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EMPATHY HEALS
THE EFFECTS OF PATIENT-CENTERED COMMUNICATION ON WOMEN
ONCOLOGY PATIENTS IN GENDER-DISCORDANT DYADS

**A thesis submitted to
Regis College
The Honors Program
in partial fulfillment of the requirements
for Graduation with Honors
by**

Emily R. Cooper

May 2019

PCC IN GENDER-DISCORDANT DYADS

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Introduction

“I have cancer.” These life-altering words must be spoken hundreds upon thousands of times every year. In the United States alone, it was estimated that, in 2018, 1,735,350 people were diagnosed with this disease and 609,640 people died from it (“Cancer Statistics”, n.d.). Growing up, I have heard those words or some variation of them more times than I can count. I’ve seen close family friends, grandparents, cousins, high school counselors, and many others suffer and sometimes die from this terrible illness. When I was young, one of my worst fears was that someone in my immediate family would be diagnosed. I used to try and reassure myself by saying there was no way things could get that exciting. We were just an ordinary family; why would something like that happen to us? As the statistics suggest, cancer is much more common than I understood it to be. It would not be long before I grasped how very wrong I was.

It was soon after my grandpa Emmett died from an extremely aggressive and rare form of bladder cancer that my mother began to notice problems with the vision in her left eye. It was becoming difficult for her to make out images on the television screen when she was sitting at the couch, and things were beginning to blur. Her eyesight had never been the best; she had gotten laser eye surgery when I was a toddler to correct a lifetime of poor vision. Seeing as I was now 15 years old, we thought perhaps it was beginning to wear off. We took this as a sign that it was time we all paid a visit to the optometrist.

A tear in her retina was what the doctor claimed my mother had upon examining her eye. From the way he made it sound, it wasn’t truly something to be concerned about.

He referred us to a specialist and said that they could probably fix it with a laser or, worst case scenario, she would need injections in her eye. I don't remember his explanation behind this. As someone with a lifetime phobia of needles and having their eyes touched, I was absolutely stunned at the treatment he was suggesting. It never crossed my mind that he might be wrong. But my mother knew. On some level, she knew the optometrist was concealing suspicions that her little retina tear might be something more. As usual, she was right.

I don't remember how much time had passed before my parents went to see the specialist our previous doctor had referred my mother to. I remember staying home to work on school with my brother while they went to the appointment. I remember being in the middle of brushing my teeth when my parents came home, and I remember opening the bathroom door to my mother's tear-stained face and having the realization of what this little tear truly was hit me like a ton of bricks before any words had even left her mouth. It was cancer. An ocular melanoma, to be precise.

As the months went by, little by little, we began to understand more about her diagnosis and what it meant for the future. She underwent many different procedures in the doctors' attempts to understand the nature of her tumor, such as ultrasounds and a biopsy, and numerous others to treat it, including laser surgery, radiation, and correcting mistakes of past surgeries. Throughout this experience, one of the things that stands out the most is how my mother was treated by doctors and other medical professionals. The worst incident that comes to mind is from her visit to the first doctor she saw post-diagnosis of her cancer. Upon looking at my mother's eye and hearing her story, the

doctor did not tell her what he believed her best form of treatment was or talk about the implications of what she was now facing. Instead, he simply looked at my parents and asked, “Well, what do you want me to do about it?” At this point in my mother’s journey with cancer, neither she nor my family understood the diagnosis well enough to even begin to know how to answer such a question. Even if we had the faintest notion of what was typically done for this type of tumor (which we did not), the doctor’s complete offhanded attitude about the entire situation was the opposite of what my mother and the rest of my family needed to hear. As this was only the first doctor my mother saw after the diagnosis of cancer, her less than satisfactory experiences with medical professionals were only beginning.

After much trial-and-error, my mother arrived at her current oncologist’s practice with thanks to a friend’s referral. Although this doctor has proved to be more capable than the first one she saw, there are still many moments when she feels his “bedside manner” is subpar. To name a few examples, my mother has a great deal of pain in her eye and, in general, a tendency to experience things that are particularly rare for her type of cancer. Her oncologist’s response to such complaints tend to fall along the lines of saying, “Well, that shouldn’t be happening,” instead of reassuring her worries and attempting to find a solution for the issue. Additionally, my mother’s particular form of cancer is extremely rare both in how it manifests itself and the fact that she has been diagnosed with it at all, given it is usually only diagnosed in young men. It often felt like the he struggled to rein in his curiosity, had a strong desire to do more procedures than necessary, and tended to disregard my mother’s pain. Lastly, he has a certain inclination

to talk to my father when discussing her condition and the steps that must be taken instead of his actual patient. These habits, along with a million other little things that my mother has noticed throughout her nearly six years of cancer, contribute to an overall picture of a lack of concern for my mother's worries. This is not the attitude you want to see from any medical professional, particularly one treating such an uncertain disease as cancer.

While one would hope that my mother's situation was simply the result of bad luck or a lack of options in terms of oncologist, this is not the case. In my secondhand experience with cancer, I have seen example upon example of medical professionals who ignore the basic principles of good bedside manner when interacting with their patients. From residents who think they know everything to a doctor who dismisses cancer suspicions as the delusions of a paranoid patient, this behavior is rampant across the field of oncology and it is dangerous. Oncology patients experience a significant reduction in quality of patient-centered care when compared to other populations (Blanch-Hartigan et al., 2016). More specifically, this pertains to the quality of patient-centered communication. Research suggests that the quality of patient-centered communication is not only important for a patient's subjective perceptions of care but also for the success of their treatment (Jiang, 2017; Street, Makoul, Arora, & Epstein, 2009). It was this discrepancy that drove my choice in thesis topic. My thesis explores this concept of subpar patient-centered communication for oncology patients within the context of gender-discordant dyads. Specifically, I examine the quality of patient-centered communication between a male oncologist and a female cancer patient. In this argument,

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I propose that the need for proper patient-centered communication is even more dire for female cancer patients that are being treated by male oncologists. I will begin this discussion by providing background information on patient-centered communication and its foundational notion of trust.

Chapter 1

What is Patient-Centered Communication?

Trust is an important component of any relationship but is particularly vital in those between a doctor and a patient. Trust can be defined by four persistent characteristics. Firstly, the act of trusting must involve a prediction made by one regarding the future behavior of the other. Second, the one who holds the trust (in this case, the patient) possesses the belief that the trustee (the physician) will perform a desired behavior. Thirdly, the act of trusting involves some degree of risk, thus resulting in vulnerability on the patient's part to the actions of the physician. Lastly, trust tends to be stronger when the consequences of breaking said trust are direr (Hillen, de Haes, & Smets, 2011). The vulnerability aspect, in particular, is more significant in relationships between a doctor and their patient. Oftentimes, patients are expected to trust in a doctor they have never met and have no previous relationship with because they do not possess the expertise and abilities to resolve health concerns themselves. As a result, the relationship comes to be defined by an imbalance of power and knowledge, in which the patient's trust in the physician is not truly a choice (Hillen et al., 2011; Mechanic & Meyer, 2000). This begs the question, what does it take for a patient to begin to trust their physician? This brings us to the idea of patient-centered communication.

Patient-centered communication (PCC) is described as a version of healthcare that is both respectful and responsive to a patient's values, their needs, and their

preferences. Additionally, it commonly encourages shared clinical decision-making between a patient and their physician (Bertakis & Azari, 2012). This type of communication consists of two different models: the biomedical model and the biopsychosocial model. Each one addresses very different aspects of a patient's care and well-being. For the biomedical model, the emphasis is primarily on the psychopathology of the patient's disease. The latter, however, tends to center more on different components of the illness, such as the effects it is having on the patient's concerns, emotions, and feelings (Dean, 2016). These two models integrate and complement one another to form the complex notion of PCC that will be discussed - this idea can be deconstructed further by revisiting the most foundational concept underlying PCC: trust.

In general, studies have shown that patients tend to place their trust in physicians when they begin to feel that their physicians are technically competent and honest (Hillen et al., 2011). While it may seem as though these perceptions (at the very least the one pertaining to the competence of the physician) would be rooted more strongly in the biomedical model of PCC, where physicians express their knowledge relating to the psychopathology of the illness, this is not necessarily the case. In fact, perceptions of competence are typically derived from factors such as the physician's reputation, status, and interpersonal communication skills, particularly those involved in one's ability to provide explanation (Hillen et al., 2011).

