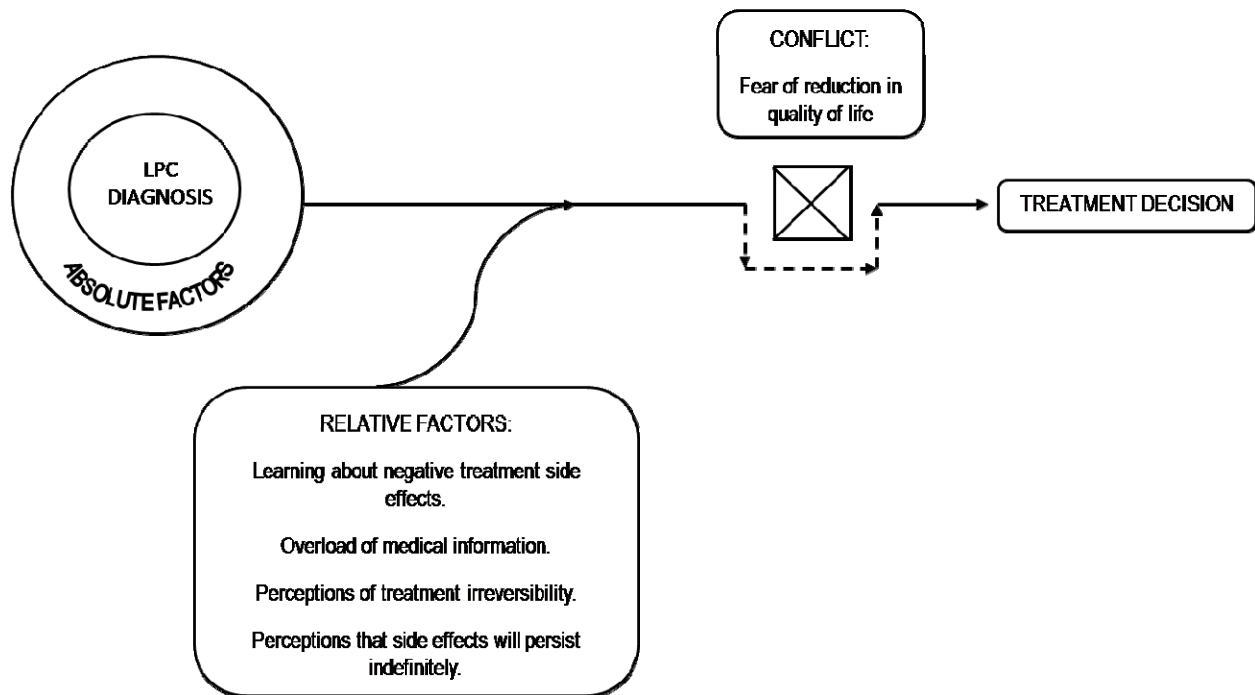


Figure 4.1: A fear of reduction in quality of life (QOL). Several examples of relative factors men experience are illustrated; these can lead to the conflict of a fear of reduction in QOL.

The primary reason men feared a reduction in quality of life was twofold. Although evidence is strong that not all treatments result in side effects, men still feared they would definitely obtain these effects. Others were under an assumption that once side effects were obtained, they would persist indefinitely. Even if men personally knew others who had suffered from side effects for a small amount of time after treatment, they assumed this would not be the case for them. One respondent articulated these concerns in the following way:

Incontinence, impotence, pain, possible damage to the rectum and bladder from radiation, and they seemed to be associated with just about any course except watchful waiting...so I was still pretty much up in the air, and I was finding that none of the procedures were absolutely free of possible undesired and long term impacts afterwards.

Another man stated,

I feel with these different types of options then the most thing that was foremost in my mind was quality of life...if I was old, that wouldn't be as big a factor, but at my age I don't want to be going through a lot of changes for a long time, because, you know, I expect to live a long time...[urinary incontinence is] the thing that is really bad in my mind, you know, not having control...and I associate that with somebody that's really ancient.

