RENAL CELL CARCINOMA: THE IMPACT OF PATIENCE EXPERIENCE WITHIN THE DIAGNOSIS PROCESS, A QUALITATIVE STUDY

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ABSTRACT: Cancer is known to be the second leading cause of death in the United States of America. More often than not, uncommon types of cancer are overlooked. Renal Cell Carcinoma (RCC) occurs in fewer patients than well-known cancer types such as breast cancer or colorectal cancer. However, RCC is a brutal cancer that results in a minuscule number of survivors and takes lives away from loved ones far too early. Although RCC is less frequent than other forms of cancer, no effective screening methods have been implemented to diagnose RCC prior to a metastatic stage. The lack of a screening method could be attributed to the survival rates RCC has. This research proposal will explore the patient experience of RCC patients. Cancer patients are usually viewed as their disease first and not as a person first. Except, the patient knows themselves the best. Our research was designed to humanize cancer patients to better understand how traditional medicine may have failed them prior to diagnosis. RCC patients cannot advocate for themselves in a system that is not currently made to support the detection of their disease. Our end goal for this research is to create a tool that will be better at detecting RCC while the cancer is in its early stages.

Introduction & Background

Overview

Cancer is the second leading cause of death in the U.S. (Siegel et al., 2022) and is expected to take the life of 609,360 people annually in 2022 (Siegel et al., 2022). All types of cancer are brutal and unrelenting disease that has taken many years to understand. Research has supported the creation of intervention and screening methods for common cancer types to reduce deaths. However, there are groups of people that have uncommon cancer types that are still suffering from a lack of screening methods and underfunded research. The consequences of not having proper screening tools can be detrimental to the overall survival of patients.

Every patient with cancer is someone's spouse, child, sibling, or parent; they have a life outside of their disease. Medicine tends to strip humanity from illness because it is easier to view a patient as that illness than their life interwoven with their symptoms. Every patient, regardless of their illness, should have the ability to be screened before their cancer is detrimental to their life and beyond the point of successful intervention. Without enough money and a reduced call to action for populations with rare cancer forms, adequate screening methods have not been created or implemented.

Cancer Statistics in the U.S.

As communicated above, it is predicted that in 2022 cancer will take 609,360 people's lives, which translates to roughly 1700 deaths per day (Siegel et al., 2022). However, it is estimated that there will be 1,918,030 new diagnoses of cancer in 2022 (Siegel et al., 2022). Meaning the overall predicted death rate of cancer in 2022 is 31.77% (Siegel et al., 2022). Breast cancer, melanoma (skin cancer), and prostate cancer will have the highest survival rates seen within all stages of cancer (Siegel et al., 2022). Prostate cancer is determined to have a survival rate of 98%, alongside melanoma which is estimated to have a survival rate of 93% among all stages (Siegel et al., 2022). However, breast cancer will have a survival rate of 90%, and the death rate of breast cancer has been 1% in recent years (2013-2019) (Siegel et al., 2022).

The impact cancer has on individuals is shocking and even disheartening. However, it cannot be overlooked how money is attributed to how each cancer is treated in the U.S. and how those findings may even correlate with survival rates. Regardless of cancer type or stage, cancer will leave an impact on all of those affected. It is a scary disease to fight. These numbers and shocking results should not be overlooked. Beyond these findings, another fundamental statistic for cancer in the U.S. is the amount of money each branch of cancer receives annually. As of August 1st, 2021, breast cancer received 153 grants which translates to 102,914,200 funded dollars, of which 71,483,945 dollars were used ("Current grants by cancer type, 2021). During the same time frame, prostate cancer received 53 grants, a total of 41,650,102 funded dollars ("Current grants by cancer type", 2021). It could be assumed that the amount of money each cancer type receives highly influences how the cancer is treated and could even be attributed to survival rates. The remainder of this proposal will highlight specifically Renal Cell Carcinoma (RCC), which is much less common. As of August 1st, 2021, RCC received 13 grants and 8,612,500 funded dollars ("Current grants by cancer type", 2021). It is important to keep these comparative statistics in mind during this proposal as issues about RCC come to light.