The importance of interpersonal skill was supported in a study conducted by Mechanic and Meyer (2000). In this study, experimenters interviewed 90 patients - who were divided into three groups based on their illness (breast cancer, chronic Lyme

disease, and mental illness). These groups were chosen based on the high severity of the illness and uncertainty of prognosis, which the experimenters argued were important factors in understanding the role of trust. Each participant was interviewed regarding their feelings on the most meaningful aspects of trust. In general, patients placed a reasonable amount of value on interpersonal competence in that aspects of it were often taken as indicators of technical competence. While this in itself is not surprising, what is intriguing was the degree to which these aspects of interpersonal competence were rooted in teachable and concrete behaviors. Some examples of characteristics patients find important include minimizing interruptions, maintaining eye contact, listening carefully, providing responsive feedback, and demonstrating understanding regarding a patient's distress and vulnerability (Mechanic & Meyer, 2000). This is consistent with other research addressing the concept of trust in doctor-patient relationships, which also cites the importance of behaviors such as listening, providing information, caring, and answering questions in promoting feelings of trust (Hillen et al., 2011). Many of the principles that are integral in the trust of a physician form the basis of PCC.

This relationship between trust and PCC can be further elucidated by breaking PCC down into its six main functions. These functions include: fostering the relationship between a patient and their clinician, responding to the emotions of a patient, managing uncertainty, making decisions, exchanging information, and enabling a patient's self-management (Mazor et al., 2013). As can be seen in the literature reviewing the role of trust in doctor-patient relationships, some of the most prevalent and reported contributors to developing trust is the facilitation of communication between a physician and their

patient and the manifestation of caring behaviors on the part of the physician (Hillen et al., 2011; Mechanic & Meyer, 2000). These parallel and inform several of the previously identified functions that compose PCC (e.g., responding to emotions of the patient, exchanging information, etc.).

A strong foundation of trust in a doctor-patient relationship also aids in the process of decision-making. Patients who trust their physicians are more inclined to accept their recommendations in terms of treatment. Overall, this can expedite the process of decision-making in healthcare and, in some cases, give patients a stronger sense of control regarding their situation due to the conscious rather than forced choice to accept their doctor's advice (Hillen et al., 2011; Mechanic & Meyer, 2000; Mazor et al., 2013). Good PCC is an important precursor to forming a trusting relationship with one's physician and for improving the health of the patient overall.

PCC and Health Outcomes

The influence of PCC on the health outcomes of the patient is best demonstrated through a model designed by Street, Makoul, Arora, and Epstein (2009; see Figure 1). The pathway in this model begins with the six functions of PCC that have been established previously. There are several different routes through which this pathway can commence, including a direct route and an indirect route. In terms of the direct route, talking to the physician alone can be therapeutic assuming the physician expresses empathy for the patient and/or validates their feelings regarding the topic of discussion. This can result in an increase in positive emotions and overall well-being for the patient, and a decrease in negative emotions (Street et al., 2009). However, the more common path of

communication is the indirect route. In this version, the functions of communication first result in what are known as proximal outcomes, which can include a sense of satisfaction for the care that is provided to the patient, trust in their physician, shared understanding between the physician and the patient, motivation to adhere to treatment, and self-efficacy in self-care. These then contribute to what are known as intermediate outcomes, which consist of further adherence, social support, and self-management skills. In general, pathways in this model result in better health for the patient in terms of both physical and emotional well-being (Jiang, 2017; Street et al., 2009). These health benefits resulting from good PCC can be classified two different broader forms.

These forms include improvements to a patient's psychological health and improvements to a patient's physical health. In terms of psychological health, this could manifest through creating encounters using PCC that influence a patient to feel hopeful, reassured, validated, and comforted. PCC can more indirectly influence psychological health through the increased recognition of chronic mental disorders, such as depression and anxiety, and the reinforcement of social support (Hack, Degner, & Parker, 2005; Street et al., 2009; Thorne et al., 2005). In terms of physical health, good quality PCC is associated with increases in a patient's adherence to their treatment, thus improving their physical well-being (Mazor et al., 2013; Street et al., 2009). These ideas can be analyzed more specifically through further sub-pathways established in the article by Street, Makoul, Arora, and Epstein (2009).

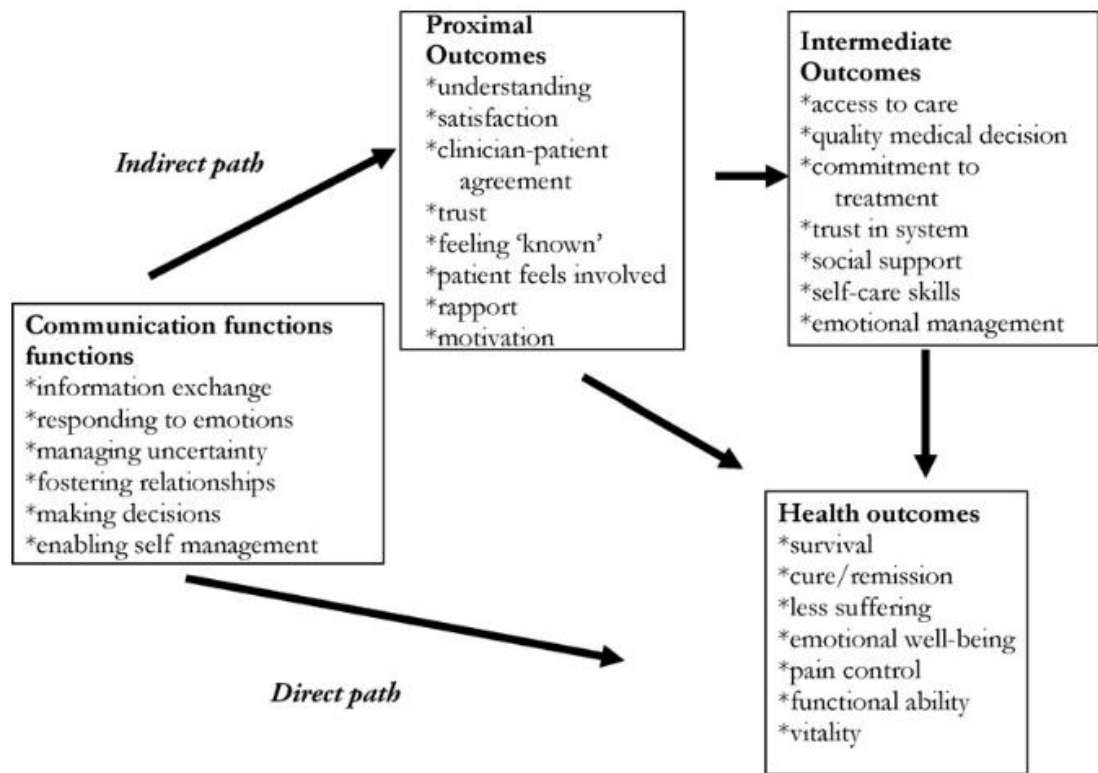


Figure 1: Direct and indirect pathways of PCC (Street et al., 2009)

Sub-Pathways of Patient-Centered Communication

In the model developed by Street, Makoul, Arora, and Epstein (2009), the authors not only propose a general pathway for the mechanisms of PCC, but also sub-pathways through which health outcomes can be influenced. These include access to needed care, increasing shared knowledge and understanding, developing skills of emotional self-management, activating social support and advocacy resources, improving medical decision quality, enhancing therapeutic alliance, and enabling patient self-efficacy and empowerment (Street et al., 2009; Figure 1).

Access to care. For the first, the author is referring to the idea that barriers to care for patients of a lower socioeconomic status (SES) can extend beyond those of the economic nature; they can take the additional form of patient lack of information and resources. Many patients of a lower SES might be at a disadvantage in the sense that they may not possess the knowledge they need to know when medical care is necessary or how to navigate complex medical resources. When this is the case, physicians can aid in explaining where to find necessary health services, facilitating communication among various health professionals, and being an advocate for the patient so they can receive clinical and community services (Street et al., 2009). This approach is rooted in PCC because it takes the focus away from merely diagnosing the patient and telling them what needs to be done. It puts the physician in a role of continuous support throughout the entire journey to better health. Without this, a patient might not be able to follow through on medical advice simply because they do not understand how to access necessary medical systems. Without these systems, they would likely suffer significant set-backs in terms of their health, depending on the severity of the illness. With this continuous advocate, patients can gain access to the information they need and improve their physical and/or psychological well-being.