Furthermore, those who valued a greater quality of life rather than quantity of life appeared to struggle more about which treatment option to choose. Conversely, men who valued quantity of life and survival over quality of life appeared to be more confident in their decision-making and less conflicted. Individuals may be initially conflicted in which they value more between quality or quantity of life. Once men made a decision that quantity of life and survival is of utmost importance, they directed their focus more on the eradication of cancer and less on treatment side effects. Justification of a particular treatment option is accepted by some patients provided it offers the highest chance of cure.

With the thought that maybe I can cure it with surgery, then that took precedence. So, getting all the cancer cells is important – more important to me know then getting...preserving sex – sex life.

There was also conflict related to quality of life from a perception that “once you decide, there is no turning back.” One man described struggling with a commitment to therapy because of his perception of irreversibility of treatment.

When you read and see TV, there's a breakthrough everyday on something. I'd hate to feel like I jumped into it and then a couple months down the road they say, “you know, all we have to do is a little laser deal and then it's gone.” And then I say, had I only waited a couple more months...There's no reverse, you know, if I go through the treatment and for some reason my quality of life is shot, it's shot forever.

4.2 TIME URGENCY

The sense of time urgency from these men primarily stemmed from experiences of family past medical histories, the fear of cancer spread, and age. Past experiences and age are absolute factors present at the time of diagnosis, but has become a conflict during the decision-making process (Figure 4.2).

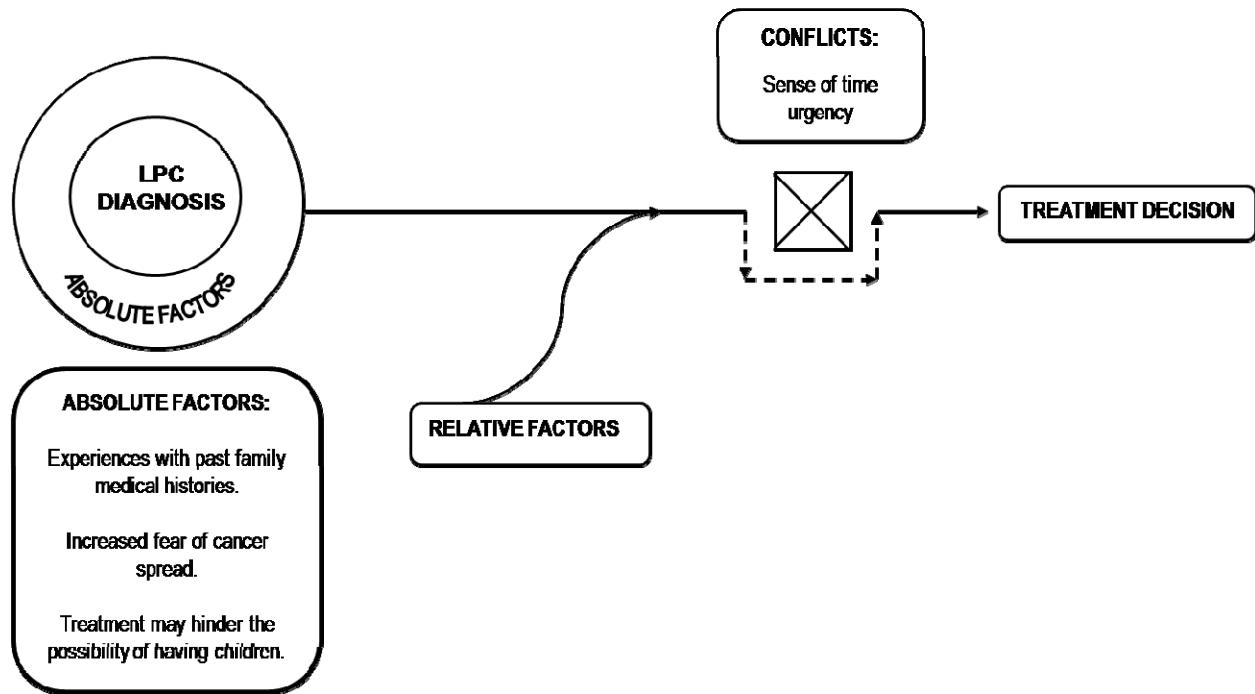


Figure 4.2: Time urgency. Several examples of absolute factors men experience are illustrated; these can lead to the conflict of a sense of time urgency.

