Patient Conceptualizations of the Patient-Provider Relationship: A Discourse Analysis of the r/dialysis Subreddit

by

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B.Sc., University of British Columbia, 2018
BSN, University of British Columbia, 2020

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We acknowledge and respect the Lək ʷəŋən (Songhees and Esquimalt) Peoples on whose territory the university stands, and the Lək ʷəŋən and W̱SÁNEĆ Peoples whose historical relationships with the land continue to this day.

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Abstract

Patients on dialysis develop unique relationships with their providers, fellow patients, and the broader healthcare system. These connections are well established as key factors influencing both their healthcare experience and mortality rates. Yet, despite ongoing efforts to improve these relationships, health outcomes remain unfavorable for dialysis patients. Exploring these relationships through a social media platform provides valuable insight into patient lived experiences, shedding light on pervasive power dynamics as seen from the patient perspective. This unique approach helps identify critical areas for improvement to enhance the experience and health outcomes of patients on dialysis. In this paper I use Foucauldian discourse analysis to examine posts and comments from the r/dialysis forum on Reddit submitted between 2012 and 2023, focusing specifically on dialysis initiation. It explores how societal discourse shapes patients' impressions, communities, and frameworks as it both forms and is formed by peer-to-peer interaction. The study highlights how power and resistance are reflected in the linguistic choices made by patients, as well as their evolving conceptualizations of the patient-provider relationship as they begin their dialysis journey. These insights add to the dearth of current literature that use social media platforms and discourse analysis in investigating the healthcare experience. They lay the groundwork for better supporting a vulnerable clinical population and provide a foundation for future academic research using this methodology.

Keywords: dialysis, patient, provider, relationship, discourse analysis, Foucault

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List of Abbreviations

Abbreviation	Unabbreviated
FDA	Foucauldian Discourse Analysis
RRT	Renal Replacement Therapy
CKD	Chronic Kidney Disease
ESRD	End-stage Renal Disease

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Dedication

To every patient I've had the privilege of caring for, and the caregivers who came to every appointment - thank you for teaching me what it means to be a nurse and a human. My work is because of you.

Chapter 1: Introduction and Overview

1.1 Positionality

Before introducing my thesis, I felt it was important for me to reflect on why I chose to do this work. Working as a registered nurse with hemodialysis patients in an outpatient unit changed my view of the world. My patients taught me many things, including the value of agency, what it looked like to love, and what it meant to have a quality of life; but above all, they showed me the impact that we as providers have on their journey. Throughout my time on the dialysis unit, patients cried to me, yelled at me, and laughed with me. I celebrated with those who received a kidney transplant, and grieved for those who never had the opportunity. I experienced the unique intimacy that came with forming a long-term relationship with patients on life-sustaining treatment. Yet there are many patients and providers who have not shared in this experience. This thesis was driven by a hope that more patients would have their voices heard, and find the faith to trust their providers; in turn, I hoped that more providers would listen, and find the courage to be their advocate.

1.2 Introduction

The patient-provider relationship is foundational to quality healthcare provision, with recent literature highlighting the numerous benefits of shared decision-making and mutual respect between patient and provider (Hreńczuk, 2021; Kohatsu et al., 2024; Shay & Lafata, 2015). Both health outcomes and the subjective healthcare experience can improve significantly with enhanced interpersonal interaction (Haverfield et al., 2020). These effects are particularly salient in dialysis-dependent patients, as they typically attend life-sustaining treatment sessions three times a week and rely on both nurses and physicians for their care. Beyond the technical provision of dialysis, renal staff provide psychological support and education (Stavropoulou et

al., 2017), as well as serve as a point of contact and coordination within the healthcare system (Cropley & Duis Sanders, 2013). Patients on dialysis are often burdened with a host of comorbidities, and the consequential physical, practical, and psychosocial challenges can require close interdisciplinary monitoring (Murtagh et al., 2007; Powathil & Anish, 2021). Healthcare providers therefore play a significant role in the creation and maintenance of quality of life for many patients on dialysis, from their initial diagnosis through to eventual transplantation or palliation.

Dialysis initiation is one of the most vulnerable periods of the renal patient's journey, with 54.5% of older adults starting hemodialysis dying within the first year (Wachterman et al., 2019). Many find it challenging to adapt to a new lifestyle, especially those who are elderly, frail, and already limited in their independence (Schaeffner, 2022). This is therefore an ideal time for providers to establish their role in the patients' lives as a positive and supportive force. There is a growing pool of research targeting the patient perspective during their transition to dialysis (Henry et al., 2017; Mitchell et al., 2009; Sedin et al., 2023), which in turn has supported the implementation of transitional care initiatives. These initiatives aim to make the transition easier through interventions such as gentler medical stabilization, dedicated spaces, and specialized staff to educate new patients (Bowman, 2019). Emerging data has been promising; however, closer inspection reveals that much of the literature around patient-centered needs employ the same methods – qualitative interviews – to collect their data. This has led to limitations that are not adequately addressed by using other methodologies, such as retrospective bias and social desirability, as well as the obscuring of alternate perspectives. The current study addressed some of these gaps by engaging in a discourse analysis of the subreddit r/dialysis, an online forum for

dialysis-dependent patients, and offered new insights into the relationships between healthcare providers and patients.

1.3 Statement of the Problem

Studies on the relationship between patient and provider are growing in number, but most existing studies use interviews as their method of data collection (Cantor-Cruz et al., 2021; Hussain et al., 2015). Interviews are a popular choice for qualitative studies due to the rich and detailed insight that the resulting data provides (Knott et al., 2022). The interviewer can ask questions to clarify or follow up on topics of interest, which allows for a more thorough understanding of the targeted phenomenon. However, using this method also comes with limitations. These limitations, if not adequately addressed, create gaps in knowledge that may be contributing to ineffective patient support. For example, transitional care units aimed at providing “optimum instruction about self-care” (Eschbach et al., 1983) have been implemented since the 1980’s, yet decades later studies on their impact remain limited (Attalla et al., 2020) and reports of dissatisfaction with patient-provider communication remain high (Bear & Stockie, 2014; Kuo et al., 2024; Song et al., 2013). Inadequate patient-provider communication has furthermore been associated with reduced treatment adherence and poorer clinical outcomes across the general patient population (Haskard-Zolnierek et al., 2021). New approaches are needed that bring different knowledge to the foreground and awareness to the relational and dynamic aspects of this unique relationship. These insights will assist in creating high-impact initiatives that enhance communication, working in tandem with existing literature to improve clinical outcomes.

1.4 Research Question

How do patients receiving hemodialysis understand and discuss their relationships with healthcare providers, as reflected on the r/dialysis subreddit? A Foucauldian Discourse Analysis (FDA) is applied to investigate the overarching power discourses that shape patient conceptualizations of their providers and provider relationships.

1.5 Research Aims and Significance of the Research

The purpose of the study was to explore hemodialysis patients' perspectives on their relationships with healthcare providers, namely nurses and physicians. While there is a growing pool of research targeting the renal patients' experience transitioning into dialysis, qualitative interviews are used almost exclusively. Moreover, few examine the patient relationship with their providers in this particular population. This study addressed both these issues and allowed a more thorough understanding of the renal patients' experience. In the context of the established importance of a positive patient-provider relationship, and the persistent vulnerability of the dialysis-dependent population, these insights play a significant role in improving quality of life and clinical outcomes.

Chapter 2: Literature Review

2.1 Transitions into Dialysis

2.1.1 The Dialysis Population

Patients diagnosed with kidney failure are treated with either renal replacement therapy (RRT) or supportive care. RRT comprises two treatment types, kidney transplants and dialysis. While transplantation is associated with favorable clinical outcomes and quality of life (Tonelli et al., 2011; Yoo et al., 2016), dialysis remains the most common treatment due to a combination of patient ineligibility and an ongoing shortage of kidney donors (Matas et al., 2023). Dialysis replicates two major functions of the kidney by removing excess fluid from the body and cleaning toxins from the blood, and is medically considered a life-sustaining treatment (Himmelfarb et al., 2020). As of 2017, it is estimated that kidney failure impacts up to 9.7 million people across the globe (Himmelfarb et al., 2020), with over 25% of these individuals receiving RRT (Kitzler & Chun, 2023), and 69% of RRT being accounted for by hemodialysis (Bello et al., 2022). Mortality rates of hemodialysis patients are invariably high across the globe, despite some differences in outcome between countries; approximately 50% of all hemodialysis patients in Canada will die within 5 years of initiation (Kitzler & Chun, 2023). When compared to other chronic diseases, the quality of life for dialysis patients is also significantly reduced (Kitzler & Chun, 2023). Despite recent literature bringing more attention to the unique needs of renal patients, chronic kidney disease (CKD) has become the eleventh leading cause of death globally from the eighteenth in the span of two decades, from 1990 to 2017 (Bikbov et al., 2020).