Renal Cell Carcinoma

Renal Cell Carcinoma is a rare cancer that has flown under the radar due to insufficient screening techniques, despite how brutal the prognosis is for the patient. This cancer is found within the kidneys and develops from renal tubular epithelial cells (Hsieh et al., 2017). RCC is roughly seen twice as much in males than in female patients (Wallen et al., 2007). RCC is a male-focused cancer, however, both men and women will be diagnosed the same as one another. RCC is an uncommon form of cancer that occurs within about 4.1% of cancer cases in the U.S. (Bethesda n.d.). Even though that percentage may seem small, that little percentage is equivalent to 79,000 patients (Bethesda n.d.). RCC has other subtypes, but the most common is Clear Cell Renal Cell Carcinoma (ccRCC) at 75% in all kidney cancers (Petejova & Martinek, 2016). Beyond RCC and ccRCC, it is important to note that there is a hereditary version of this cancer that occurs in every 1 in 30,000 RCC patients. The genetic form of RCC can be caused by the mutation of the von Hippel-Lindau (VHL) gene (Maher, 2018).

70% of RCC patients are diagnosed through accidental findings and are either advanced within the local area or already metastatic (Chen & Uzzo, 2011). This occurs because only 10% of patients present with the "Classic Triad" (Padala et al., 2020), which is defined as hematuria (blood in the urine), flank pain (pain within the mid/side of the back), and palpable masses (masses that can be felt through abdominal examinations) (Padala et al., 2020). Diagnosing RCC can be difficult due to the typical set of diagnostic markers being present in such a small number of patients. It is important to note that most of the time, a suspicion of RCC isn't the reason an imaging procedure will be performed. We must take into consideration the survival rates RCC has during this proposal. Even though there appears to be a good chance of survival, the public may not be aware of what different stages implicate for survival rate. A patient with stage 1 RCC has a 5-year survival rate of about 84% (Rossi et al., 2021), but most patients are not diagnosed this early. The majority of patients are diagnosed closer to a metastatic stage which presents with a 5-year survival rate of 6% (Rossi et al., 2021). This cancer is a killer by nature. With the no effective screening methods and late-stage discovery being normal, patients diagnosed with this cancer have little to no chance of beating this from the start.

Current Screening Techniques for RCC

Out of a plethora of literature being reviewed, only one piece of literature had the intention of

discussing the expansion of screening methods. It reviewed what patients' thoughts on current screening method options would be, which follows our "Classic Triad" (Padala et al., 2020). Most patients, from the literature, only wanted to take the option of blood or urine screening methods, as it was perceived that CTs may be too invasive (Freer-Smith et al., 2021). However, blood and urine tests do not do an efficient job of indicating an issue within the kidneys. Typically, after these tests have been completed, doctors would be prompted to look deeper through imaging tests. However, most patients do not have the three most common symptoms let alone even one of them. These patients' tumors are found by accident while performing a CT or ultrasound. Our current practices are inefficient, and though imaging can be viewed as intimidating, it would be the most effective test we have today. Relying on uncommon symptoms to appear to indicate an uncommon problem is only letting the cancer progress further. Hence the reason when it is finally found by accident, it is usually an advanced form of cancer beyond treatment for eradication.

Importance of Cancer Screening Techniques

In this proposal, we have displayed what screening techniques exist for RCC. However, in order to create a more efficient method for RCC, it is important to discuss what already works for other cancer types. Due to research and time, we are able to detect certain types of cancer before it reaches a point of detriment. Over the years, multiple screening methods have been introduced for a plethora of cancer types. In this section, we will be reviewing methods that have specifically been implemented for colorectal cancer and cervical cancer.

A study done in Japan tested the effectiveness of immunological fecal occult blood tests (Nakama & Kamijo, 1994). The research involved collecting data from current CRC patients with varying stages of cancer, healthy

individuals, and a mass screening technique of individuals. It was found that these tests were an effective method of screening for CRC after an extensive study. Even though early colorectal cancer screening methods were developed in the late 1960s (Smith, 2020), annual fecal blood testing was not implemented in high-risk groups until 1974 (Smith, 2020).

Pap smears were developed in 1957 (Smith, 2020) to help diagnose cervical cancer and were encouraged to be done annually by the American Cancer Society (ACS) (Smith, 2020). A qualitative study researched what it was like for women to receive an abnormal pap smear result to determine how much they knew and why they chose to partake in the screening process. It was found that most individuals related screening to being a healthy individual, and some had personal experience with cervical cancer in their family or friends, which led them to take action (Er Güneri & Şen, 2019).