Delving into these specific issues showed that these men were emotionally distraught, anxious and conflicted when applying family cancer experiences to their own. In several cases, men had made treatment decisions influenced by experiences with family members who had suffered through illness. Interestingly, the primary illnesses that would arise in stories from men

were of family with non-prostate cancers. Men discussed treatments that created horrible, painful experiences for their family members, and used that as one reason for not choosing a certain treatment option, even if the two experiences were completely unrelated. They were not able to disassociate prostate cancer from other cancer types.

My mother died of lung cancer...My nephew, he was 17, he had bone cancer of his leg, it metastasized to his lungs, and he lived about a year...Anyway, watchful waiting was not an option in my case.

Patients who suffered through an experience with family members who had non-prostate cancers compared their two experiences closely, even if the only common denominator of the two cases was the word “cancer”. Prostate cancer is typically understood to be a “slow-growing” cancer relative to other cancers, which is a clinical characteristic emphasized to patients by most urologists. Men with early stage prostate cancers are usually allowed months before a treatment decision must be made. However, when men had experiences of family members with non-prostate cancers, men felt they had to make a decision immediately, perhaps to ease their apprehension and fear of metastasis or death.

My daughter had pancreatic cancer...when she was diagnosed, she was given six months. And it was about six months, that was about it...I think in this case there might have been an element of, “you better do something about this because look at [my daughter] and what happened to her.”

In some cases, the anxiety related to decision-making created a conflict for that particular individual. Anxiety from these experiences immobilized people without proper guidance and support from others, particularly clinicians. One man described the source of conflicts in his experience, and how anxiety created a halt in his decision-making process.

My mother-in-law died from cancer...I was there when she died...terror is the right word, that’s what the hell it is. Because you have to deal with, “what are you letting go of? What are you frightened of? Is it physical pain, is it letting go? Is it you don’t get to do some of the things you think you need to do?” So there was a lot of anxiety there, that kind of thing. When I was finally diagnosed, I think I was running on adrenaline for probably about two weeks or a month...I think there was some denial. I think I just went away somewhere even though it was obvious something was, you know, serious business, you know, you have to make some goddamn decision.

Altogether, it appears that some men cannot disconnect LPC from other cancer types, and become especially conflicted if they had experiences with traumatic past family medical histories. The anxiety of decision-making and a feeling of limited time “before something bad happens” created enormous amounts of conflict for these men. They felt they must seek treatment immediately, or they may result in the same fate as their family members.

Similarly, there was a time urgency to make a decision quickly because of the fear of cancer spread unrelated to past experiences with cancer.

And going through the three to six months of hormone therapy...I began to be a little concerned about the spread of cancer...and most of what I had originally read did not talk about fast growing prostate cancer. In fact, I was told quite often that I would probably die of something other than prostate cancer, before prostate cancer would become symptomatic. What I had began to find was that people did die of prostate cancer, and that it did metastasize, and that it could be faster acting than what I had been given to understand before.

If men felt they were choosing the best possible treatment option to eradicate their cancer, they had a feeling of hope. This seemed to alleviate some anxiety related to time urgency.

I had hoped that if all the cancer were removed with the prostate, that I could rest more easy that there wouldn't be any more cancer. I understand that's not necessarily a guarantee...But it at least was maybe something I could hope for.

Previous discussion of time urgency stemmed from a feeling of anxiety because the man must quickly make a decision for fear of ill fate. Other forms of time urgency include a hesitancy to make a decision because of age and desires for family. As discussed earlier, age is typically a strong factor in decision-making taken into high consideration by both patients and clinicians. The consideration of age, in most cases, does not impede decision making. A man's perception of how “young” or “old” he is and his stage in life, related to family, are clear guides to which treatment options are best for that individual. When a man is still considering the possibility of having children in his future, there created hesitancy in decision-making.