Each renal patient's journey is unique. Hemodialysis is often associated with long-term CKD that eventually progresses to end-stage renal disease (ESRD). For some, initiation of treatment is expected after years of gentle decline despite their best efforts at managing the

disease. For others, it can come on suddenly after an acute injury, such as an infection or myocardial infarction (Forni et al., 2017). Acutely injured kidneys have a chance of full or partial recovery, but this is difficult to predict and requires weeks of monitoring for potential improvement. After 90 days, most patients are considered “chronic” and will have to consider their options for maintenance dialysis (Forni et al., 2017). Dialysis options generally include peritoneal dialysis, which uses the peritoneum as a filter, or hemodialysis, which uses a machine. Patients with more functional independence may be eligible for peritoneal dialysis or home hemodialysis, which grants them more flexibility and control; however, for a variety of physiological, practical, and social reasons, many do not qualify (Walker et al., 2015). All patients on dialysis must make critical decisions around their treatment and modality choices, with reassessments over time as circumstances change. These patients’ lives are uniquely fraught with feelings of hope for recovery or transplantation, often mixed with hopelessness from waiting for years with no guaranteed success. Many become frustrated and disillusioned with the healthcare system, feeling like they have been failed or forgotten. Many still manage to find resilience, hope, and even acceptance of their disease, and continue to enjoy the time that has been given to them through this life-extending treatment (Mehta et al., 2024).

There is a diversity in the population of patients being treated with dialysis. Some undergo initiation in their childhood after renal failure from a genetic disease; others may start during young adulthood due to acute injury (Shaheen & Al-Khader, 2005). As diabetic nephropathy becomes the leading cause of ESRD, the majority of patients on hemodialysis are now over 65 years of age (Shaheen & Al-Khader, 2005). This percentage continues to rise, a trend associated with factors such as improved preventative CKD care and earlier initiation of dialysis (Tamura, 2009). Many of these patients live with frailty (Johansen et al., 2007) and

multiple comorbidities, most commonly diabetes and cardiovascular disease (Gomez et al., 2015), and living with these comorbidities has been associated with higher incidence of adverse events and mortality (Gomez et al., 2015; Zhang et al., 2020). Studies have also shown higher incidence (Nicholas et al., 2015) and lower survival rates (Chandra et al., 2015) amongst patients of lower socioeconomic class, with income, education, and occupation having variable influences (Tao et al., 2019). Notably, while CKD is more commonly diagnosed in women, only 40% of RRT recipients and less than 50% of hemodialysis patients are female (Cobo et al., 2016). Social disempowerment and economic disadvantage are theorized to be third variables and may explain the relatively low number of women on hemodialysis (Tong et al., 2022).

2.1.2 Challenges of Dialysis Initiation

Transitioning into dialysis is well-documented as a highly vulnerable period of the renal journey (Bowman, 2019; Wachterman et al., 2019). While the initiation period is typically defined as the first 12 months after starting dialysis, 35% of all dialysis patients die within the first 90 days (Broers et al., 2015). This transition is associated with multiple significant changes to the patient's lifestyle, as well as physiological stress as the body adapts to artificial filtration (Broers et al., 2015).

Upon initiation of dialysis, patients may experience side effects such as hypotension and nausea during treatment sessions, as well as fluid overload or uremic symptoms from toxin accumulation. These symptoms are multidimensional and often present concurrently, resulting in considerable distress, and can be difficult to manage (Jablonski, 2007). New medication regimes and dietary restrictions are also introduced upon initiation, and fluid measurements become stricter as residual kidney function declines. Patients report these restrictions as demanding and a "constant struggle," especially when food plays significant roles in their cultural and personal

identities (Ozkan & Taylan, 2022). Maintaining these diets can feel socially isolating and become an ongoing challenge for both new and chronic patients (Zhu et al., 2024).

Many of the practical changes that come with hemodialysis also result in social and psychological sequelae that consequently impact other parts of patient lives. For example, in-centre hemodialysis typically requires four-hour sessions three times a week to prevent fluid and toxin build-up. This requires patients to arrange their lives around their treatment, which not only impacts their social lives but can prove challenging for employment. The combination of frequent sessions and fatigue from dialysis often results in patients being under- or unemployed (Muehrer et al., 2011) and may result in financial strain for them and their families. Patients may also feel strain in their relationships with their loved ones (Powathil & Anish, 2023) as dialysis alters the physical, emotional, and practical assistance required from family and friends. All hemodialysis patients require vascular access in the form of arteriovenous fistulas or central venous catheters, but both can feel intrusive, disfiguring, and a constant reminder of their disease (Casey et al., 2014). These changes during the transition period can be significant disruptors to previous routines and contribute to depressive symptoms (Watnick et al., 2003), feeling constrained (DePasquale et al., 2020), or feeling overwhelmed (Mehta et al., 2024). The dependence on the hemodialysis machine and the existential knowledge of a limited life expectancy become key aspects of the patient's narrative, and integrating these into their self-perception can be a lengthy process (Hagren et al., 2001).

The transition into dialysis is a time of adaptation. Patient reports highlight the profound impact of their initial visit to the dialysis centre, as well as the need for supportive providers, timely education, and informed decision-making (Mehta et al., 2024). Herein lies an opportunity

for providers to support new dialysis patients in developing coping strategies and adjusting to their new lifestyle.

2.2 The Patient-Provider Relationship

In this study, "provider" refers to both physicians and nurses, as they are responsible for a significant percentage of the care provided to patients on dialysis. Broadly speaking, the nephrologist prescribes the treatment whereas the nurse provides direct care. Many principles remain the same in the creation and maintenance of supportive healthcare relationships, despite some differences in the interactions that occur between the patient and provider. Perhaps the most significant difference is the discourse of nursing as the "caring" profession (Allande-Cussó et al., 2022), when compared to physicians who are typically positioned as the dominant authority in scientific knowledge (Ridd et al., 2009). This departure in philosophy is evident in the literature as we trace how professional paradigms and principles lead to specialized clinical reasoning (Vreugdenhil et al., 2023). The relationships cultivated with patients may therefore reflect core differences in their approach to patient care. Patients develop different expectations of each role through their clinical encounters, and the power manifested within these experiences may take on different qualities (El-Haddad et al., 2020; Najafi Kalyani et al., 2014; Sobczak et al., 2017).

Renal nurses have distinct roles as healthcare providers in the dialysis unit. Due to their frequent proximity with the patient and the patient-focused nature of their job, many develop a close and therapeutic relationship over the years. Patient perspectives on nurse relationships tend to be focused on trust, where having faith in their nurses means feeling confident that the decisions they make have their best interests in mind (Rørtveit et al., 2015). Mok and Chiu (2004) describe four parts to the trust between patients and nurses: understanding patient needs,

exhibiting caring behaviors, providing holistic care, and advocating for the patient. Patients describe feeling secure and safe when cared for by a trusted nurse, and have appreciation for them being there for support during difficult times (Hreńczuk, 2021). A positive patient-nurse relationship can be nurtured by supportive dialogue and proven competency in ongoing encounters (Rørtveit et al., 2015), following very similar principles to physician-patient relationships.

2.2.1 Self Management and Empowerment

The patient-provider relationship has been long established as a foundational element of good health, linked to improved patient compliance and satisfaction for both patient and provider (Rathert et al., 2022; Sihvonen et al., 1989). Current literature highlights the need for healthcare to move away from paternalistic approaches in favor of more patient-focused models, although this change in paradigm continues to face challenges in implementation (Rathert et al., 2013). In the chronic disease population, this relationship is most often associated with a significant positive impact on self-management and patient satisfaction.

The concept of self-management revolves around retaining “normalcy” and functionality in everyday tasks, and is especially vital in chronic conditions where there is no cure (Curtin et al., 2005). Self-management has been closely associated with the notion of empowerment, which has its roots in philosophy and critical social theory (Hickmann et al., 2022). Within the healthcare context, it often refers to the growth of a patient’s skills, knowledge, and confidence to participate in their care. Empowering a patient involves “shift[ing]... the balance of power” and can be seen as both a process and a state of being (Hickmann et al., 2022, p. 4). By empowering patients with the ability to engage in their own healthcare decisions and self-care activities, providers can support them in developing their confidence and competence to manage

their illness. In those with chronic disease, providers who support self-management and prioritize communication are likely to achieve better patient satisfaction (Carlin et al., 2012). One study with women with chronic diseases reports that closeness and partnership with their provider increased their sense of security and well-being, giving them improved confidence in self management (Fox & Chesla, 2008). Another found that collaboration between patient and provider reinforced self-management competence in the context of chronic care (Angwenyi et al., 2019). Patients skilled at self-managing their chronic disease experience higher quality of life as they learn to navigate both practical and emotional challenges in their day-to-day life (Harvey et al., 2008). Unfortunately, in the dialysis population, many patients do not feel confident in their ability to self-care. The availability of social support and effective education are key influencers in encouraging self-management in this vulnerable population (Li et al., 2014).