Increasing shared knowledge and understanding. In order for a patient to make educated decisions regarding treatment, they must first have a clear understanding of their illness as well as the risks and benefits of a variety of treatment options. On the other side of the relationship, a physician must have prior knowledge regarding their patient's preferences, values, and beliefs regarding their health and treatment. This can be

difficult as patients and physicians often understand health and treatment through very different perspectives, which are oftentimes based in experiences. To achieve this shared understanding, both the patient and the physician must be active participants in their exchanges, providing information to the other and demonstrating the willingness to explore and adapt their own beliefs. In the event that this is successful, the result can be increased satisfaction in the medical exchange, an advanced ability for the patient to cope with their illness, facilitated participation in the doctor-patient relationship, and increased amounts of trust the patient has in their physician. Combined, this has the potential to result in an enhanced dedication to treatment on the patient's part (Street et al., 2009). Long-term, this should increase the patient's health and well-being.

Developing skills of emotional self-management. Particularly in cases of severe illness, health concerns can result in a variety of negative emotions, such as worry, fear, anger, and sadness. Because of this, another valuable pathway in the process of developing PCC involves helping the patient develop skills of emotional self-management. Without such skills, negative emotions may come to threaten both emotional and physical well-being. To prevent this, there are various methods that can be attempted by physicians. For example, physicians can be mindful of the clarity and depth of their explanations of the patient's health and their treatment options. This can help the patient to feel a greater sense of control over the situation, manage their uncertainty, and feel more hopeful about their prospects. Physicians may also help their patients by treating their emotions with the same importance as their physical condition. This might be accomplished through not only validating their emotions, but also directing the

conversation in such a way that the topic of emotions is prompted into discussion and explored. In cases where the patients suffer from conditions such as depression and anxiety, which are common in cases of severe physical illness, the effects of these conditions can be reduced. Lastly, physicians can structure their communication in such a way that they can give their patient a sense of motivation, meaning, and energy toward activities in the patient's daily life. While this may seem like a great deal to expect, it can be accomplished through enhancing a patient's feelings of worth, confidence, and hope. This is a valuable contribution to their health as it can provide the patient with the desire to go about their daily lives despite their illness and improve their quality of life overall (Street et al., 2009).

Activating social support and advocacy resources. When we refer to social support, we are referring to the access a patient has to emotional, fiscal, and tangible resources within their social network (Street et al., 2009). This can lead to an increase in health in a number of aspects. For one, social support can contribute to physical health through lowering physiological arousal and reversing the impacts of processes such as psychologically-induced immunomodulation (i.e., induced adjustment of the immune response). In terms of mental health, social support can enhance a patient's emotional well-being by contributing a sense of connectedness and increasing opportunities to discuss difficult topics to their relationships. Additionally, having a supportive social network can lead to the provision of instrumental assistance, such as financial resources, transportation, encouragement, and advocacy for gaining access to required health

services. Within the context of the doctor-patient relationship, communication can contribute to the development of this network in a variety of ways.

On one hand, proper patient-centered communication can act as a form of support in and of itself. When this quality is achieved, it can provide reassurance, encouragement, praise, advice, and advocacy to the patient. This support can also take a more external form. For example, clinicians might discuss ways to enhance a patient's existing social network outside of the doctor-patient relationship as well as suggest new sources of social support, such as those found in online support groups. Lastly, physicians might also assist their patients in countering sources of negative support, such as peer pressure to engage in maladaptive behaviors (Street et al., 2009). Overall, achieving good quality PCC so that these benefits can be easily accessed in discussion can provide a number of physical and psychological advantages to the patient, both inside and outside the doctor-patient relationship.

Improving medical decision quality. This sub-pathway is more complex than those that have been previously described. When elucidating upon this concept, Street et al. (2009) incorporate another sub-pathway specific to decision-making that was defined in an article by Charles, Gafni, and Whelan in 1999. These authors propose the idea that decision-making within the medical context progresses through three primary stages: information exchange, deliberation, and making the decision. To briefly expand upon these stages, information exchange involves the sharing of physician and patient perspectives. This can include, on the physician side of this exchange, the clinical evidence behind the condition of the patient and the expression of patient expectations,

values, beliefs, and preferences on the patient side. Deliberation refers to a type of discussion that finds its focus in determining common ground, reconciling the differences in terms of opinions and beliefs, addressing uncertainty, and reaching a sense of shared understanding when it comes to the patient's health status and the risks and benefits associated with different treatment options. The last stage simply refers reaching the point where a decision can be made (Charles et al., 1999; Street et al., 2009).

In contrast to the claim by Charles et al. (1999) that these three stages have distinct differences when considering different styles of decision-making, Street et al. (2009) asserts that flexibility can exist in one's progress through these stages. This is to say that certain decision-making styles can be prevalent in some stages while other decision-making styles predominate in others; the styles that predominate are heavily influenced by patient preferences, among other things. Moving forward, one of the most important ideas to understand about the process of medical decision-making is that it holds its own set of unique challenges.

One component that tends to complicate many medical decisions is the clinical evidence behind them. This refers specifically to decisions regarding treatments. Some treatments may lack clinical evidence while others may have ambiguous or conflicting support. In general, this could result in patients receiving conflicting recommendations from medical professionals, contributing to a sense of uncertainty or confusion about what should be done. On another note, patients may find clinical information difficult to understand while physicians may struggle to make this information relevant to the patient's specific situation. The physician and the patient may also have different

understandings of risk (Street et al., 2009). These are only a few of the complications that can be associated with medical decision-making. This all is to say that the process itself is complex and prone to misunderstanding. PCC plays a valuable role because with the practice of good PCC comes the increased likelihood that there will be fewer complications in terms of decision-making. While no one is perfect, if a physician is actively pursuing good PCC in their practices, improved quality of medical decisions should be the result. This overall concept becomes more complicated with different diseases, which will be elaborated upon later in the paper.

Enhancing therapeutic alliance. When we mention therapeutic alliance, we are referring to the interrelationships between the patient and others, including the various professionals providing their medical care, friends, family, and any of their caregivers. These types of relationships are referred to as a patient's "therapeutic alliance" because their quality can affect health outcomes in several ways. One of the first ways is through influencing a patient's emotional well-being; this is particularly applicable if the patient's disease is life-threatening. This can be accomplished by affecting the perceptions that their care is of good quality, assuring them that they will not be abandoned, and leading them to feel understood. The second way in which therapeutic alliance can impact a patient's health relates to the amount of trust they have in the healthcare system and their physician. As we have seen, this trait can elicit numerous benefits such as improved care continuity, commitment to treatment, and a patient's level of satisfaction with medical decisions. As is the trend with these pathways, therapeutic alliance is improved when physicians are both informative and empathetic toward their patients, when patients have

the opportunity to discuss their concerns, and when coordinated care is prevalent between a patient's healthcare professionals (Street et al., 2009). As we have seen through previous evidence, these aspects of care are often enhanced with good quality PCC. This is to say that, if physicians cultivate a sense of trust in their patients through the practice of good PCC, then they may also experience an increase in therapeutic alliance between themselves and their patients and both improved physical and emotional health for their patient.

Enabling a patient's self-efficacy and empowerment. This aspect of communication refers specifically to enabling patients to be active participants in their own healthcare. This could take the form of a patient participating fully in medical conversations and decision-making as well as developing skills to manage their own care on a daily basis. The former allows for medical decisions that fit a patient's unique situation, which may not be easily reached if the physician makes the decision alone. Improved communication such as this can be achieved through the exercise of various aspects of good PCC that have been discussed previously, including physicians' expression of concern for the patient, helping patients actively search out information relating to their illness, and making goals of treatment clear. They may also discuss topics such those centering on improving a patient's self-efficacy, autonomy, specific skills in one's self-management of their health, and where resources pertaining to self-care can be accessed (e.g., websites, community groups, and help with coping). In general, these topics lead to greater ability and motivation on the patient's part to seek out solutions for problems relating to their health, cope with complications, and demonstrate commitment

for their treatment (Street et al., 2009). Again, in order for benefits such as these to be accessed, good PCC must be a central component in doctor-patient interactions.

Conclusion

Patient-centered communication is a valuable component in doctor-patient interactions, if done well. In general, exercising good PCC is related to an increase in patient trust, sense of concern for their well-being from their physicians, and improved care, among other things. We can therefore logically conclude that poor PCC would lead to patients feeling less trust for their physicians and less control over their situations, reduced quality of care, and less of a sense that their physician cares about their well-being. Subsequently, we would not see these patients reaping the benefits of improved physical and psychological health. This is a significant issue, especially for those facing life-threatening and chronic conditions, such as cancer.