One forty-six year-old man discusses a variation of time urgency from age and his desire for a family:

I think another thing that's really holding me up is that I don't have any children even though I know I'm old, but there's a chance that I could have children...And so, you know, that kind of weighed heavily on me. I think if I had kids, then that would change my decision, too.

4.3 LACK OF TRUST IN THE PHYSICIAN

Another overarching theme that caused conflict in decision making appears to be a lack of trust in the physician, primarily the urologist overseeing the patient's case. If the physician is viewed as a source of information, they are a relative factor in decision-making. On the other hand, it is a patient's past experience with healthcare as an absolute factor that is creating conflict (Figure 4.3). Four subthemes developed including (1) skepticism stemming from past negative experiences with healthcare, (2) a belief that physicians are biased to their specialties, and are not necessarily making the best choice for that man's individualized case, (3) a struggle between following the physician's advice versus following the man's intuition, and (4) a divide between the physician and the patient because of race and socioeconomic status.

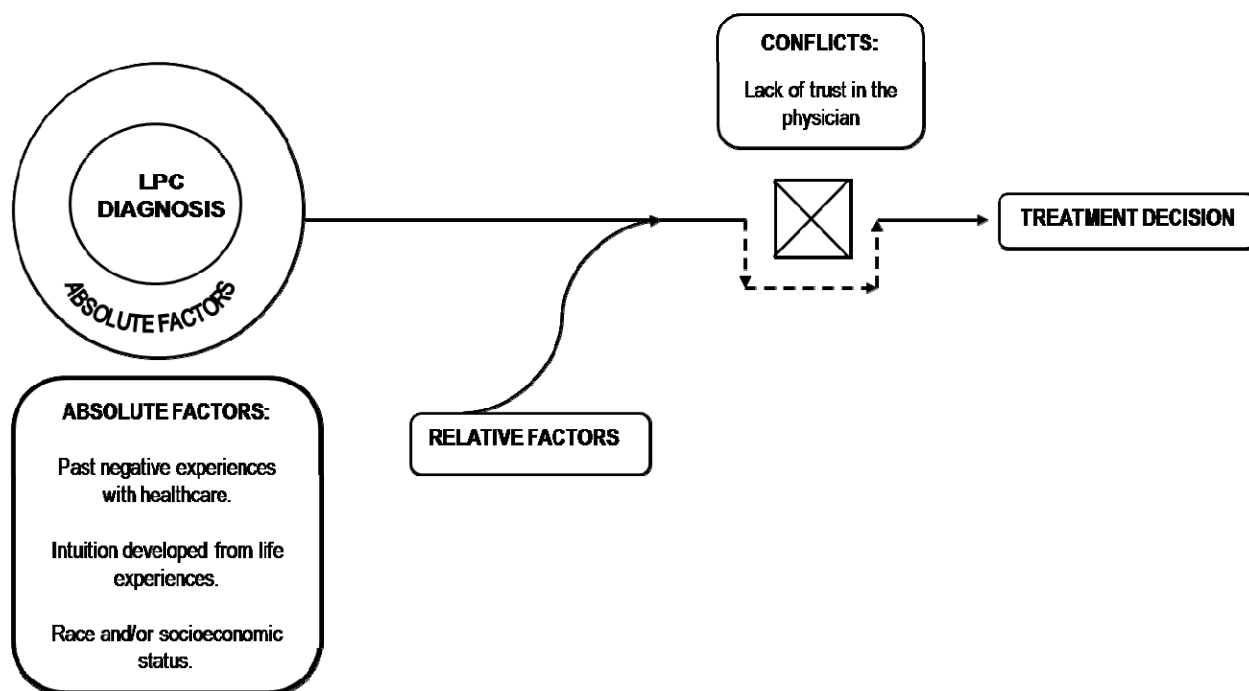


Figure 4.3: Lack of trust in the physician. Several examples of absolute factors men experience are illustrated; these can lead to the conflict of a lack of trust in the physician.

Some men became skeptical of clinicians, possibly due to past negative experiences with healthcare, and were conflicted as to whether or not they should follow the physician's treatment advice. One patient discussed two past experiences where he had a condition that the initial physician advised operation, but after a second opinion, the condition was resolved from noninvasive procedures.