When looking at new screening methods, researchers need to be aware that patients of different backgrounds and situations may approach screening differently. Part of finding an effective screening method is adapting it to be accessible and learning from groups that may struggle more than others. For example, a study was done to learn how patients in highly deprived areas who were at high risk for lung cancer responded to possible screening methods or medical treatment (McCutchan et al., 2019). An effective screening method will take both accessibility and effectiveness into consideration while the tool is being developed.

Gaps in Knowledge & Significance of Proposal

As of right now, there is no definitive screening method that will help catch RCC before it is metastatic. With a lack of education and public knowledge, this cancer will continue to take the lives of more patients. Since there is no effective screening method for RCC

currently, it is difficult to find literature that only supports RCC. Methods have been tested, and social opinions have been recorded, and yet none have been implemented as an actual efficient screening method. This leaves a large amount of room for researchers to learn. However, it is difficult to declare specific data that supports this research proposal. Most of the literature reviewed was based on other forms of cancer and the methods/screening tools created for other types of cancer. Some literature had very specific populations in which actual cancer patients may not have been involved, and that can skew literature in a direction that is not entirely helpful to this research proposal. Most of our answers will lie within the lives of the people who experienced this cancer firsthand. There is still so much left to learn, and with an obvious lack of quantitative statistics, the best approach is to view this cancer in a qualitative manner in hopes of urging for the development of quantitative data.

Beyond that, every patient knows their body better than anyone else and is more likely to feel or notice a problem before blood or urine tests (Freer-Smith et al., 2021) demonstrate measurable symptoms. This cancer is deadly and has no true treatment. If patients were encouraged to look for telltale signs of this cancer, just like women are encouraged to perform self-breast exams for breast cancer (Smith, 2020), more people may be able to survive. Just because this cancer cannot be seen within a large percentage of the general population does not mean that it carries any less significance among those who watch family members get diagnosed and ultimately die of this cancer.

Research Question and Hypothesis

This proposal was created to humanize RCC patients and to understand their experience with their RCC diagnosis. The intent of the study is to determine if there were similar symptoms, trends with miscommunication and disinformation, and a lack of urgency among healthcare providers that the patients underwent. Patients are the best at knowing what is wrong with themselves. If doctors were to be aware of specific factors that are not always detectable via standard tests, there may be a way to reduce how many patients are falling into the metastatic 6% survival rate category (Rossi et al., 2021). Information for the patient and more attention from medical staff could be the difference between life and death. These ideas prompt the question of this research: How could a patient's experience leading up to their diagnosis and knowledge of their own body influence the recognition of RCC in an earlier stage of development?

This proposal will follow a qualitative manner of research to identify themes amongst patients who were diagnosed with RCC. Though predicted results may be different than a true outcome, it is expected that there will be commonalities among RCC patients' experiences throughout their diagnosis process. We anticipate seeing some similar symptoms patients felt before diagnosis, such as extreme fatigue and pain in the body. As well as we expect to see a trend of miscommunication among doctors and patients during this study. Already, it is likely that most patients will express that the identification of their cancer came from an incidental finding since research has proven 70% of patients are diagnosed this way (Chen & Uzzo, 2011). Due to the rate of incidental findings, as stated above, naturally, there will be a wide range of data collected. It is important to note that this study will likely be broad at first, although we can hypothesize which experiences may overlap between patients, there is no guarantee they will. Our mission for this research is not to reiterate this statistic, but rather to promote the ideology that there may be a factor that doctors are missing, but patients notice. The hope is that the answer to this specific research question will begin to open doorways to finding an effective method of screening for future RCC patients.

Research Approach

Research Design

As stated above, the study will take a qualitative research approach, specifically survey qualitative research. It was imperative to choose this method as this research will turn words and experiences into data via one-on-one interviews. Although statistics are an important aspect of research, they are not all-encompassing of emotional feats some may have experienced. For these reasons, the research will collect data that will undergo thematic coding. Our target group is current RCC patients who have had a range of experiences through their diagnosis. As mentioned previously, we are specifically looking for miscommunication between doctors and patients and similar symptoms felt between our patients. A variation of diagnoses is welcome to make our proposed screening tool the most comprehensive of RCC patients that it can be. This study was designed to be different, as there is not much to build off of since RCC screening research is limited. Though experiences may not seem like the most effective method to determining a screening tool, it will help doctors and other healthcare professionals understand what these patients experience. In order to convey the importance of RCC and shine a light on our current screening flaws, this research design was the best layout.