Chapter 2

Patient-Centered Communication in the Context of Cancer Diagnoses

Now that we have established a groundwork of what patient-centered communication is, we will begin to narrow our focus to a specific population of interest when studying PCC: cancer patients. I would first like to establish precisely what it is about cancer patients that makes them so interesting when it comes to studying PCC. Within this context, practicing good PCC tends to be much more difficult than it would be otherwise. In fact, research on this matter shows a general trend of subpar PCC when examined in reference to those with cancer (e.g., Blanch-Hartigan et al., 2016; Lerman et al., 1993; Venetis, Robinson, LaPlant Turkiewicz, & Allen, 2009)

Research studies suggest that trends in reduced quality of PCC for those diagnosed with cancer are related to numerous factors. These include but may not be limited to the nature of the disease itself, particular difficulty establishing trust in the case of cancer, and disruptions in the physician's desire to practice good communication skills. In terms of the disease itself, the name "cancer" carries with it many implications in terms of the emotional effects it will have on the patient as well as the type of information that dominates medical discussions. Because cancer is such a life-threatening and critical illness, managing it in one's daily life often involves considering the possibility of death, understanding complex information relating to the disease, handling the side effects of treatment, making difficult decisions regarding this treatment, and

living with the fear of recurrence post-remission. Each of these effects has substantial impacts on the patient's quality of life (Arora et al., 2001; Arora, 2003; Gotay & Muraoka, 1998). These burdens resulting from the nature of cancer lead to a greater need for physicians to practice good PCC and tend to the emotional as well as physical burdens that weigh on a patient's well-being.

Another important consideration when examining the decreased quality of PCC in oncology settings is the level of difficulty in establishing a sense of trust. Because of the type of care a cancer diagnosis demands, patients may struggle to establish a sense of trust with their team of physicians and caregivers. Although research demonstrates that most patients have trust in their personal physicians, the appearance of cancer typically demands the transfer of care to a more specialized team of physicians with whom the patient likely has no previous relationship (Blendon et al., 1998; Mechanic & Meyer, 2000). Given a predictor of trust is the presence of a continuous relationship, cancer patients are at an immediate disadvantage in terms of trust with their healthcare teams (Hillen et al., 2011; Jones et al., 2009; Kao et al., 1998; Tarrant, Colman, & Stokes, 2008).

While the potential for reduced trust is detrimental alone, there has been concern in recent years that what trust is present in healthcare interactions is eroding with changes in the overall healthcare organization, resulting in a decreased continuity of care and less personal attention for the patient (Goudge & Gilson, 2005; Hillen et al. 2011; Mechanic & Meyer, 2000). When we mention continuity of care, we are referring specifically to the care of an individual by a single physician or group of healthcare professionals over time,

as well as the effective and timely communication of a patient's healthcare information (Cabana & Jee, 2004). Again, we see the relation between the quality of trust and that of communication. Based on this, we can expect to see a further breakdown of good PCC and valuable communication in general as these changes in the structure of the healthcare system remain. While this affects all patients involved, patients with life-threatening illnesses may experience more detrimental impacts due to the imperative role of PCC. For cancer patients in particular, this issue exacerbates an already problematic situation, making it even more difficult for a physician to practice good PCC as trust erosion continues.

There are also instances in which PCC suffers due to disruptions in a physician's desire to practice good communication skills. While it is a rational belief that most physicians have a desire to practice good PCC and help their patients, there are several situations in which this desire may be disrupted. As is often the case with skills of any variety, physicians' abilities pertaining to good healthcare may decrease in quality with fatigue. This in turn can contribute to effects such as medical errors, which strongly impact a patient's ability to place trust in their physician and the subsequent quality of PCC (Epstein & Street, 2007). In addition, physicians that may not be as dedicated to providing good quality healthcare might make their needs a priority over their patients'. This can take the form of avoiding topics that are uncomfortable or laden with emotion, or limiting time spent in consultations to maintain their schedules (Epstein & Street, 2007). While this is likely not the case for all physicians, it may be an issue that many face in the field of oncology, given there are often emotion-heavy topics that must be

discussed, including depression or anxiety. The potential for avoidance can have a significant impact on the quality of PCC as good PCC often requires that physicians aid their patients in things such as emotional self-management (Street et al., 2009). In terms of time spent in consultation, many patients are more equipped to manage their emotions when they feel they are listened to and that their concerns matter to their physician (Street et al., 2009). Now that we have established a basis for why PCC may be of worse quality in oncology settings, we will begin to examine how health outcomes from previously discussed sub-pathways would interact with the diagnosis of cancer.

Applications of Sub-Pathways in Cancer Care

Access to care. In order to understand the application of PCC within the oncology setting, we will revisit the seven pathways of PCC from the Street et al. (2009) article which were outlined previously (Figure 1). We will begin with the sub-pathway of access to care. As previously mentioned, access to care includes not only economic barriers but also factors such as the navigation of complex medical systems (Street et al., 2009). In the case of cancer patients, many are likely to be unfamiliar with medical systems specific to cancer treatment and care unless they have prior experience with the system either through past diagnoses or the diagnoses of loved ones. That being said, it is imperative that healthcare professionals work to the best of their abilities to assist with barriers such as low SES in order to facilitate understanding. Another way physicians can assist with improving access to care is through the facilitation of communication between healthcare professionals (Street et al., 2009). Because cancer patients often require care from a multitude of healthcare professionals, such as the various specialists in different

forms of treatment and nurses, coordination among these professionals is important in providing the highest quality care and communication for their patients. This may be important in managing the patient's uncertainty and for their well-being overall.

Increasing shared knowledge and understanding. Physicians must communicate to patients in such a way that the illness itself as well as the risks and benefits of a variety of treatment options are understood in order to make informed choices. Likewise, patients must communicate and physicians must listen in such a way that the physicians have an understanding of the patient's values, preferences, and beliefs regarding healthcare. When this understanding is fostered, physicians are able to provide clear explanations, have a better idea of what treatment approach is best suited for the patient, what language should be used, and validate the patient's emotional state. This is important for cancer specifically due to the nature of the treatments available; many involve adverse side-effects and varying effectiveness depending on the type of diagnosis (Epstein & Street, 2007; Street et al., 2009). Unfortunately, physicians often poorly judge their patients' perspectives, which also includes their preferences, satisfaction with care, understandings and beliefs about health, emotional states, and likelihood to follow treatment (Epstein & Street, 2007). However, when this sub-pathway is successful, the patient will have a greater ability to cope with their cancer diagnosis and place greater trust in their physician. This will increase both the patient's adherence to their treatment and the quality of PCC, which will have a positive impact on the patient's health later on (Street et al., 2009).

Skills of emotional self-management. As mentioned, increasing shared knowledge and understanding may also positively impact the patient's emotional state. This brings us to the next sub-pathway, which involves developing skills of emotional self-management. This in particular can be difficult for physicians, as they can be poor judges of the types of emotions that patients often experience. Additionally, patients may try to mask their distress or believe that their negative emotions are not relevant to the care of their physician (Street et al., 2009). In fact, studies show that, in follow-up consultations with survivors previously diagnosed with colorectal cancer, very little attention was paid to psychosocial concerns. On average, 14.3 biomedical exchanges took place compared to 1.2 psychosocial exchanges (Arora, 2003; McCool & Morris, 1999). Research also demonstrates that, compared to primary care, psychosocial aspects of the illness are much more prominent than biomedical aspects when cancer is the concern. For example, cancer typically brings greater amounts of uncertainty, fear, anxiety, frustration, and vulnerability than other types of illnesses (Engel, 2012; Mishel, 1988; Venetis et al., 2009). With the proper practices of PCC, these psychosocial aspects of care would receive the level of attention necessary in order to provide optimal care for cancer patients.

Enhanced social support and advocacy resources. Although social support is typically coming from family or friends, as we have established in the previous chapter, it is also something that can be provided through good practice of PCC by physicians and healthcare professionals. This source of support may be particularly important for those experiencing highly stressful life events, such as cancer, and for those for whom support

outside of the healthcare setting is poor. Kornblith et al. (2001) examined the role that social support plays in the mitigation of severe psychological distress as a result of breast cancer diagnosis. The results of this study demonstrate that, in order for social support to have an impact on the level of psychological distress, the amount of social support for the patient must be extremely high (Kornblith et al., 2001). If the quality of PCC is poor, as is often the case with those diagnosed with cancer, then patients are lacking a significant source of potential support, preventing them from attaining the amount needed to impact their distress.