Patient: I'm very skeptical.

Interviewer: You saw there was an alternative to surgery and it worked, so you had a good experience with the alternative.

Patient: Yeah...My greatest fear is that something...would be removed unnecessarily...but a surgeon will, you know, at the slightest hint of infection he'll remove it.

Other men were skeptical of physicians because they simply lacked trust in the physician's judgment.

And then the more I was thinking about it, I want a second opinion too because I, I just wasn't sure, my PSA was within that normal range, and I thought well maybe he's just awfully anxious or eager.

Skepticism may also have stemmed from a lack of faith in the healthcare system because they may have had family members with conditions whose treatment was unsuccessful.

I asked [Dr. 2] some questions of him like what was his batting average...because of what I watched with my family, and I'm the last [of them alive], I was a little bit concerned. And I never really could get much out of him except he was a surgeon and he explained to me that there were about six or seven different ways of handling prostate cancer, and however we understand he was a surgeon...That meant that he wanted to remove my prostate.

Another concern was a perception that physicians were biased to their specialties and are not necessarily making the best choice for that man's individualized case. As shown in the original results of Berry's research, she demonstrated that men often want the "best choice for me (2002)." This theme also presents conflict for these men because if they felt that physicians were not personalizing their care to each case, they may not have been receiving the best possible treatment.

And in the course of this internet stuff, of course I read that somebody had done a survey on urologists, most all of whom are surgeons, and 92% of them say that radical prostatectomy is the only way to go, and 75 to 76% of [radiologists] say that radiation is the only way to go.

Another man stated,

I think I kind of drew the conclusion that urologists want to cut, radiologists want to seed implant, and cryogenicists want to freeze.

One man discussed that when the physician made a treatment recommendation other than his or her specialty, such as a urologist specializing in surgery who recommended radiation, that the physician was more trustworthy.

I fully expected [this urologist] to say well, prostatectomy is the way to go, and he didn't, and so, you know, it's like bringing your car to a mechanic and [the mechanic] saying well, all you really needed was to have this wire attached here, it doesn't cost you anything, you know, in incontinence, when somebody goes contrary to the stereotype of a mechanic who's going to say well you need a \$500 part here. So that put some credibility into what [the urologist] was saying.

Furthermore, if the credibility of that physician was verified through some means, such as a physician's reputation verified by other healthcare workers, the patient was more trusting of advice given to him.

[The first] urologist bet me \$2000 I did not have prostate cancer...A few months later [my] biopsy was positive. The urologist could never remember my name, read through my chart, mumbling, "That's not good." After the urologist introduced treatment options, I told him the first decision I'm going to make is never come back here again...My wife is a nurse and checked out different doctors and UW, and we decided on the [second urologist] because when she said his name to the OR nurses they smiled and when she said the [first] surgeon's name they looked weird and didn't smile.

Some men struggled between following the physician's advice versus following their own intuition.

I have over my life developed maybe a modified sense of being able to know what decisions to make based on, a sort of modified clairvoyance or whatever...I talked with [my second urologist] initially, and he was for the prostatectomy. And I agreed at the time that he and I talked, but on the way back home I thought now, this is not right, this isn't right, it's not for me.

One African American man discussed a divide between the physician and the patient because of race and socioeconomic status. How this affected decision-making is unknown, but it does suggest the patient may be more skeptical of the physicians advice, and may have believed the physician was insensitive to the needs of certain populations.

Some of the side effects were loss of sexual function...he talked about devices and stuff like that. I worked as a third party insurance administrator, and I know that they don't cover half that stuff. All this stuff, good stuff that he's talking about, that we can do this and we can do that – all that stuff costs money...And to me that was, it's kind of unfair to tell people, to give people hope for something they can't ever afford that insurance will not cover...I don't think that that many people, especially African Americans, because they tend to be, you know, less financially stable, can take advantage of that...to even suggest that, it's totally unfair...I think it's more crushing at that point...I think to suggest that is a total disservice.