The rise of the internet in recent decades has vastly increased patient abilities to independently source health information. This has altered the patient-provider dynamic and how patients participate in healthcare decision-making. Patients would traditionally receive clinical advice and diagnoses solely from their physicians or nurses, but many patients now turn to the internet for this information (Tan & Goonawardene, 2017). This is especially true if their previous encounters with providers have been negative, including dismissive remarks, unanswered questions, and difficult terminology that is not explained appropriately (Costello, 2016). Topics that may feel uncomfortable to bring up are often also researched online (Costello, 2016). As famously explored by Foucault's power theory (1972), having information – or "knowledge" – is linked to the deployment of power, suggesting that patients who can find their own answers are now empowered by it. This, however, does come with limitations. Critical appraisal and digital literacy skills are required to parse through the variable quality and high

volume of data on the internet to avoid misinformation (Jacobson, 2007). Conflicting views can also create confusion and potential distrust in the healthcare system, especially if preceded by negative provider encounters. The patient-provider relationship must navigate this relatively new dynamic to support patient empowerment and collaboration through encouraging open and ongoing dialogue at clinical encounters (Langford et al., 2020). Studies show that the primary reason patients seek online information is so they can participate more actively in decision-making, suggesting that trust can be maintained and even encouraged so long as providers do not attempt to control or dismiss their patients (Tan & Goonawardene, 2017).

2.2.2 Domains of a Positive Patient-Provider Relationship

The First Impression. Researchers have theorized many models over the years for healthcare providers to conceptualize patient-system relationships, in hopes of guiding and influencing their approach to care provision. One example is Thorne and Robinson's (1988) three stages of healthcare relationships between the chronically ill patient and their provider or system. The first stage is defined by naive trust, where the patient believes that modern medicine will "fix" their medical condition. The second is disenchantment, where they become angry after realizing their hopes cannot be fulfilled. The third stage is guarded alliance, where new relationships are formed between the patient and provider, forced partially by the patient's dependence on the system to survive. What comes after this stage is dependent on whether the tensions within the relationship can be resolved and evolve into one of trust. Following this model, the provider can establish themselves at this stage as an ally in the patient's care, and as a trusted liaison between the patient and the rest of the healthcare system.

The initial contact between patient and provider can have lasting effects on the relationship's trajectory. Literature suggests that a person's first impression may remain stable

and persist throughout the relationship, although this can be influenced and revised with time, motivation, and subsequent experiences (Cone et al., 2017). These rapid evaluations are used to predict what the other party will or will not do, creating a basis on which the individual determines their own actions moving forward (Cone et al., 2017). Studies show that after an impression is made in the first few minutes of clinical consultation, successive judgments are strongly influenced by it, including their judgment of the provider's communication (Rimondini et al., 2019). A positive impression can facilitate the quick establishment of trust and compliance to treatment (Krot & Sousa, 2017), as well as encourage openness in sharing concerns and areas of need (Chandra et al., 2018). For the dialysis patient, the experiences they have with their providers in their initial treatment sessions will create the foundation of their relationship. This is further highlighted by the increased vulnerability of this population in the first year of dialysis. Despite the potential for slow change over the years, perceived support and trust in their providers must be rapidly established in the transition period to help prevent negative outcomes.

Effective Communication. One of the most commonly cited tenets of a positive relationship is effective patient-provider communication. Effective communication has been associated with improved clinical decision-making, collaboration, meaningfulness, and enhanced clinical outcomes, and is furthermore reported to save time and reduce costs to the healthcare system (Drossman & Ruddy, 2020). Both verbal and non-verbal factors can influence the patient's perception of good communication, such as open postures, active listening, and non-judgmental, clarifying questions (Drossman & Ruddy, 2020; Sihvonen et al., 1989). Consideration towards accessibility needs, such as an interpreter, audio/visual cues, and health literacy level, is also crucial in removing barriers to communication (Patak et al., 2009). Literature highlights a large number of variables that can impede participation in shared

decision-making, including a condescending communication style, complicated and lengthy explanations, the patient's perception of themselves as a passive listener, and the patient's limited confidence in their own clinical knowledge (Lederer et al., 2015). Unfortunately, many reports from patients with chronic disease describe disrespectful encounters that create long-lasting distrust in providers and the overall healthcare system (Thorne, 2006). It is important to note that these negative experiences are also influenced by many other factors, such as increasing demands on provider time and differing expectations between patient and provider (Drossman et al., 2021).

Beyond how providers choose to communicate, it is also important to consider what is being communicated. Psychosocial and emotional needs must be encouraged and addressed to create a sense of security in the relationship, and patients highly value being given time and feeling heard (Salt et al., 2012). Providers are expected to listen to patient concerns and answer their questions without judgment or dismissal. Information dissemination in clear "layman" terms and explanations of all potential options are considered key aspects of effective communication; moreover, patients report wanting honest opinions individualized to their case by a provider they feel has their best interests in mind (Salt et al., 2012). Patients are significantly more likely to participate in shared decision-making when they feel their provider listens to their concerns, and that they are fully informed (Williams et al., 2017).

Defining Concepts. One of the outcomes of effective communication is value concordance between patient and provider, which can lead to shared decision-making and collaboration between two parties. These concepts are often examined alongside patient-centered care and patient engagement. Although these terms are used interchangeably across some texts, there are distinctions between these concepts. Concordance speaks to both parties being 'on the

same page' about the goals and values of their treatment decisions, while shared decision-making explores how both patient and provider have equal or similar authority on the decision that is ultimately made (Hickmann et al., 2022). Patient-centered care contrasts the traditional paternalistic approach of medicine by positioning the patient as an individual whose wants and needs must be considered first (Hickmann et al., 2022). Patient engagement is unique in its emphasis on a sustained relationship between patient and provider as the patient participates in their care and decision-making (Hickmann et al., 2022). Ultimately, these concepts all revolve around the empowerment of the individual to participate in decisions equally with their provider at every point of their healthcare journey. While both patient and provider consistently report positive attitudes towards such relationships, actual experiences that reflect these are lacking (Williams et al., 2017). The patient and provider are both essential and central to shared decision-making, with many narratives depicting a dynamic negotiation of trust and control that often proves challenging to navigate (Kinchen et al., 2020).

Chapter 3: Methodology

3.1 Theory & Overview

For this study, I collected data from the online forum r/dialysis (www.reddit.com/r/dialysis) posted from 2012 to 2023 and hosted on the Reddit website. This was done through *Teleoscope*, a novel machine-learning tool created to assist researchers in data collection. Keywords revolved around the concept of the provider, starting with broad topics: "nurse," "physician," "nephrologist," "doctor," and "provider." Terms such as "transition" or "initiation" were added to focus on the initiation period, where patients begin to frame their relationships. Relevant search terms were also added as they were inductively discovered. Through an iterative collection process, selected posts were systematically organized on an Excel spreadsheet with tags and annotations. This was repeated until data redundancy was achieved. The analysis was guided by five objectives that were inductively uncovered throughout the data collection. As the study was exploratory and qualitative, with a large initial dataset, reaching the point of data redundancy implied sufficient data saturation. A Foucauldian Discourse Analysis (FDA) was then applied to investigate the overarching power discourses that color patient understanding of their providers and relationships.

3.1.1 Foucault's Theory of Power

Power is a pivotal element in the patient-provider relationship, influenced by factors such as the perceived medical expertise of the provider, and the formal authority of providers to provide treatment and access to care. In the lens of Foucault (1980), these presentations are tied to the interconnected nature of power, knowledge, and discourse. I chose to use Foucault's theories in my analysis for his emphasis on power at a societal level, and its parallels to the nursing discipline's focus on institutional factors when seeking improvement to patient care

(Kitson et al., 2013). These parallels ease the translation of the insights gained from this study into practical and useful initiatives.

Foucault's Theory of Power highlights the pervasiveness of power on a macro-level scale and the reciprocal relationship between power and knowledge. His theory discusses the power in discourse, exploring it as a productive phenomenon. To Foucault, interactions between two actors and the power behind them are not specific to the individual; rather, they are a force that define and reinforce the form and nature of knowledge (Foucault, 1972). In this, Foucault emphasizes how certain knowledge is reiterated and normalized to construct social realities. These realities are known as dominant discourses, or patterns of practice that can be dispersed, reproduced, and traced (Foucault, 1980). Dominant discourses are created through intersections of "power, right, truth," (Foucault, 1980, p. 93), not by individuals, and are embedded in institutional contexts as well as within societies (Foucault, 1972). Power permeates into society through specific power mechanisms that then produce "discourses of truth" (Foucault, 1980, p. 93). By creating domains of visibility and invisibility, certain knowledge is societally internalized while others are discursively excluded. Power and discourse are therefore fundamentally intertwined, as power determines what discourses dominate across specific time periods throughout history.