Improvement of medical decision quality. Perhaps one of the most important sub-pathways in regard to cancer, specifically, is the improvement of the quality of medical decisions. Medical decisions within this context are particularly complicated because they necessitate both the ability of the physician to convey all pertinent information in a way that is understandable to the patient as well as an accurate understanding of the patient's beliefs, values, and preferences on the physician's part. The role of decision-making, in particular, seems to have a large impact on both the psychological and physical well-being of cancer patients. In a prospective study conducted on 30 women diagnosed with early stage breast cancer, Morris and colleagues found that women who were given a choice of whether to have surgery experienced less mental illnesses (i.e., depression and anxiety) and improved physical functioning compared to those not given a choice (Morris & Royle, 1988; Morris & Ingham, 1988). These findings were further supported in another study conducted on 269 women diagnosed with early stage breast cancer. The findings of this research by Fallowfield and

colleagues stated that women treated by physicians who preferred to offer a choice in terms of treatment tended to experience less depression and anxiety long-term (Fallowfield, Hall, Maguire, & Baum, 1990; Fallowfield et al., 1994). These findings remain consistent across several other studies regarding the effects that choice can have on a cancer patient's well-being (Deadman et al., 2001; Street & Voigt, 1997). Although it is ideal that patients would have a more independent choice in their treatment, there are of course situations in which the type of diagnosis or other factors limit the possibilities. This is where PCC plays a role.

Numerous studies have found that trust plays a substantial part in the satisfaction that cancer patients have with decisions made by their physicians, which may also transfer to situations in which physicians must strongly recommend one treatment option over another. Cancer patients feel more encouraged to accept their physician's recommendations for treatment if they have a trusting relationship with their physician. Physicians also report that trusting patients tend to be extremely helpful in the decision-making process (Charles, Gafni, & Whelan, 2004; Henmana et al., 2002; Hillen et al., 2011; Salkeld, Solomon, Short, & Butow, 2004; Shephard, Tattersall, & Butow, 2008). As we have already learned, trust and good PCC tend to go hand in hand. If physicians are practicing good PCC, then their chances of developing a trusting relationship with their patient are improved. Furthermore, they have a much better chance of knowing what treatment options would work best for their patient because of an enhanced understanding of their patient's values and preferences, resulting in increased patient satisfaction. Even

if alternative options are not available, patients will be more comfortable with the recommendations made by their physician than they would be otherwise.

Enhancing therapeutic alliance. Also important to the quality of care for those with cancer is enhancing therapeutic alliance. This pertains largely to concepts of trust, coordinated healthcare, and the patient's sense of respect, which act as indicators of therapeutic alliance (Street et al., 2009). These indicators relate back to previous concepts of trust and the importance of good communication, both between the physician and the patient and between the members of the patient's healthcare team. In order to cultivate a strong therapeutic alliance, physicians must work to practice the principles of PCC and form a trusting relationship with their patient as well as bear in mind what is best for the patient. This allows for a unified team working towards the patient's best interests and well-being. This is particularly important in cancer care, as patients often have many different individuals providing healthcare and may have difficulty establishing trust with their physicians.

Enabling a patient's self-efficacy and empowerment. Lastly, the importance of enhanced patient agency in the case of cancer has been demonstrated through a number of studies conducted concerning the topic. In one such study, it was found that the sense of control that cancer patients feel over the disease was linked to both emotional well-being and coping during their period of survivorship (Street & Voigt, 1997; Street et al., 2009; Taylor, Lichtman, & Wood, 1984). This is valuable in the initial diagnosis stage as well as aiding these patients in living their lives during remission. The latter is also an

important consideration, as we often focus on the care of patients during their battles with cancer and less on those who seem to have won the battle.

Conclusion

From these sub-pathways, it can be seen that PCC is a valuable tool in addressing the unique challenges that cancer patients often face. Without PCC, it is difficult for physicians to fully understand their patients' needs and desires, for the physician and the patient to develop a successful relationship, and for patients to understand the entirety of their resources, among other things. Through promoting good PCC in patient-doctor interactions, cancer patients can not only have their unique needs met, but also reach a point where they can advocate for themselves and manage their own physical and psychological health.

Chapter 3

Patient-Centered Communication and Cancer in Gender-Discordant Dyads

Not only is the practice of PCC affected by the situation in which it is used but also various demographic factors. One main predictor of the quality of PCC is gender. For this discussion, we will consider both the gender of the physician and that of the patient. Factors such as gender of the physician and the patient can impact the psychological well-being of the patient, practice styles of the physician, and the utilization of PCC overall. In this research, we will be focusing specifically on male physicians and female cancer patients and how PCC can be both especially lacking and vital within this context. We will begin by investigating the various factors that make good PCC particularly vital for female oncology patients.

Struggles for Women Oncology Patients

With the diagnosis of cancer comes the manifestation of many other issues, from psychological impacts to treatment complications to general distress. Some of these issues are either specific to or more prevalent in women. These include mental illnesses (e.g., depression and anxiety) (Massie, 2004; Pattingale, Burgess, & Greer, 1988), problems with body image resulting from treatment side-effects (Favez et al., 2014; Fobair et al., 2006; Helms, O’Hea, & Corso, 2008), and a loss of self (McWilliam, Brown, & Stewart, 2000). These psychological complications tend to lead to a more multifaceted experience with cancer than one might originally expect, given its biological

nature. In order to understand the relevance of these factors in this discussion, it is important to understand their application in female cancer diagnoses, specifically.

Mental illness. Depression and anxiety are illnesses that have been revisited time and time again in our discussion of PCC. While they are not illnesses that are exclusive to women, the literature demonstrates that they are more prevalent in women as well as common consequences to the types of cancer treatment more commonly experienced by women. A study conducted with 168 patients with either breast cancer or lymphoma demonstrated that women diagnosed with lymphoma tended to be more depressed and anxious than men diagnosed with the same type of cancer. Women also tended to be more anxious than men at sequential appointments, and women with breast cancer had greater anxiety than the other cancer patients studied in general at their 1-year follow-up (Pattingale et al., 1988). These symptoms characteristic of mental illnesses can be the result of struggling to cope with distress from the beginning of one's treatment, developing independently of cancer (Bloom, Stewart, Chang, & Banks, 2004; Burgess et al., 2005; Favez et al., 2016; Shimozuma, Ganz, Petersen, & Hirji, 1999).

Depression is also a typical consequence of certain cancer treatments. For example, women experience alopecia, or loss of hair, is a common side-effect of chemotherapy. Literature demonstrates that alopecia is often associated with psychological consequences, such as anxiety and depression (Choi et al., 2014; Hunt & McNale, 2005). Although hair loss is not something that is exclusive to women, due to the typical associations of hair with femininity, attractiveness, and personality, it is considered one of the most traumatizing and distressing experiences for women with

breast cancer (Choi et al., 2014). This alopecia-induced concerns about femininity and attractiveness can also result in body dissatisfaction, which is another serious struggle that women diagnosed with cancer face (Choi et al., 2014; Hesketh et al., 2004; Pallandino Green & Pritchard, 2003).

Problems with body image. Negative body image tends to become a concern for women cancer patients in the first weeks after surgery, particularly after they undergo mastectomies (breast cancer) or chemotherapy (Favez et al., 2014; Fobair et al., 2006; Helms et al., 2008). In addition to breast loss and alopecia, surgical scarring, breast deformities, tissue damage, decreased range of motion, weight change, muscle loss/weakness, and lymphedema (swelling of the arms and/or legs as a result of lymph node damage) can all negatively impact body image and quality of life (DeFrank, Mehta, Stein, & Baker, 2007; Elmir, Jackson, Beale, & Schmied, 2010; Helms et al., 2008; Lam et al., 2012; Moreira & Canavarro, 2012). This negative body image is more common in women undergoing more radical surgical procedures (e.g., mastectomies) and can be mitigated by procedures such as reconstructive surgery (Brunet, Sabiston, & Burke, 2013; Rosenberg et al., 2012).