He continued to state,

I'm sure [the urologist] gives the same spiel to most of the patients...it's not good, it's not really a viable option for most individuals. Especially if you're talking about the African American community. If you get them in there, I don't think that you should feed them that type of information without giving them the whole story. I mean, it's just not fair to me.

5.0 DISCUSSION

5.1 PRIMARY STUDY

The original study done by Berry and colleagues aimed to, “systematically document meaningful and relevant aspects of treatment decision-making reported by men with localized prostate cancer.”³ While the original study focused on describing global factors, the purpose of this secondary analysis study was to more deeply evaluate research within these factors to describe the conflicts men undertake when making a treatment decision. A separate study by Berry of treatment decision-making categorized themes of uncertainty to include: whether the respondent understood the options, the pros and cons of each option, the relative importance of the issues for his particular situation, and support/advice from others. When more factors contributed towards uncertainty, patients had lower post decision-making satisfaction.⁷ Additionally, when men were assisted in retrieving more information they assumed a more active role and had lower levels of anxiety.²⁴ Conflicts also appear to result from fear. In the study by Steginga and colleagues, men described several fears which possibly conflicted with their decision-making progress. Such fears included fear of the cancer spreading (37%), uncertainty about the probabilities of obtaining a cure (43%), uncertainty about the probabilities of side-effects (27%), uncertainty about the best treatment choice (25%), and fear of making a decision they would later regret (18%).¹³

Classification of nine personal factors are presented by Berry and colleagues, along with definitions and exemplar quotes, which include age, what I do, priorities, health status, personality, lifestyle, experiences, philosophy, and ethnicity.³ A core process of making “the best choice for me” was highlighted by the authors as the process when men take all information available, and individualizing the treatment decision to his case. This process most likely develops in the majority of illnesses when the nature of uncertainty in a gold-standard treatment presents more patient autonomy in decision-making. Also described is the aspect of an “influential other” illustrated by 43 of their 44 participants. This influential other could be the physician, or other lay individuals such as friends, business associates, family members and celebrities, and their experiences or stories had influence on their treatment decision. Men relied on these people to “widen their horizon, or move toward or away from a specific treatment modality.”³

5.2 SECONDARY STUDY

In this secondary analysis study, the influential other is a dynamic factor in decision-making, but hardly presents as a conflict. Many men described seeking out others who had prostate cancer to ask of their treatment decision, but it was not evident if men were conflicted after speaking to others, or if they could not find such an individual. What did produce conflict in men was a family member’s past medical history of cancer, particularly non-prostate cancers. It is clear in some cases men cannot dissociate their LPC from other cancer types, and often compare the two experiences. Even when men are knowledgeable about the “slow-growth” attribute of LPC, and

may even describe their cancer as “early stage”, men are still apprehensive during decision-making for fear of cancer spread or treatment complications.

Therefore, as clinicians, it is not only important to ask, “what is your past family medical history of cancer?”, but to also ask, “what is your *experience* with family members who had cancer?” One study comparing fear of cancer spread before and after treatment shows that the fear of cancer recurrence significantly improved after receiving treatment.²⁵ After undergoing a procedure, men may feel some element of control over their health and disease. Conversely, though fear decreased after treatment, fear of cancer recurrence remained constant over time, and still produced burden after two years of treatment.²⁵ Nevertheless, when cancer treatment misconceptions are present among patients, we must attempt to understand where they originate.

The uncertainty of side effects, and struggling with a commitment to therapy because of a perception of irreversibility, is found extensively in medical literature to be a considerable factor during treatment decision-making.⁶ In this study, however, it is observed as a relative factor that creates conflict for men. In Berry’s study, the importance of survival and/or its relationship to quality of life was addressed by 26 of the 31 individual interview participants.³ The most commonly addressed treatment complications were of incontinence, sexual dysfunction, and concerns for the spread of disease.³

Interestingly, the aspect of decision-making that appeared to present the most conflict was a man’s relationship with his physicians and the healthcare system. Once again, a man’s past experiences may influence his personality, perceptions, beliefs, and understanding of society. The lack of trust in the physician is present in several dimensions, and these men appear conflicted with the validity of this essential information source. Through the exploratory nature of this study, we as researchers can discover these conflicts as a source of uncertainty and

anxiety. Yet how can clinicians also discover and, furthermore, *address* such issues? Skepticism, beliefs that physicians are specialty biased, recommendations going against personal intuitions, disconnection in patient-physician relationships due to race and socioeconomic status – these are all dilemmas that we can assess to provide a deeper, meaningful understanding of our patients.