In the healthcare context, providers such as physicians and nurses have the authority to diagnose and assign terminology to specific symptom presentations. The words that are used to describe and diagnose have significant weight within society's healthcare institutions, ultimately deciding what treatments the patient has access to. What the healthcare system considers a disorder comes from a wider scientific and medical discourse that has been accepted as "truth" in our society. Further, within the interactional micro-lens of the patient-provider relations, the

provider has been imbued with power through the healthcare institution as the de facto keeper of medical knowledge. The etiquette that is followed at every clinical encounter, and the pathways followed to achieve access to care, have been normalized and reiterated at each appointment. Physicians and nurses are conduits of power imbued by the broader societal discourses. Conceptualizing power through the lens of Foucault asks us to consider where the views and practices we take for granted come from, and helps uncover the subtle ways healthcare discourses show themselves. These revelations are crucial in untangling and changing how power is deployed, as Foucault asserts that "power is tolerable only on condition that it masks a substantial part of itself" (Foucault, 1978, p. 86).

3.1.2 Dataset and Participants

The chosen dataset included all posts submitted to the r/dialysis subreddit from the forum's inception in 2012 to the end of 2023. In 2024, Reddit published a new Public Content Policy that aims to protect users from the misuse of their data by commercial companies. While data remains available for research purposes, the company is now in the process of developing new channels for accessing large datasets moving forward (Reddit.com, 2024c). The current study therefore used data downloaded previously from before the policy's implementation, specifically through to the end of 2023. While the selection process was done through skimming the parent post, comments were also explored during the analysis phase. This dialogue provided vital insight into the ways peer-to-peer interactions influenced conceptualizations of their healthcare relationships.

Posts were selected for analysis if they discussed providers, the patient-provider relationship, or clinical encounters that may have involved the influence of providers. Foucauldian theory emphasizes the importance of both the said and unsaid when conducting

discourse analysis, suggesting that criteria should be broad to encompass these potentially "invisible" threads (Foucault, 1972). Demographic information about the users posting on r/dialysis was scarce given the anonymous nature of the forum. However, selection criteria still applied. Only posts by patients were selected for analysis, as this study focused on patient perspectives. Furthermore, patients must have been treated by hemodialysis at a dialysis unit, as opposed to peritoneal dialysis or home hemodialysis. The experience of different dialysis modalities as well as the different eligibility criteria can vary significantly, which may impact their perceptions of their relationships with their providers. The current study focused only on the largest subset of these narratives, or those who were dialyzing at outpatient dialysis centers. Posts were also not chosen if the user was not currently being treated with dialysis, as a major strength of the study was its emphasis on "in-the-moment" narratives. Discretion was used when the post included insufficient data to conclusively determine if they meet criteria.

3.2 Reddit

Reddit has rapidly become one of the most used social media platforms, with over 52 million daily users in 2020 and more than 100,000 active communities (Reddit.com, 2020). It features user-driven news aggregation, content rating, and discussion forums, allowing users to both "upvote" and "downvote" a post to decide its popularity. The most popular posts then become more visible to the rest of the online community, gaining more "upvotes," comments, and engagement. Reddit accounts are free to create and linked only to an email address, allowing users to create one-time "throwaway" accounts for sensitive topics to avoid being identified. Alternatively, users can choose to engage with a single account and participate more openly within their selected communities. Reddit consists of many forums, or "subreddits," dedicated to specific communities or subjects. These communities can choose to be public, restricted, or

private and have moderators to monitor and enforce forum rules. Public subreddits allow anyone on the internet to access the posted content, and any user who creates a Reddit account to contribute to the forum (make posts, vote, comment, etc.). Restricted subreddits allow everyone to view the post's contents, but only certain users on the approved list can post or comment; and private subreddits require invitations from moderators to view or engage with the posts. Moderators have historically been allowed to swap between these three tiers at any time, allowing subreddits the continuous freedom to choose how public their content is to the online population. Starting September 30, 2024, subreddits are still able to change their publicity settings but require approval from the Reddit administrators (Reddit.com, 2024a).

r/dialysis is a public subreddit dedicated to supporting patients on dialysis, their family, and their friends. Their description states, "Got questions about kidney failure or dialysis? Want to share your experience dealing with kidney issues? Feel free to join." (Reddit.com, 2024b). Created in 2012, posts on the subreddit explore both the challenges that dialysis-dependent patients and loved ones face, as well as occasional celebratory posts from transplants or recovered kidney injuries.

3.2.1 Social Media as a Dataset

As our world becomes more reliant and interconnected with the internet, researchers have increasingly turned to social media datasets. With an exponentially increasing amount of information being shared on social media, these websites become full of rich narratives that were previously difficult to acquire. Before the popularity of Reddit, researchers commonly used Facebook, Instagram, or Twitter to draw both qualitative and quantitative data (Abkenar et al., 2021; Snelson, 2016). Compared to traditional methods of data collection, such as questionnaires

or interviews, social media datasets highlight posts and dialogue that view familiar problems in a different light, with distinct strengths and, at times, unexpected insights.

Each online platform has slightly different functionality, providing specific kinds of media in different formats for particular audiences. User behavior evolves rapidly and can vary significantly between different demographics and even individuals (Weller, 2016). There has been no universally agreed upon or confirmed rationale behind many user behaviors, such as why people “like” photos or follow other accounts. Despite this, there can be broad generalizations made about the intent behind each platform. Of the aforementioned platforms, Facebook was the earliest created in 2004, followed by Twitter in 2006, and Instagram in 2010 (Alhabash & Ma, 2017). Reddit was created in 2005 (Reddit.com, 2020) but only gained significant popularity in 2011 when they reached 2 billion pageviews (Martin, 2012). A study by Alhabash and Ma (2017) found that users on Instagram and Twitter used the platform primarily for entertainment, while Facebook was used most often for convenience. Furthermore, Facebook and Twitter are used more often for information sharing than Instagram. Users over the age of 50 have conventionally used Facebook and Twitter, but recent literature has highlighted how this population is growing and adapting to different social media platforms (Hutto & Bell, 2014). Twitter has been found to have closer relations to political posts than other commonly used social media platforms (Jungherr, 2016), and Instagram has a younger demographic with its focus on images and videos (Laor, 2022). When compared to these three websites, Reddit is unique in its emphasis on being a community-focused and user-driven platform, where users can post photos, videos, and text with ease and follow groups of similar interest. Its user anonymity allows more open sharing of information, ranging from intimate to silly, with lower risk of personal identification and few limitations. Moreover, it has a global reach and wide scope of

topics that can easily be found and engaged with. Reddit was chosen in this study for its global reach, in conjunction with the low barrier of entry and community-focused "safe spaces."

3.2.2 Patient Forums in Dialysis

The ability to cope with the stressors of chronic disease is positively associated with quality of life (Harvey et al., 2008), and one variable that significantly impacts this is social support (Li et al., 2014). Patients on dialysis face challenges maintaining close relationships after initiation due to the many practical and psychological impacts of their treatment regime (Powathil & Anish, 2023). Traditionally, they would be bound locally, both due to their frailty as well as the need to attend hemodialysis sessions multiple times a week. While patients can theoretically travel and attend sessions at alternate dialysis centers, many find the logistics challenging and require support in making arrangements (Wongboonsin et al., 2021). Moreover, the disease and its treatment often come with significant fatigue, and patients can face anxiety over being cared for by new and unknown providers (Wongboonsin et al., 2021). With the networking abilities of the internet, dialysis patients can connect with peers and allies across the globe without the need for travel. Ahmed et al. (2017) conducted a study on Facebook conversations around dialysis and found that dialysis patients, their families and their care providers all participated in the dialogue. Participants shared information and experiences, and provided both emotional and social support. These platforms provide opportunities to build a larger community than may be feasible on a local level. Furthermore, they allow patients to participate in spite of any financial barriers or disabilities that prevent them from traditional in-person meet-ups, as long as they have access to the internet, and are available to engage with at all times on any day.