There are a number of theories for why body image is such a pressing concern for women experiencing cancer. On one hand, in our society women are commonly taught that their value is heavily based in their appearances (Brown & Jasper, 1993; Brunet et al., 2013). There are also many stereotypes associated with conditions involving weight gain, which these patients may internalize. Some of these stereotypes involve the idea that weight gain is equivalent to a lack of personal control, adding to feelings of control

loss that women with cancer already experience because of their disease (Brunet et al., 2013; Hefferon, Greal, & Mutrie, 2010; Sabiston, McDonough, & Crocker, 2007; Tiggemann & Rothblum, 1997). The negative connotations that many have with these consequences of cancer treatment may also contribute to a loss of self.

Loss of self. Feeling a loss of self or self-image is common in those experiencing chronic illnesses, such as cancer (McWilliam et al., 2000). With this loss of self also comes an absence of confidence in one's health and bodily processes. Overall, this often requires that the individual experiencing chronic illness rely on the support and strength of others until they can regain their sense of self. This heightens the feeling of vulnerability that someone diagnosed with cancer may already have (McWilliam et al., 2000). Heightened vulnerability can often increase the intensity that women with breast cancer experience in moments of communication with their physician which render the valence of these moments, whether they be positive or negative, more powerful (McWilliam et al., 2000). This brings us to the other half of the dyad: the physician.

Communication Styles of Physicians

One general distinction that we can make between male and female physicians is their communication styles. While they do not necessarily hold true for every physician, the trends are relatively consistent through numerous studies. To give a summary of these results, research demonstrates that male physicians tend to take a more assertive and biomedical approach when addressing their patients. They also typically give more advice and interpretation and spend more time on more technical aspects of care (i.e., physical examinations and medical history) than female physicians, who tend to spend

more time on social and family issues. Additionally, female physicians also tend to engage in partnership building, positive talk, and question asking, as well as nonverbal cues that prompt discussion more often than male physicians (Bertakis, 2009; Fang, McCarthy, & Singer, 2004; Hall et al., 1994; Hall & Roter, 1995; Roter, Hall, & Aoki, 2002). They are also more likely to discuss the disease as well as the experience of the disease with patients more often than their male counterparts and have more satisfied patients overall (Bertakis, 2009; Bertakis, Franks, & Azari, 2003; Bertakis, Franks, & Epstein, 2009).

This idea of relationship-building in medical settings holds particular importance when we consider the implications of a working relationship.

In a study conducted by McWilliam et al. (2000), the researchers sought to understand the experiences of women with breast cancer in terms of patient-doctor communication. The findings of this study revealed the value that a working relationship with one's physician has in the overall satisfaction of care. Through speaking with these women, experimenters identified four consistent overall themes that are involved in a working relationship. These include feeling vulnerable, sharing information and relationship-building, creating the experience of control, and mastering the experience of the illness (McWilliam et al., 2000; Figure 2). Experimenters also identified the circumstances under which negative experiences with doctor-patient communication took place, within the frame of these four themes.

Much like positive experiences with patient-doctor communication, negative experiences begin with the feeling of vulnerability. From previously summarized points,

we know that feelings of vulnerability can increase the intensity with which these patients feel moments of good or bad communication. When the next theme, sharing information and building relationships, goes awry, however, the rest of the interaction fails to result in a working relationship. Instead, it was shown that physicians tend to provide poorly timed information, little reassurance, and fail to leave their patient with feelings of hope. As a result, patients typically react by developing a negative view of their physician as well as with feelings of anger and lack of acceptance for both the physician and the information they provided (McWilliam et al., 2000; Figure 2).

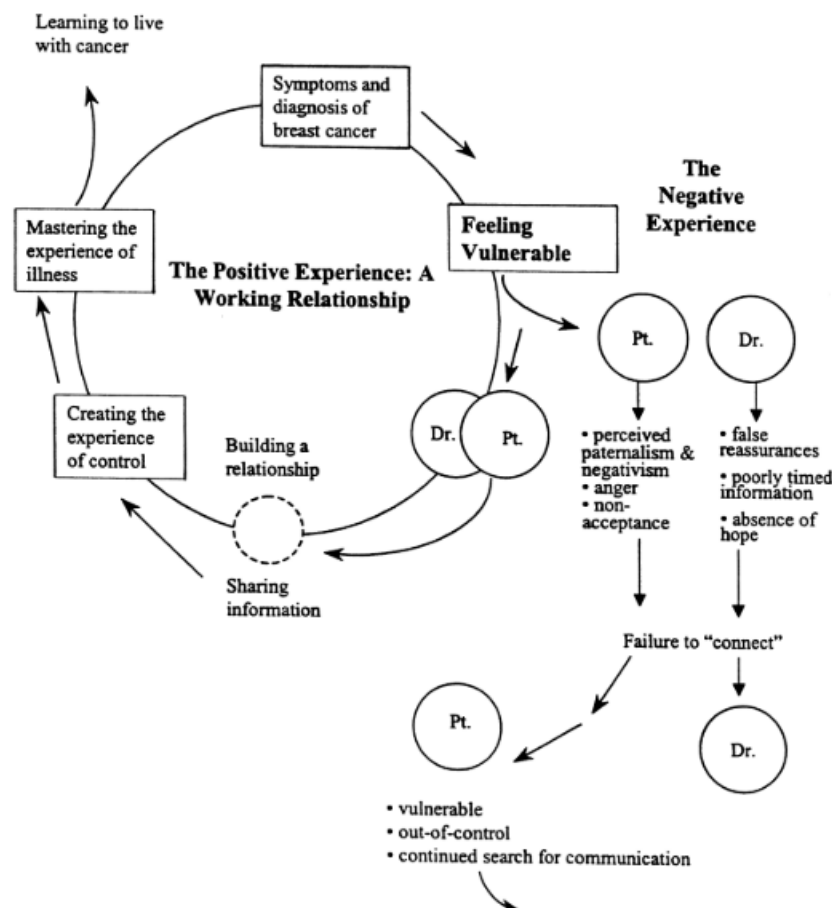


Figure 2: Types of experiences breast cancer patients have with patient-doctor communication (McWilliam et al., 2000).

The results of this study demonstrate quite clearly the value of psychosocial aspects of care. Because women physicians tend to be more successful at this aspect of their profession, we can postulate that male physicians in general may struggle with developing this working relationship, which we can see is very important for the overall well-being of their patients. This ties into PCC in a large way. For example, the fostering of the relationship between a patient and their physician is one of the six main functions of PCC, which were discussed previously. When we see this working relationship established and good PCC practiced, there are many positive outcomes for the patient such as reductions in symptoms of mental illness and emotional distress and increases in empowerment overall (McWilliam et al., 2000).

While these trends in practice style are not inevitable for every physician, this tendency for male physicians to struggle more in practicing PCC can have substantial outcomes for women facing cancer. Research demonstrates that male physicians frequently miss certain signs of distress in their patients, such as depression, physical side-effects of treatment, reactions to physicians' attitudes, issues with prostheses, and psychological reactions to the loss of a breast (McWilliam et al., 2000). Many of these were included in the types of struggles faced by women oncology patients that were outlined earlier. Furthermore, the results of another study conducted by Bertakis and Azari (2012) suggest that the least amount of PCC was observed in gender-discordant interactions between male physicians and female patients occurred. Combined, these

ideas indicate that PCC suffers the most within this type of dyad (male physician and female cancer patient) while simultaneously being the most needed, considering the struggles faced by women cancer patients and the typical communication styles of male physicians.

Conclusion

To conclude, the discrepancy in PCC within this specific gender-discordant dyad is something that must be addressed. As the research has demonstrated, male physicians tend to display communication styles that err more biomedical in nature. This can limit the quality of PCC that can be expressed, given that PCC necessitates a combined biomedical and psychosocial approach. Given the benefits that PCC can have for the patient, it is imperative that it be present in doctor-patient interactions. This is particularly true when struggles such as those faced by women cancer patients specifically are considered. From a higher prevalence of mental illness to highly negative senses of body image, cancer impacts women in a unique and multidimensional way. In order to fully address all of the potential impacts that cancer can have on a woman, physicians must be mindful of how they communicate and work to integrate PCC in their work on a regular basis.

Chapter 4

Another Perspective: Gender-Discordance in Oncology Settings through the Eyes of Healthcare Professionals

In order to gain a deeper understanding of the role that PCC plays in oncology care, I felt it important to seek out the perspectives of those employed in the field. Unfortunately, attempts to recruit multiple oncologists for interviews was not overly successful; however, I was able to obtain views from one male oncologist, specializing in retinal diseases including eye cancers; a female oncology RN; and a female oncology social worker. Due to the varying nature of their professions, these individuals were not asked a consistent series of questions but rather an array of questions tailored to fit their specific job titles and responsibilities. Consequently, instead of reviewing the responses given for each question, I review general patterns I found in their responses that are relevant to my research.