Study Population and Sampling

This study will be enrolling participants from Fred Hutch Cancer Center (FHCC) in Seattle, WA. Enrollment will be between 15-20 RCC patients. Within this study, convenience sampling will be used. Patients within the population of FHCC will be easier to find and access. Preferably, this study would include patients of any stage of RCC and have any subtype of RCC, such as ccRCC. In this study, it would be optimal for at least one of the patients to have the VHL gene and at least one patient to have been diagnosed in the local RCC stage. This study will be voluntary. Our team will provide fliers inside the facility and ideally be able to speak to patients at the Seattle, WA, location. However, researchers will not be permitted to persuade the patient into this study. The researcher will not be able to tell patients they may be ideal for this study. The research team will be able to elaborate on the mission and answer questions about the study for the patient. Patients may be referred to join the study via provider. However, the provider will not be permitted to enroll the patients in the study. All patients will need to undergo screening via the researcher to qualify for this study. This will allow for patients to join on their own terms and ensures that the patient will not be manipulated into joining this research study. The goal is to create a welcoming environment for RCC patients to disclose their experiences with a researcher who has the intent to create a functional screening method for future RCC patients.

Operationalization and Measurement

This chart will help define what different stages of RCC imply for this research. For example, this proposal speaks about advanced or metastatic RCC vs local RCC. In order to reduce confusion so this study could be done in other places again, these stages will be defined in Figure 1. Due to the nature of this study, there are no measurable variables. This study will be using words as data. The data will be collected via our individual interviews. This study will be conducted with the hope to create an efficient screening tool in the future.

Data Collection

After participants have been enrolled via voluntary sign-ups and have been screened, this study will collect data via one-on-one individual interviews. These interviews can be done either virtually with a research lead or in person This is to allow patients to feel comfortable within their environment. Each participant will be interviewed with the same 10-12 open-ended questions that will build the foundation

Figure 1 – RCC Staging Definitions

Stage 1	The tumor is less than 7 cm and is still within the kidneys (Atkins, 2022). This is considered Local RCC.
Stage 2	Tumor has grown beyond 7 cm but only remains in the kidneys, and there is no spread to outer lymph nodes or organs (*"Kidney cancer stages: Renal cell carcinoma staging",* 2020). Alternatively, the tumor has extended into the renal vein or vena cava but has not extended into the adrenal gland (*"Kidney cancer stages: Renal cell carcinoma staging",*2020). This is still considered Local RCC
Stage 3	At this point, the tumor may be any size, it may be outside the kidney in nearby lymph nodes (*"Kidney cancer stages: Renal cell carcinoma staging",* 2020). However, at this point, it has not left the local region, meaning there are no new spots seen in outer lymph nodes or organs (*"Kidney cancer stages: Renal cell carcinoma staging",*2020). This is still considered Local RCC.
Stage 4	The tumor has progressed into the outer layer of the kidney tissue and adrenal glands (Atkins, 2022). Or cancer has spread to other lymph nodes both close to the origin or far away, or tumors are found in other organs (Atkins, 2022). This is considered Advanced or Metastatic RCC.

for possibly finding similar symptoms or miscommunication patterns. Please see Figure 2 to see examples of the study's intended research questions. Their responses will be consensually recorded by the researcher, and notes will be taken during the interview. All documents will be held under confidentiality laws and no specific details of the person's identity, such as name, birth date, etc., will be revealed in the data analysis. Individual interviews are the best research design for this study as they will allow patients to have their own personal time to express their moments clearly to the researcher.

Data Analysis

This study will gain its data using coding and thematic analysis from the interview transcripts and notes taken by the researcher. Each individual transcript will undergo a coding process for the researchers to identify themes. After this has been completed, each coded transcript will be compared with other transcripts in order to reveal if the hypothesis is true and if common themes, such as miscommunication and symptoms, can be seen between our patient's stories. It is important to note that his study is not limited by stage or subtype, which creates a wide variety of RCC patients. This research was designed to include different stories or experiences. Each story should be taken into consideration for a potential screening method. An exception to data collection will be determined if a patient has to withdraw from the study and we have only collected partial data via interview. Their data will be removed from the study, and a new participant may be needed. It is imperative that we have full interview notes and transcripts to code as the designed open-ended questions layer on top of each other to find key thematic elements in an efficient manner. If our hypothesis is correct, we anticipate seeing a theme of miscommunication between doctors and patients prior to or during their diagnosis. We also anticipate seeing a higher noted rate of fatigue in these patients' compared to healthy individuals prior to diagnosis.