Patient forums serve not only as a platform to build a social network, but potentially as an opportunity for patients to express themselves in a space they consider safe. Literature strongly supports a cathartic or therapeutic effect of sharing personal narratives online, especially in those with chronic pain (Merolli et al., 2015). Reading about others' experiences may also influence the patient's sense of isolation and their adjustment to a chronic disease. Learning about others' experiences with the healthcare system and providers can assist the individual in navigating it themselves, or bias the way they approach it (Ziebland & Wyke, 2012). Perhaps most importantly for this study, others' stories and experiences may help the patient make sense of and visualize their disease, as well as serve as a practical and emotional framework for their new lifestyle (Ziebland & Wyke, 2012). Reading about how other patients and families speak of and about certain topics will invariably influence their own constructed narrative. This process in itself is theorized to be therapeutic, if done in a positive light (Ziebland & Wyke, 2012). The practice of sharing and receiving narratives with other like-minded peers is an essential part of the transition into a different sense of self. The ability to examine these narratives as the individual experiences them is therefore a key strength of this study. The r/dialysis subreddit allows users to share their stories and respond to others as the transitions and experiences happen, creating a rich network of dynamically created conceptualizations that can be explored through their dialogue.

3.2.3 Teleoscope as a Tool

Teleoscope was created by Paul Bucci and his team and is described as "an interactive web-based system for exploring large datasets (100K-1M) of short documents such as social media posts" (Bucci et al., 2024, p. 2). It was developed to address the challenge of exploring large-scale data in qualitative research. Bucci identifies that researchers often have a different

idea of document similarity when compared to the machine, leading to difficulties in searching for documents. *Teleoscope* uses machine learning to train the tool to match the user's "schema" of what they ideally wish to find within the dataset (Bucci et al., 2024, p. 2). To use this tool, the researcher first chooses key terms to explore the dataset, then uncovers similarities between documents and groups them into folders. These are then connected in a *Teleoscope* function, where the machine finds and produces similar documents. The researcher can then alter their key words or input new documents into these folders in an iterative process, to ultimately refine the machine's "schema" and match it to their own. *Teleoscope* therefore helps streamline the search process for qualitative researchers, especially with a large social media dataset that may not have sophisticated search functions.

Using *Teleoscope* in this study was not only a choice of efficiency, but also one that provided unique advantages. Traditional methods may require the application of certain parameters to the dataset, such as specifying a time frame, to maintain a more practical project scope. This gives the researcher sufficient time logistically to read through each post to check if providers have been mentioned, and add the relevant posts to their working document. If they uncover any new key terms, they can be added to their search criteria. This method, while generally effective, has the potential to miss data through exclusion, and is unable to identify any changes that may happen over time given the specified time frame. Missing any key phrases or specific terminology can result in the omission of important data points. It furthermore can be time-consuming to keep track of and search with the many different constellations of key phrases during the data collection. Machine-learning mitigates some of these limitations by searching through the entire forum, from its time of inception, and finding similar documents without the need for specific keywords.

3.2.4 Ethical Considerations

Numerous papers have come out in recent years discussing the ethics of using social media platforms as datasets (Adams, 2022; Boyd and Crawford, 2012; Golder et al., 2017; Hunter et al., 2018). Reddit has been no exception as it gains more popularity with both the public and in research. In general, formal approval by an ethics board has not been required, and the substance of research ethics discussion varies substantially across the literature. While some studies dedicate paragraphs to careful documentation of their ethics considerations, others simply state that no ethics approval was obtained (Fiesler et al., 2024). After reaching out to the Human Research Ethics board at the University of Victoria, I received an exemption for this study as they consider Reddit posts to be public data (see Appendix); nonetheless, a thorough review of the relevant ethical questions follows below.

A key point in these ethical discussions is the public nature of Reddit data. If data on Reddit is considered public, then informed consent may not be needed; otherwise, each participant should be aware and willing for their data to be used in the study. As a website, Reddit requires no formal registration to access and anyone browsing the internet can access the content posted. It states that it is an "inherently public platform," (How to make your content non-public section, para. 1) and offers options for those who wish not to contribute publicly, including only sharing in private communities, deleting their posts, or disassociating their account from posts they have made (Reddit.com, 2024c). Reddit also explicitly states that "use for research purposes is OK provided you use it exclusively for academic (i.e. non-commercial) purposes, and don't redistribute [their] data or any derivative products or services based on [their] data" (Reddit.com, 2024d, Research section, para. 1). It is important to remember that

regardless of legality, the researcher has a duty to be aware of and mitigate any potential ethical violations when conducting and disseminating research with potentially intimate data.

Informed Consent and Autonomy. Researchers have been open in their criticism over using datasets without caution. For example, Boyd and Crawford (2012) note that accepting data as public does not preclude the need for rigorous evaluation of ethics, and that public posting cannot be equated to full and unequivocal permission. Hunter et al. (2018) similarly argues that the relational and interactive nature of social media makes it "ill-suited to standard consent models" (p. 343) and highlights the problematic nature of implied consent. It is discussed across these studies that the current formal understanding of consent has not been updated to suit the needs of a digital world. To further emphasize this, the literature highlights how social media users feel uncomfortable knowing their data was used for research purposes without their approval (Beninger, 2017; Golder et al., 2017). The researcher has an ethical responsibility to consider these issues and protect their participants, even without a formal requirement from an ethics review board.

One of the most commonly cited rationales for public use of online datasets is that users of social media platforms have already agreed to terms and conditions upon registration. These contracts include a privacy policy and consent for their data to be used for public and research purposes (Moreno et al., 2013). However, not only are users coerced into agreement to complete their registration, but many do not read or understand what they are signing (Kaphle et al., 2022). A social justice perspective posits that the technological literacy of each user cannot be assumed and exploited for research purposes (Starzomski et al., 2023). The researcher must also consider the increasing prevalence of social media in both business and personal spheres (Clark et. al, 2018). Users may have sufficient autonomy to decline the terms and conditions, but not

necessarily sufficient agency if they wish to remain connected to society. Many privacy policies are furthermore intentionally difficult to read to help dissuade users from reading them thoroughly (Hunter et al., 2018). These issues can significantly impact the elderly population, and in turn the dialysis population, who are often unfamiliar with technology and simultaneously desire social connectedness. Consent obtained in this light cannot be considered voluntary or informed.

The third aspect of consent is an emphasis on an ongoing process. Traditional studies have participants consent with the understanding that they may withdraw at any time, hence ensuring consent is continually renewed. Similarly, Reddit allows users to delete their posts and even their profiles, granting them ongoing control over their data's public accessibility. When these posts are replicated for research, participants lose the influence they had over what and how their data is used (Adams, 2022), resulting in an inability to withdraw. The discussion around this revolves around the rights of the patient to their own data once it has been published to the website, and their awareness of the risks they are taking when they do. It does not impact the population equally, as again those who are less technologically literate and more emotionally vulnerable are less likely to be aware. Patients may be consenting to their data being posted on the internet, but not necessarily for their thoughts to be analyzed in research contexts.

Patient Vulnerability, Anonymity, and Context. While research studies can appear benign, there are many scenarios in which maintaining anonymity is crucial for participant protection. Research drawing on intimate narratives from social media requires particular attention to ensure the populations studied remain protected both during the study and after results are published. Yet fully anonymizing participants can be difficult. Verbatim quotations can be reverse-searched, and the original source may be found through a search engine despite

their usernames being erased. This creates significant risk as user post histories may be accessible or identifying data found on their profile, resulting in their identity being exposed (Adams, 2022). Not using direct quotations, however, can be seen to compromise academic integrity (Webb et al., 2017), especially in discourse analyses that heavily rely on analysis of key terms and phrases.

Consideration must also be placed on the intentions of the forums or discussion groups that data is drawn from. Many social media groups position themselves as safe spaces for specific demographics to engage with their peers, host intimate discussions, share traumatic stories, or ask for personal advice. While these forums could be seen as public spaces, information disclosed may not be known by even their closest companions, implying it is intended for privacy regardless of the platform's publicity (Stommel & Rijk, 2021). Furthermore, a post's existence on a public platform does not mean it was intended for everyone to read (Boyd & Crawford, 2012). Golder et al. (2017) identifies concerns from social media users around posted information being analyzed without context, potentially distorting their intended meanings and being used to reach conclusions they do not support. These posts are made within the wider context of the message board or group they were submitted to, as well as within the greater narrative of the user's life experiences. Isolating data without considering these contexts runs the risk of inaccurate portrayal of their original intentions (Adams, 2022).

Risk and Reward. When proposing and conducting research, the risks and benefits to the participants or patients must be considered. Researchers may be tempted to offer justification for ethically gray areas, stating the study is for the greater good and evoking beneficence. Analyzing users' posts on social media, however, can have significant risk for moral harm to the individual given potentially confidential data as previously outlined. The need to analyze such

intimate accounts must be tempered with respect for the individual's wants. As the researcher begins to formulate the goal of their research study, it may be important to consider whether its results will truly benefit the targeted population. For the current study, this entailed a deeper reflection of how patient accounts in a potentially safe space can help support our understanding of the dialysis-dependent patient's experience. The quality of life and mortality rates for this population are significant fields that must be addressed. An exploration of their perspectives without the influence of an interviewing researcher was expected to uncover gaps in our current care that we can improve on moving forward.