Interview 1: Male Oncologist

One of the most important aspects to note in this interview is the oncologist's familiarity with the concept of PCC. At the start of my interviews, I asked each of my interviewees about their familiarity with the concept in order to gauge our common understandings. When asked this question, this interviewee mentioned that PCC was a common concept in medical education and residency, citing its importance in courses and lectures on patient interviewing. Even though the interviewee recognized the importance of PCC and expressed an understanding of it, his understanding and practice of it seemed

to have a distinctly biomedical emphasis. For example, when asked how he might define PCC, he responded primarily in terms of communicating medical facts at an appropriate level for the patient's understanding and putting it into context for them. While he also mentioned asking about and responding to anxieties and concerns of the patient, this was the only psychosocial aspect of communication that he mentioned. This is interesting when we consider the multiple functions and components of PCC. Additionally, he seemed to recognize the vulnerable position cancer places individuals in but did not mention anything along the lines of relationship-building in our discussion.

The results of this interview show consistency with what the research has been telling us about the communication styles of male physicians. Although he understood PCC and knew what its applications were in his patient interviews, he seemed to struggle in practicing it to its full extent. This may be due to a tendency to focus more heavily on biomedical aspects of care, unintentionally neglecting the balance necessary in good PCC, or the result of an educational emphasis. Regarding his female patients, he felt his treatment of them did not vary greatly from the treatment of his male patients. As a general observation, he believed that women were more likely to ask questions and express emotions than men were but did not mention if his approach varied to compensate for this difference.

This interview specifically put me in a unique position as the oncologist I spoke to is my mother's doctor. Through her accounts and my own observations, it would seem his PCC leaves something to be desired. While he spoke of the importance of nonverbal actions, such as eye contact or physical touch, in expressing empathy, he often neglects to

make eye contact with my mother and will instead look to my father. Contradictions such as these suggest to me that he may not even be aware that his PCC needs improvement in some areas.

Interview 2: Female Oncology RN

Something that I found striking from this interview was that, despite the fact that the oncology RN had never explicitly defined PCC, she practiced it to a greater extent than it seemed the oncologist did. She spoke a great deal regarding sensitivity with the timing of certain information, maintaining a focus on the patient's values no matter what her own may be, and allowing the patient to gain full understanding through responding to questions and concerns. When asked about whether there was heavy emphasis on this concept in her training, she mentioned that nursing school highly values a holistic approach to medicine and care of the patient. I felt this resonated well with the functions and components of PCC.

This understanding was reflected in the ways the interviewee described expressing empathy for her patients. She seemed to take a heavier psychosocial approach to this than the oncologist, stating that she tends to express empathy through techniques like active listening, sensitivity with timing of information, respect of the patient's beliefs and desires, demonstrating compassion with her responses, truthful and forthright responses to questions, and demonstrating respect through both her body language and her words. She also expressed an understanding of the importance of relationship-building through speaking of cancer as a continuum that requires continual as opposed to one-time care of the patient.

In terms of how the RN understood care of women specifically, she seemed to operate under the same understanding of the oncologist in that she mentioned women were more likely to have emotional responses than men. One thing I found particularly interesting was that the interviewee mentioned that, when new symptoms arise, women are more likely to report them right away while men often try to “tough it out.”

Additionally, she mentioned there being a greater need of specific and informative questions with men as they tended to speak very generally about their symptoms while women tend to give a lot of detail about them. I wonder if this is a result of patient gender or gender concordance/discordance. If the RN was male, I wonder if she would have the same struggles in obtaining information from her male patients or if they would feel more comfortable disclosing their symptoms fully.

Interview 3: Female Oncology Social Worker

Much like the RN, the OSW had an in-depth understanding of PCC; she mentioned obtaining her bachelor’s degree in medical anthropology, which had a heavy focus on patient-centered interviewing. Her definition of this concept involved first and foremost keeping the patient’s goals and values at the center of their care. Additionally, she viewed her role largely as bringing a sense of humanity and connection back to the experience of cancer. When asked how she goes about expressing empathy for her patients, she mentioned the importance of listening to get a sense of the person as an individual rather than just a patient, focusing on that identity as a person, and acknowledging/validating her patients. Another thing that I feel is significant is she mentioned she is often able to give more time to the patients and rush less than

oncologists typically do. From research, we know that patients feel their quality of care is higher when their physician is not rushing through or late to their interaction and that this is a substantial barrier to good PCC (Epstein & Street, 2007). When asked about her perceptions regarding how oncologists typically express empathy and concern for their patients, she was unable to speak specifically on the topic as she is often not in the room with them during appointments but mentioned that generally they seemed to do this through pausing to ask how the patient is feeling and occasional physical touch.

Another finding I feel is important to mention is the typical barriers to PCC that the OSW sees arising in doctor-patient communication. She mentioned how she often needs to coach patients to ask specific questions of their oncologists for information they desire but haven't been given. This can be the case when the disease is incurable, and the doctor is hesitant to say this because they are unsure of the patient's level of interest/desire for this information. She mentioned that patients tend to want different styles of communicating information, which can be difficult for physicians to assess. This is particularly true when family or other caregivers are involved in the process as they may desire different levels of information than the patient does. This difficulty in assessing how much information the patient desires is a common theme in the literature but is also extremely critical for good PCC.

Conclusion

Overall, these interviews are consistent with research demonstrating a key difference in approach between men and women in that men tend to be more heavily focused on biomedical aspects of care while women seem to be more at ease integrating

biomedical aspects with psychosocial ones (Bertakis, 2009). This may be a result of specific training or gender socialization or both. I recognize that my sample of interviewees was limited; this is partially due to significant struggles I faced in contacting oncologists who were unwilling or unable to call me back and speak to me regarding the topic. This is problematic as it does significantly inhibit the generalizability of my interview results. Nonetheless, the consistency of trends in the interviews with trends in the literature is interesting and suggests that qualitative data with a larger and more widespread sample size in terms of profession within the field of oncology may lend profound insights to this area of research.

Chapter 5

Concluding Remarks: So What, Who Cares?

The question that must be answered now is, “Why does this matter?” While the answer may seem self-explanatory, this particular topic has relevance in a number of different dimensions and disciplines. Through my education at Regis University, I have been taught how the Jesuit values can have roles in many aspects of our lives; this is no exception. I would now like to remark on how this topic is valuable in light of the values this institution holds dear as well as its importance in my life and future career.

The Jesuit Mission

Although each value in the Jesuit mission has its own particular importance, I would like to focus on three that I feel are especially pertinent to this discussion: *cura personalis*, men and women for and with others, and contemplatives in action. The first, *cura personalis*, means “care of the person.” Not only does it refer to care of the person, but it demands care of the *whole* person. We must consider multiple dimensions (i.e., spirit, body, and mind) when we are caring for others and ourselves. In healthcare, if we are only to address the biomedical concerns that cancer brings, we are neglecting the care of the whole person that values such as *cura personalis* demand. When we engage in good practices, such as exercising PCC in all situations and contexts, we come closer to expressing *cura personalis* in its entirety.

The next value, *men and women for and with others*, refers to having an attitude of service and standing with those who are in need. This can be understood from several perspectives in the topic at hand. For one, we must stand with those who are experiencing cancer and not receiving the proper care. When we recognize injustices in our healthcare system and in the practices of healthcare professionals, we must speak out against them and strive for justice no matter the consequences. From another perspective, we must also stand with the physicians who are providing care for cancer patients. Although many of their communication approaches are not perfect, nothing ever is. We need to aid them in improving care instead of solely pointing out the flaws in their work. When we see discrepancies, we need to take action to bring awareness to them instead of placing the sole burden on healthcare professionals.

This brings me to the last value at hand, *contemplatives in action*. When we recognize problems in our society, we cannot simply think about them; we need to take actions against them. While there is great value in researching issues like PCC discrepancies in oncology care, what good is this knowledge if we do not use it to enact change? What we need is not only a deeper understanding of the quality of PCC in various contexts but also ways in which we can change policies or practices to eliminate problems. We cannot simply think; we must act. Therein lies the importance of contemplatives in action.