It is worthy to observe how trust and patient autonomy in decision-making are related. A study by Kraetschmer and colleagues surveyed 601 patients in breast cancer, prostate cancer and fracture clinics, and overall found 6.3% had blind trust, 36.1% had high trust, 48.6% had moderate trust, and 9.0% had low trust.²⁶ The authors continue to explain that blind trust was seen more in females, less educated, and elderly, and never found in those with post-secondary education. Interestingly, more autonomous patients had relatively low levels of trust, passive respondents were more likely to have blind trust, and shared respondents had high but not excessive trust. In prostate cancer, treatment decision-making is often a collaborative effort, and this study concludes “shared decision-making often accompanies, and may require, a trusting patient-physician relationship.”²⁶

In many clinical situations, patients often ask the physician, “if you were me, what would you do?” Berry recognizes this situation to be another way patients request a customized recommendation from their clinicians.³ Often physicians are concerned a straightforward answer could appear coercive or infringe in patient autonomy in decision-making, yet circuitous answers, or outright refusal to answer such questions could leave patients feeling unsupported, and promote a disconnection in the relationship. One study comments on this dilemma, and advises physicians to be attentive of the role of patients’ values, have an awareness of the force

of language, and portray a sense of empathy. Furthermore, the authors state the medical facts are necessary, but without the discussion of values, they do not lead to a truly informed decision.²⁷

Through one man's experience, there appears to be an estrangement between the physician and the patient due to race and/or socioeconomic status. The physician is perceived by the patient as indifferent to the needs of specific populations, or is unaware, insensitive, or thoughtless about advice and recommendations given during doctor visits. It has been reported that when African-American patients visit African-American doctors, they are more involved in medical decisions, have higher trust, and have higher satisfaction with their doctors than if they visited non-African-American physicians. One study of 252 adults, and 31 physicians in 16 primary care practices found that visits were two minutes longer and the patient's affect was more positive when the physician and patient were of the same ethnic background.²⁸ Further studies to understand factors to explain these differences are warranted, but one possible explanation is that patients and doctors communicate more effectively when they are of similar ethnic background. Another explanation suggested by researchers is the formation of mistrust between patients and clinicians from the unethical practices in the infamous Tuskegee Syphilis Study.²⁸

Researchers suggest that solutions to increase ethnic diversity among physicians may be the most direct strategy to improve healthcare experiences for minorities.²⁸ While this may be a straightforward answer, its feasibility is obviously questionable, and reliance on this solution alone is unrealistic. An editorial by Delbanco supports this notion stating, "to what degree should we try to anticipate and cater to patients' desires?...that 'separate but equal' should never be a goal, any move that results in segregating some patients and doctors from others could prove ruinous."²⁹ Clinicians of divergent ethnic backgrounds should instead attempt to

understand why these conflict persists, and proceed towards improved understanding of cultural sensitivity. In another study of patient-physician communication in the presence of racial disparities among breast cancer patients, a physicians' emotional support had no effects on outcomes. Instead, the mitigation of racial disparities is influenced more by patient-empowering communication in terms of self-efficacy, knowledge, and coping.³⁰ Overall, clinicians must be attentive of how they can improve the way they work with all patients, regardless of ethnicities. Both physician and patients have different anthologies of knowledge and experience, and drawing from both individual perspectives can yield the most satisfying care.²⁹