In this study, several steps were taken in consideration of the ethical discussions outlined above. During the data collection phase, particular attention was placed on the context of the post, with annotations serving as reminders following each data point from analysis to dissemination. Consequently, tags such as whether the patient is female or male, if relevant to the context of the narrative, were continually associated with each story. During dissemination, quotes were paraphrased to avoid reverse-searching and to maintain the anonymity of the original user. Research triangulation was used to preserve the meaning of the phrase. Transparency in my positionality and the reasons I make certain ethical choices was also paramount in sustaining trust between researchers and the dialysis community.

3.3 Foucauldian Discourse Analysis

Foucauldian Discourse Analysis (FDA) can be difficult to define, as the details of his method are vague and at times contradictory (Hook, 2001; Ong et al., 2024). Critical literature has consequently argued against a single "pure" Foucauldian method, instead advocating for multiple "Foucauldian-inspired" approaches created by other academics. Despite the uncertainty in the details of his method, scholars can follow the tenets of his theory for a more abstract

approach; namely, his emphasis on dialectical discourse, historicism and genealogy. Foucault believes that cultural and societal phenomena are heavily influenced by events in history, and that dominant discourses are both produced and propagated by institutions of power. The researcher therefore focuses on the discourses and events in history that lead up to modern day, examining how they each played a role in shaping current phenomena (Graham, 2011). Comparing discourses of different eras allows the researcher to investigate changes that occurred between time periods. Foucault asserts that systems of thought are discursive formations governed by rules that work subconsciously in the individual, determining the ways and limits of thinking in a certain period. A given system of thought is therefore a result of specific paths and causes in history, not inevitable trends, reflecting Foucault's approach to genealogy (Graham, 2011). By combining this emphasis on historical contexts with Foucault's understanding of power and discourse, the researcher approaches their chosen texts with a "Foucauldian-inspired" perspective.

Arribas-Ayllon and Walkerdine (2017) offer an exemplary example of how researchers may choose to approach FDA. They begin by choosing a corpus of statements, or a selection of discourse samples (text) that will be analyzed for the study. The researcher examines the formation of the discursive object (text) and its relations to the present, asking questions such as "what circumstances and by whom are aspects of human being rendered problematic?" (Arribas-Ayllon & Walkerdine, 2017, p. 116). This process is known as "problematizing" to identify the limits and characteristics of the problems at hand. They then consider the technologies of power and self that assert influence on the targeted phenomenon. Technologies are considered a "form of practical reason," (Arribas-Ayllon & Walkerdine, 2017, p. 116) or an assemblage of persons, knowledge, or objects that influence human behavior from a distance. Thus, technologies of

power refer to mechanisms that "submit" the body to certain conducts, and technologies of the self refer to mechanisms the individual effects onto themselves. The researcher examines what forms these technologies take and what impact they have on human practice. The next consideration is subject positions, or where the individual is located within a particular structure. The individual can exist in multiple positions at once within the different societal structures they fall under, each enforced by one or several broader discourses. The researcher explores not only which structures they fall under, but how these discourses may intersect each other. The final consideration is subjectification, or the "making of subjects through technologies of power and self" (Arribas-Ayllon & Walkerdine, 2017, p. 117). This step relates to ethics, defined as "the self-forming activity by which subjects establish a relation of self to itself" (Arribas-Ayllon & Walkerdine, 2017, p. 117). In it, the researcher examines how the individual enacts ethical conduct in their decision-making through their own moral universe, and how their decisions are impacted by their discursive positions.

Ahl (2007) offers another excellent example of an approach to FDA. She outlines both her detailed methodology as well as the principles of Foucault that she follows. These include the principle of reversal (what is excluded?), the principle of discontinuity (there is no single grand narrative, but a series of potentially disconnected ones), the principle of specificity (the social world is created through discourse, and regularities found are from people constructing and practicing the same; one discourse cannot be seen through a prior system of meanings), and the principle of exteriority (look to external conditions of existence, not internal "hidden" meanings). She details the analytical framework she constructs in her approach, including ten points or objectives that make up her larger research question. These include concepts such as which ideas are taken for granted, which voices are excluded, and the publishing practices and institutional

rules that dictate who can speak. Each of these points are explored individually in unique ways. For example, in one objective she deconstructs the text by underlining terms used to describe 'entrepreneur' and explores antonyms for each phrase by using a dictionary. In others, she creates and populates Excel sheets to compare multiple texts and extract themes, and studies external resources for contextual information. This systematic approach to her FDA effectively breaks down an impressive question into smaller, manageable pieces, and ensures that both the said and unsaid are examined equally.

Although Foucault himself did not provide clear steps in conducting discourse analysis, 'doing' Foucault is best approached with a thorough understanding of his principles of power and broader theoretical standings (Ong et al., 2024). In this study, I used an inductive approach during data collection that informed my points of interest for analysis. This was modeled after the approach taken by Ahl (2007), while the formation of these points was informed by the focus on technologies and subjects in Arribas-Ayllon and Walkerdine (2017). The initial readings of each post therefore served as both a screening for appropriateness as well as inspiration for the branching questions. Once these were established, I investigated each topic individually. I had the option of going back and re-analyzing certain facets of the research question as new threads arose, to continue the iterative and inductive analysis process. By systematically investigating the different sub-categories of my larger research question, both the visible and invisible became evident and informed my final conclusions. Researcher triangulation was important in enhancing the validity of the extracted results, and my findings were continually shared and discussed with research colleagues throughout the process. Additionally, as reflexivity and transparency were paramount in this qualitative and abstract methodology, I kept a journal to track my thoughts and create a decision-making trail.

The following chapter is a publication in which I outline the findings that address the specific objectives that I developed as part of the overall process. Insights into the methodological application of Foucault can be read in a manuscript I co-authored (Ong et al., 2024).

Chapter 4: Publication

(to be submitted to Qualitative Health Research)

Insights into Dialysis Initiation: A Foucauldian Discourse Analysis of the r/dialysis Reddit forum

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Abstract

Patients on dialysis develop unique relationships with their providers, fellow patients, and the broader healthcare system. These connections are well established as key factors influencing both their healthcare experience and mortality rates. Yet, despite ongoing efforts to improve these relationships, health outcomes remain unfavorable for dialysis patients. Exploring these relationships through a social media platform provides valuable insight into patient lived experiences, shedding light on pervasive power dynamics as seen from the patient perspective. This unique approach helps identify critical areas for improvement to enhance the experience and outcomes of patients on dialysis. In this paper we use Foucauldian discourse analysis to examine 41 posts and their associated comments from the r/dialysis forum on Reddit, focusing specifically on dialysis initiation. It explores how societal discourse shapes impressions, communities, and frameworks as it both forms and is formed by peer-to-peer interaction. The study highlights how power and resistance are reflected in the discursive choices made by patients, as well as their conceptualizations of the patient-provider relationship as they begin their dialysis journey. These insights add to the dearth of current literature that use social media platforms and discourse analysis in investigating the healthcare experience. They lay the groundwork for better supporting a vulnerable clinical population and provide a foundation for future academic research using this methodology."

Key Words: dialysis; patient; provider; relationship; discourse analysis; Foucault

Insights into Dialysis Initiation: A Discourse Analysis of the r/dialysis forum on Reddit.

The patient-provider relationship is fundamental to quality healthcare (Hrehczuk, 2021; Kohatsu et al., 2024; Shay & Lafata, 2015). This is particularly true for patients with chronic disease, who are profoundly impacted by their interactions with nurses and physicians. Clinicians have leveraged this knowledge across various populations to support patients throughout their healthcare journey. Renal patients, for example, experience heightened vulnerability during dialysis initiation as they adjust to a strict new lifestyle (Wachterman et al., 2019), prompting the development of Transitional Care Units to facilitate their adaptation (Bowman, 2019). This transition is pivotal to the course of their clinical journey as patients begin to shape not only their own sense of identity, but also their perceptions of the providers, peers, and healthcare system they will engage with over time.

Research on supporting this transition for dialysis patients has expanded rapidly as the concept of patient empowerment gains increasing recognition (Hickmann et al., 2022). Research has focused on the importance of shared decision-making, with the majority relying on interviews as their primary method of data collection. However, this approach leaves significant gaps in our understanding as it overlooks insights from other methodologies, reflected in the persistently high dissatisfaction of care in the population (Bear & Stockie, 2014; Kuo et al., 2024; Song et al., 2013) and lack of meaningful documented change (Attalla et al., 2020). This study addresses these methodological gaps by analyzing a dataset from the r/dialysis forum on Reddit, applying discourse analysis to examine posts and comments shared by dialysis patients on a public platform. By examining the broader societal discourse embedded in these patients' posts, this article offers new insights into how the healthcare system and providers can better support patients on hemodialysis as they begin their journey. In this Foucauldian discourse

analysis, we explore the following research question: How do patients receiving hemodialysis understand their relationships with healthcare providers, as reflected on the r/dialysis subreddit?