Future Directions

On that note, we must now consider what steps can be taken to correct this discrepancy. Issues with PCC can be addressed in two main ways: by focusing on the

patient and by focusing on the physician. The importance of this dual emphasis is seen in the ecological theory of PCC (Plsek, 2001; see Figure 3). This theory is a systems-oriented approach that suggests clinical communications research should be addressing multiple aspects of communication. These include the mutual interactions between physicians and patients and the social and clinical contexts in which these interactions take place (Hoerger et al., 2013). These mutual interactions include the patients' and their caregivers' assertive behaviors and the physicians' facilitative behaviors in medical interactions as well as how they interact to reinforce the participatory behavior of the patient in discussions about their care (Cegala & Post, 2009; Post, Cegala, & Miser, 2002). Assertive behaviors may include expressing opinions, asking opinions, and making requests (Street, Gordon, & Haidet, 2007; Street et al., 2009; Street et al., 2010), while facilitative behaviors may include addressing patients' concerns and helping patients participate in their care (Clayton, Hancock, Butow, Tattersall, & Currow, 2007; Dimoska, Tattersall, Butow, Shepherd, & Kinnersly, 2008).

One example of something that can be done to promote assertive behavior in the patient is patient activation interventions (Epstein & Street, 2007). This intervention relates to something the OSW that was interviewed said regarding how she addresses barriers in doctor-patient communication. To review, she mentioned the need to coach her patients to ask specific questions to receive desired information from their oncologists. Similarly, patient activation interventions center on teaching patients to be more participatory in medical interactions through question-asking and playing larger roles in decision-making (Epstein & Street, 2007), which are similar ideas to those

suggested by the ecological theory (Hoerger et al., 2013). This demonstrates that, while this thesis primarily focuses on the physicians' side of this relationship and the roles and responsibilities they have in PCC, every relationship is a two-way street. Participation in medical interactions is one example.

Although assertive behaviors in patients are important, research shows that these kinds of approaches from patients can have detrimental effects, such as decreased patient satisfaction and increased physician frustration, when the physician is not prepared for the change in behavior (Kinnorsly et al., 2007; Street et al., 2010). Therefore, physicians must also be trained in facilitating this assertive behavior. An example of a study that takes into account the mutual interactions and ecological framework of PCC is one conducted by Hoerger et al. in 2013. This research, entitled the VOICE study, focuses on applying interventions on both sides of medical interactions. While the study has not yet been conducted due to several challenges, its design proves promising through its multi-dimensional focus and is one example of how both assertive behaviors in patients and facilitative behaviors in physicians might be improved to enhance PCC (Hoerger et al., 2013),

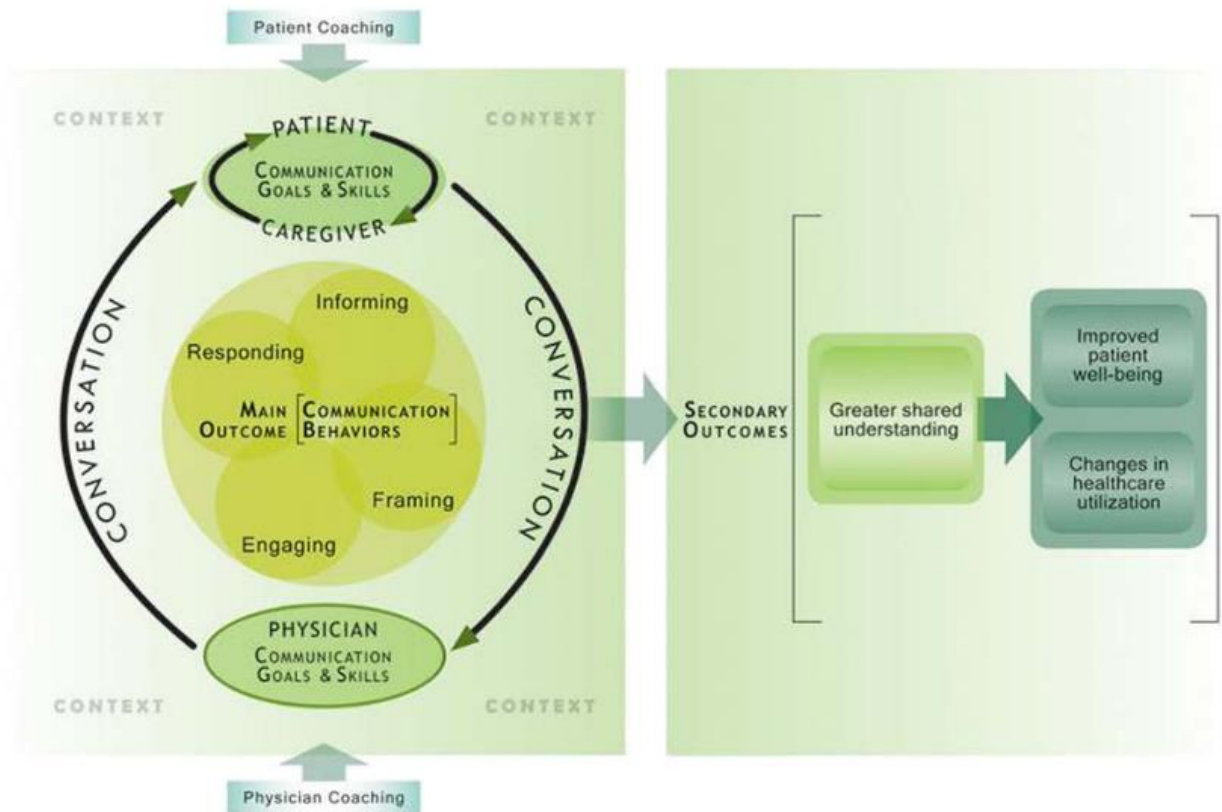


Figure 3: Ecological model of PCC (Hoerger et al., 2013).

Research Limitations

Literature Review. To address potential limitations in my research, many of the studies cited (especially in the section on struggles faced by women cancer patients) focused primarily on women diagnosed with breast cancer. This is understandable, given that breast cancer is the most common cancer for women worldwide, accounting for 25.4% of diagnoses (Brunet et al., 2013; Ferlay et al., 2010; “Worldwide cancer data”, 2018). However, this may raise some concerns regarding the generalizability of the findings. I would argue that, while some components of the experience of breast cancer cannot be generalized to other cancers (e.g., the impacts of a mastectomy), many of the

other impacts are present in a number of other cancers. For example, chemotherapy is a treatment commonly used for individuals experiencing a wide array of diagnoses.

Subsequently, alopecia would also be a struggle commonly experienced. Depression and anxiety are also effects that many suffer, as well as weight gain, surgical scarring, muscle weakness, and loss of self. This is to say that, although the studies specifically target breast cancer, the impacts of cancer do not. Therefore, I would argue that, although this may be a potential limitation in my research to some extent, the results can be generalized overall.

Interviews. In terms of my interviews, there are two main limitations that come to mind. The first is my sample size, With only three professionals providing qualitative information, my sample size was fairly small. This is a limitation because it inhibits the generalizability of the information obtained from the interviews. Although the information demonstrates some consistency with trends found in research, we cannot make definitive statements regarding its validity to populations outside of my three participants. Another limitation was the fact that I only had one oncologist with the rest of the professionals focusing on a different aspect of the field. This is an issue because the oncologist's training likely contributed substantially to his views on PCC and how he practices them in his work. The same holds true for the other professionals. Therefore, it is a definite possibility that variations in how they practice PCC could be due to their training instead of their gender. In order to definitively determine this, we would need a much larger sample size with multiple professionals working in these careers,

Personal Relevance

This topic, as you might guess, holds a great deal of personal significance for myself. I have watched loved one after loved one suffer and die from this disease. Will cancer ever be cured? I have no idea. But I know that the destruction caused by cancer is not limited to the physical damage to the body. It can wreak mental and emotional havoc just as easily and in many different ways. Maybe it is through the stress caused by the disease itself or maybe it is through sub-optimal practices that have been made the norm through decades of fighting against this illness. I can't cure cancer. I don't know if anyone can. But we can show love and empathy toward those suffering from it. This is what I want to do with my life and my future career in oncology social work. If I can make just a small difference in the hell that those diagnosed with cancer are facing, I will consider my life a success. Topics such as this give me hope that this can be accomplished. While it is a significant issue, it is not unresolvable. If individuals like myself who care for those with cancer can address some of these problems, then differences can be made even if cancer itself isn't cured.

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