5.3 LIMITATIONS

Secondary analysis of data from previous research presents as a limitation to this project. As a result of the secondary analysis, interview questions were not tailored to the goals of this study. The aims of the original study by Berry and colleagues were to discover general, global factors taken into consideration by men during decision-making, and did not necessarily center on whether or not these factors created conflicts. A secondary analysis of data can be beneficial, however, as it is more cost-effectiveness because subjects do not have to be recruited, the research requires less time, and it is an efficient use of data already collected. Other limitations include a small sample size relative to quantitative studies. However, saturation of themes associated with conflict was attained when analyzing these transcripts. These interviews demonstrated some conflicts that may persist in men outside of the study, yet miss other possible conflicts not found in this sample. Berry also states that findings are "limited by the exploratory

nature of this study...Drawn from another population, the participants may have reported a different experience.”³

Furthermore, the demographic information of this study group is not reflective of the population of the United States, limiting generalizability. This sample includes few minorities, and continues to demonstrate how the study of minorities in prostate cancer research is strongly lacking. College and graduate degree attainment in this group of participants is high compared to the United States population. This is most likely due to a subject recruitment site that is located at an academic medical center where these men have access. According to the U.S. Census Bureau in 2003, 8.9% of the population attained graduate degrees,³¹ whereas 43.2% of this study sample achieved a graduate degree.³ The majority of participants were retired (50%), married (70.5%) and made over \$50,000 in annual income (50%).³ The decision-making abilities of this group may be more sophisticated compared to the general population, with possible greater proficiencies in processing and expressing information and experiences. However, it is interesting that these educated men still presented with conflicts, and found some difficulty resolving them. Men of other demographic characteristics, such as lower education and income, may perceive and process the same information differently, consequently presenting with different, unique conflicts. This study also specifically concentrates on men with localized prostate cancer, and does not address other malignancies. Men with metastatic prostate cancer may have entirely different decision-making experiences due to the nature of the disease and differences in treatment options. Overall, the generalization of these results to the population is precarious, and further quantitative studies with larger sample sizes, in multiple centers, are recommended.

6.0 CONCLUSION

This secondary analysis of Berry's data confirms her results of the personal factors found among these participants, along with evidence of the "influential other(s)" and "making the best choice for me." A deeper look into these individual interviews shows that inherent, multifaceted conflicts persist. The exploratory nature of this study contributes more understanding and awareness to the field of decision-making in prostate cancer research. However, we must then ask, what can practically be changed globally to address these dilemmas? Many of these conflicts stem from profound past experiences that may require a more comprehensive assessment by clinicians than what is done in a typical doctor visit.

This study further demonstrates how psychological aspects of the patient are equally as important as clinical characteristics. More attention may be required in incorporating advanced communication skills and therapeutic discussion into medical academic curricula. In some populations, the dissipation of sensitive patient-physician relationships second to race and socioeconomic status could be years from being sufficiently resolved. Clinicians should recognize this could be a particular barrier to effective medical counseling, and must tailor their communication style appropriately. On the other hand, physicians are already demanded to hold a great deal of knowledge and skill to treat the patient, and to request further advanced training in effective communication skills may not be practical. Physicians are not independent entities in the healthcare system, and must draw from the resources available to them to fulfill a patient's

psychological, emotional and educational needs. Nurse educators are possible solutions to this dilemma, as they can spend more time with the patient to learn about the individual's factors and conflicts, and address such issues appropriately. This may relieve some pressure placed on the urologist, as many nurses are experienced in treating the holistic patient, and not just the physical disease.

Conversely, the work force may not be sufficient enough to provide a national supplementation of nurses in this field. Researchers, such as Berry, have approached this dilemma by creating a web-based program, called Personal Patient Profile - Prostate (P4), to aid in decision-making.³² Participants in this randomized, multisite study can choose to use P4 on a computer at home or on a touch-screen computer in the clinic; the overall study is currently ongoing and results are pending.³² The research and formation of decision aids is already well established in literature,³³ although no one universal aid is currently in use. The use of aids is to the discretion of the urologist, further illustrating the lack of consensus in this field of medicine. The time and cost required to improve outcomes by addressing such issues is unknown, but we can, however, appreciate the decision-making complexity found in LPC patients.

Future studies should focus on discovering realistic, cost-effective methods to address patient conflicts and fears. If clinicians wish to individualize care, knowing men heavily rely on personal factors, they must understand the uniqueness of a man's life experience will undoubtedly influence decision-making.

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