Background

Patient-Provider Relationships in the Hemodialysis Population

The relationship between patients and providers, identified in this study as nurses and physicians, is dynamic and often complex. Patients on hemodialysis rely on their providers to deliver this life-sustaining treatment, in addition to essential education on managing their disease in the community (Stavropoulou et al., 2017). Providers are often crucial players in supporting patients to build their capacity for self-management, centred conceptually on the ability to retain a sense of normalcy in their daily lives (Curtin et al., 2005). By leading their lives independently outside the hospital, patients report feeling more satisfied, more empowered, and more capable of participating in their own care (Angwenyi et al., 2019; Carlin et al., 2012; Fox & Chesla, 2008; Harvey et al., 2008). A positive patient-provider relationship can influence healthcare trajectories and encourage patients to exercise control, where possible, in their lives.

Establishing trust during the initial stages of dialysis can be crucial in encouraging compliance to treatment (Krot & Sousa, 2017; Sihvonen et al., 1989) and an openness to share concerns with their providers (Salt et al., 2012; Chandra et al., 2018). However, literature shows that first impressions have significant impacts on a relationship, even years after they are formed (Rimondini et al., 2019). Change in relationship dynamics is possible, but often slow, and requires focused intention (Cone et al., 2017). Hence, patient perceptions of their provider created in this stage of their journey are of vital importance. Studies show that these perceptions are influenced by multiple factors; and while many are related directly to providers, others are gained through shared experiences and frameworks endorsed by peers (Ziebland & Wyke, 2012).

Patient Forums in Dialysis

While patients' empowerment and knowledge were traditionally gained through providers and the healthcare system, use of the internet has shifted these dynamics (Tan & Goonawardene, 2017). Patients now have the ability to not only search for healthcare information independently, but discuss thoughts and emotions globally with others. Social support is a significant factor in the development of self-management capacity (Li et al., 2014). Patients on dialysis traditionally had their social circles limited by location, both due to physical frailty and their need to attend dialysis sessions multiple times a week. The advent of online forums addresses this challenge by providing a platform for sharing information, experiences, and emotional support. These forums can offer a supportive space for patients and their families to ask questions and express emotions that might otherwise go unnoticed by providers (Ahmed et al., 2017).

Beyond the connections that form between peers, reading and sharing in others' experiences can influence a user's understanding of the interactions with care providers and help them navigate a difficult time (Ziebland & Wyke, 2012). Peer dialogue can assist in sense-making as the patient transitions into a new lifestyle (Ziebland & Wyke, 2012). The patient forum can therefore provide a unique snapshot of peer interaction and emotions in real time. When compared to information derived from qualitative interviews, these narratives are "unfiltered" and relatively free of the retrospective bias that can shape other accounts. Insights from such "real-time" posts are needed to fill the gaps in the current literature.

Methodology

This study collects data from the r/dialysis subreddit (www.reddit.com/r/dialysis), a forum dedicated to supporting dialysis patients and their caregivers throughout their renal

journey. A machine-learning tool named *Teleoscope* was used to select relevant posts by patients on hemodialysis posting within the first year of initiation. A Foucauldian Discourse Analysis (FDA) was then applied with a focus on patient-provider relationships.

Teleoscope and the Dataset

Teleoscope is described as "an interactive web-based system for exploring large datasets (100K-1M) of short documents such as social media posts" (Bucci et al., 2024, p. 2). Created by Paul Bucci, it aims to assist qualitative researchers in exploring relevant data from a large dataset through the evolution of document similarity. Machine learning is used to refine the system's schema based on the documents identified as appropriate, and suggests increasingly relevant data accordingly (Bucci et al., 2024).

All posts from 2012 to the end of 2023 on the r/dialysis forum were uploaded and filtered using key words. These search terms were iterative and adaptive, starting with terms such as "doctor," "nurse," and "provider," and resulting in a total of 41 posts being selected. All posts were commented on by other users, with numbers ranging from 2 to 51 comments, and variable response rates by the original poster. Posts were deemed eligible if the writer identified being in the first year of hemodialysis, did not mention previously being on a dialysis modality, and had sufficient narrative to support analysis, as per researcher discretion. Further, posts were excluded if the poster self-identified as being under 19 years of age.

Table 1

Search terms used in the selection of posts from the r/dialysis forum through Teleoscope

	Provider		Initiation
Hemodialysis	nurse*	doctor*	new
	RN	nephrologist*	start*
	tech*	provider*	begin*
	LPN	docs	month*
	technician	MD	week*
		clinician*	first
		practitioner*	
		physician*	

Note. Boolean searches were used with a combination of one or more phrases under each of the three columns: “Hemodialysis”, “Provider,” and “Initiation.”

Foucauldian Discourse Analysis

Foucauldian Discourse Analysis (FDA) emphasizes power at a macro-level, paralleling the nursing discipline’s focus on institutional factors for improvement of patient care (Kitson et al., 2013). Mirroring this framework allows initiatives to most easily be implemented in healthcare settings in practical and meaningful ways.

FDA has its foundations in Foucault's theory of power, which emphasizes the pervasiveness of power in society and its interconnectedness with knowledge and discourse. It positions discourse as a productive phenomenon that reinforces the form and nature of knowledge through interactions between individuals (Foucault, 1972). Social realities are constructed when knowledge is reiterated over time and normalized, ultimately creating a dominant discourse for the particular era (Foucault, 1980). In this process, certain knowledge is made visible and internalized while other knowledge is discursively excluded. Discourses of truth are produced in this way through mechanisms of power embedded in and exercised through institutions (Foucault, 1972). Power and knowledge are thus reciprocal and fundamentally intertwined.

Implementing FDA can be a challenge due to the lack of analytic guidance left by Foucault (Ong et al., 2024). This has led to the varied application of the methodology in modern literature (Hook, 2001), with all research arguably using a 'Foucauldian-inspired' approach. After considerable investigation into prior approaches to FDA, the current study uses a framework modeled after a study by Ahl (2007), combined with guiding principles set by Arribas-Ayllon and Walkerdine (2017). Ahl (2007) details the core principles of Foucault and creates multiple smaller objectives under an overarching research question to help guide analysis. Principles include reversal, discontinuity, specificity, and exteriority, which are used to ensure both the 'said' and 'unsaid' are examined appropriately. Objectives are created in an iterative manner as data is collected and reviewed. Arribas-Ayllon and Walkerdine (2017) approach their analysis by first selecting a corpus of statements, before assessing its formation, problematizing the text, and considering technologies of power and self that assert influence on

the discursive object. Their process highlights the need for technologies in driving the researcher's frame of reference.

In this study, five guiding objectives were iteratively formulated throughout the data collection phase:

- What assumptions are made about providers and healthcare institutions in these texts?
- In what ways do institutionalized practices influence how narratives are shared?
- How are discourses co-produced by dialogue between posts and their comments? Who is allowed to speak, and what is allowed to be spoken?
- What is implied in the ways users of r/dialysis refer to their healthcare team?
- How is power displayed and discussed in the posts shared on r/dialysis?

Given the nature of FDA, research findings were discussed with other authors throughout the collection and analysis process. A journal was kept by the first author for reflexivity as well as transparency in decision-making.

This study was exempted by the Human Research Ethics board at the University of Victoria, as Reddit posts are considered public data. However, the ethics of using social media as datasets has been an increasing concern in academic circles (Adams, 2024; Fiesler et al., 2024; Golder et al., 2017; Hunter et al., 2018; Moreno et al., 2013; Stommel & Rijk, 2021; Webb et al., 2017); hence, ethical concerns that could arise were thoroughly discussed prior to the study. Topics of discussion among the research team included implied consent, autonomy over posts, patient vulnerability, anonymity, contextual importance, and the risk versus reward of conducting this study. To mitigate the potential harm to users on the forum, particular attention was placed on the context of each post and annotations attached accordingly throughout analysis. Furthermore,

all quotes used in this article are paraphrased to maintain anonymity, and researcher triangulation was leveraged to ensure meaning is preserved for academic integrity.

Findings

This study generated valuable insights, driven by the five objectives. The findings were organized into three interrelated discursive categories: *Technologies of Self, Technologies of Power*, and *Provider as System*. In this paper, we explore the findings that both align with the identified research topic and hold potential to inspire meaningful change. While we acknowledge the presence of other discourses in the data, they are not discussed here.