Figure 2 – Research Question Example

Themes	Preliminary Question Outline
Patient Background	1. What was your occupation prior to diagnosis? 2. Did you have any risk factors for RCC prior to diagnosis?
Miscommunication	1. How many doctors did you see before the final diagnosis, and what was that process like? 2. Did you feel heard during your doctors' appointments prior to diagnosis or during diagnosis?
Symptoms	1. How were you feeling, physically, prior to the diagnosis? 2. Did you have any notable symptoms that seemed out of the ordinary from day to day?

Ethical Considerations

This study will obtain IRB approval in order to protect the participants throughout the duration of the research. All participants will be protected by HIPPA, a federal law that protects sensitive patient health data from being distributed without knowledge or consent ("Health Insurance Portability and accountability act of 1996 (HIPAA)", 2022). In order to allow for consideration, all participants will be given direct information about the intentions of the study via paperwork. The patients will be able to ask any questions before they are admitted into the study and may continue to do so for the rest of the study's run time. Each participant will need to sign paperwork indicating informed consent after the distribution of this information and time for questions has been allocated. This study may become emotionally taxing as re-evaluating the patients' diagnosis could be especially triggering. At any point during the study, if the participant chooses to withdraw, they will be able to exit the study immediately. The physical and mental health of the participants is of utmost importance and will be protected for the duration of the study.

Discussion

Significance

Renal Cell Carcinoma may not take up a large portion of the general population's mind, but it does not make this cancer or its effects any less real. RCC is a killer. There may only be 79,000 (Bethesda n.d.) patients who die annually from this cancer, however, every single one of those people was important to someone else. Without more information on this cancer, RCC will remain a silent killer, one that takes loved ones with little to no warning and under everyone's nose. A cancer that kills patients due to insufficient screening methods should be a center of focus and researched significantly more. Researchers have clearly devoted disproportionate amounts of money to other cancers to find effective screening methods. For example, as explored above, breast cancer patients are expected to have a 90% survival rate with a death rate of 1% and 153 grants donated

by August 1st, 2021 ("Current grants by cancer type, 2021). As for RCC, it is holding steady at a 6% survival rate (Rossi et al., 2021) and has lower funding per year via grants with a total of 13 ("Current grants by cancer type, 2021). RCC may not impact as many patients as breast cancer, but RCC does not allow a patient to fight cancer due to its nature. The U.S. has roughly 2.5 million breast cancer survivors (Bodai & Tuso, 2015), whereas RCC will kill the person they were and the patient they have become before the patient gets a chance to become a survivor. Screening methods and techniques will improve the amount of lives lost to this cancer, but time and money must be devoted to the cause first and foremost.

Limitations

Currently, there are no efficient screening methods present for RCC. Without a backbone of science, the study is building itself. A study that involves the observation and analysis of a patient's emotions can be risky. There may not be enough volunteers to sign up for the study and go through with the data collection process. Though the intention of the study is to regulate a safe environment where patients can be heard, and their frustrations can be taken into account, there is still a chance what we hope to see is not produced. Another limitation of this study is the precision of the location. Out of convenience, this study will take place in Seattle, WA. However, these results will not be accurate for the general population. For more results, this same study would need to be conducted amongst RCC patients in multiple cities and states of the USA at other cancer facilities.

Future Directions

As said previously throughout this research proposal, currently, RCC does not have a screening method that correctly identifies this cancer before it is too late. Ideally, this research would open the door to creating an efficient and important screening method for RCC. The hope

is that the experiences of the patients will allow doctors to create a method for seeing potential RCC signs before it is too late. Medical professionals use screening methods that are easy for patients to use frequently in daily practice. For example, mental health screens for Major Depressive Disorder (MDD) uses the PHQ-9 form, and General Anxiety Disorder (GAD) uses the GAD-7 form (Pranckeviciene et al., 2022). Both forms were created to help doctors detect MDD and GAD via a questionnaire by the patient (Pranckeviciene et al., 2022). If the results from this qualitative research study were able to create a questionnaire for patients to detect symptoms sooner, we may be able to detect their RCC before it is metastatic and beyond removable.

This proposal was also created with the hope that some attention will be brought to this cancer. In this lifetime, it would be wonderful to see an effective quantitative screening method created. But, for now, a qualitative approach will hopefully start the conversation and create some screening tools until a quantitative answer can be found.

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