Technologies of Self

Foucault defines 'technologies' as the methods and techniques humans use to interpret and control both themselves and others. He identifies four types: production, sign systems, power, and self (Foucault, 2005). While these technologies are distinct, they rarely function in isolation, instead operating through ongoing and interconnected interaction. A focus on technologies of self explores the tools used by humans to define and produce an ethical self-understanding. This discursive category explores the practices by which individuals can influence their way of being to attain certain states of "happiness, purity, wisdom, perfection, or immortality" (Foucault, 2005, p. 18).

Positioning and Presentation. Many posts by patients in their first year of hemodialysis began with an introduction, typically including demographic details such as age and gender. These introductions were frequently accompanied by a statement of how long they had been undergoing hemodialysis, with some expressing lack of familiarity and identifying as new to the process. As one user stated, "I've not been long in the saddle yet."

Users generally presented as friendly and inviting, often sharing their story and asking for advice or emotional support. There was notable use of emojis in some posts, with icons ranging from hearts and smiles to angry faces. These were generally used as emphasis in expressions of gratitude or as a form of humor, both of which were prominent sentiments in the selected posts. For example, gratitude was emphasized with a heart emoji when a user thanked responses to their story "in advance", while humor is seen when another user stated his "fat butt" was the reason for a prolonged stay in the hospital, accompanied by an eye-roll emoji.

There were also a handful of posts by users who presented as more emotional or upset, seeking help from the community to resolve a specific problem or find encouragement. These posts did not use emojis and instead used punctuation to portray their urgency. One patient, for example, used multiple question marks when asking if they were the only patient experiencing a certain symptom, while another wondered if being dead was "any worse than [life on dialysis]???"

Concepts of "Good" Patients and Providers. Many new dialysis patients appeared to share a similar concept of how a 'good' patient and provider should act. This is shown through their positioning of specific actions as variously positive or negative: "doing … what the nurses and doctors want" is framed with pride, while missing appointments is associated with shame. This was often echoed in the comments as other users respectively praised or criticized the action. Patients would further report doing "everything right" by "cleaning up their diet," having good blood work, or being patient with new nurses. Not complying with treatment regimens was then labeled as something "stupid" to do.

Some patients appeared to experience tension between their pre-existing identities outside of dialysis, and their new identity as a hemodialysis patient. Most often, their inability to work as

they did before dialysis is expressed as a source of regret or stress. Users asked questions about other patients' abilities to continue working during treatment and shared feelings of missing their jobs, along with efforts to maintain employment despite their condition. Some even stated that the ability to continue working was a "big factor" in their decision-making around modality and treatment scheduling. Accepting a change in their perception of themselves was a significant part of the dialysis transition, as they endorsed "still trying to accept things have changed," accepting no longer "being Superman," and "[losing]... such a big part of [themselves]."

Concepts of what made a 'good' provider were more explicitly endorsed than concepts of a 'good' patient. Patients praised doctors for "actually caring" about their needs and appreciated nurses for "making them laugh" and "feel comfortable". Moreover, information-sharing by providers was a prominent source of relief. Whether it was physicians sharing diagnosis details or nurses explaining the dialysis machine, patients appreciated providers telling them "what they're doing and why."

Self-Monitoring and Interactions with Comments. Patients starting dialysis would often apologize in their posts for "complaining" or acknowledge that they were feeling the "wrong" way. Sometimes this was illustrated through expressions of regret and justification of posts that shared a pessimistic outlook. For example, one user apologized for their "incoherent rant" and explained that it was due to their fatigue, while another finished a post with "anyway" as a means to shift away from their perceived negativity. Users often expressed feeling temporarily "sorry" for themselves, or acknowledging that they "should be" more positive by continually "trying… to not let everything get [them] down."

An examination of the interactions between selected posts and the associated comments revealed patterns of encouragement and support. Comments were often written by self-identified

“veterans” (i.e. those who had lived experience as patients on dialysis), who shared their stories or advice on many of the posted narratives. A commonly made suggestion was to ask more questions and gather information to “make informed decisions”. These were often accompanied by encouragement to continue “working for it” and “fighting” in pursuit of “being in control”. Comments would also empathize with patients’ struggles, stating “Lucky us…” (with sarcastic intent) and “you’re not alone”, with one user even stating, “we dialysis patients… [must] stick together”. These demonstrations of compassion and empathy were paired with acknowledgements of things “being the way they are” and emphasizing the need to sometimes “just do [things]”. Despite this awareness of dialysis-related struggles, comments almost universally adopted a positive perspective on their shared dialysis journey. Shows of support such as “hang in there”, “you got this”, and “it will get better” were scattered all across the comments in each post.

Technologies of Power

In contrast to technologies of self, technologies of power have a distinctly external focus and operate from a higher-level perspective. Power is exerted through these technologies to shape the subject’s conduct and objectify them. A classic example is Foucault’s panopticon, where the structure itself is the technology that channels the disciplinary power of surveillance (Gane, 2012). Mechanisms of power within the healthcare system have been studied extensively in the literature, often driven by the need for equity and improved patient outcomes for vulnerable populations (Mattioni et al., 2021). This discursive category explores how technologies of power may be presented within dialysis narratives of Reddit users.

Medicalized Terminology. Some users on r/dialysis introduced medicalized language in their posts that a lay person may not typically be aware of or use on a regular basis. One user

reported having “multifocal stenoses… increased flow through the palmar arch… [and] compression of [their] fistula” while another used the term “hemoglobin” over “red blood cells” and “BP” over “blood pressure”. Use of terms such as “acute”, “interstitial inflammation” and “atrial flutter” suggest that these users are more attuned to specific medical processes than the general public. However, these terms are usually mixed with other lay terms, such as being “plugged in” to the machine, “hooked up,” having a “fistula cleaning” or a “shoulder catheter”. Of note, some posts even used the term “BP crash,” a phrase often used by direct care staff, but not typically endorsed in formal textbooks. Users were also seen to adopt the healthcare system’s emphasis on fluid volumes, reporting that they “did 1.7, 1.3… then 1… but [then only] got to .5”. Such medicalized terminology is often used by providers when speaking to or about patients and may be consciously or subconsciously adopted by patients to describe their dialysis experiences. As such, it functions as a technology of power that can influence the patient’s framing of their experiences.

Questioning and Accepting Authority. Providers are positioned within medical institutions as gatekeepers to treatment and essential healthcare services. The exercise of this authority in patient-provider interactions can function as a technology of power. Accordingly, narratives by new dialysis patients often endorsed feelings of powerlessness or uncertainty. One user stated that they “had no choice” when it came to treatment compliance to avoid being “kicked off” the transplant list, while another reported being “being attached to… the centre” and simply “not knowing what to do”. Another post asked if anyone had advice or if they just “have to live with this [feeling]”. A common phrase used across narratives was the statement of feeling tired, not in reference to physical fatigue but rather being weary of certain situations. For example, one post described being tired of “being awake as… tubes [were] put in and out [of

their body]" while another recounted being tired of people looking at them "like they're dying". Yet another reported simply being "tired of dialysis".

In contrast to the narratives that focused on emotion, some posts were centred around asking questions or expressing doubt. Questions were typically about peer experiences, either directly related to dialysis or their interactions with the healthcare system. Users would also question the veracity of their providers, preferring instead to check with their peers for guidance on what to do. For example, one post asked if they could ask their provider to "continue using [their] central [line]" and another stated that they still felt like something was "terribly wrong with their heart" despite provider reassurance. This struggle with authority could be seen as users continued to ask their peers for advice regardless of what was given by providers; one post, for example, reported that their providers recommended a switch to peritoneal dialysis, but that they would only trust someone that had "personally gone through the experience".

Provider as System

Language is an inseparable part of our daily lives that enables us to communicate ideas in both direct and non-direct ways. Choices made when writing in a forum can therefore inform our understanding in ways beyond what is outwardly said. The use of certain pronouns can be subliminal or explicit, and has been shown to facilitate 'othering' through its qualities of inclusion and exclusion (Alinezhad & Nemati, 2019). Linguistic choices can also inform the reader's understanding of where the speaker positions others within their social circle (Yates & Hiles, 2010). This discursive category explores the choices made by r/dialysis users when referring to their care providers and to the healthcare system as a whole.

Use of "They". Patients new to dialysis would refer to their providers as a collective, using "them" or "they" over professional designations. For example, one post reported that "they

created a fistula" and "they pricked me," with no acknowledgement of who "they" are or that the two "they"s refer to different people. Another stated that "'they' are removing the stitches on their central line" but is unclear on who the "they" refers to. At times, it seems that "they" is not a single person but instead the healthcare system as a whole.

Despite the subtleties of the implication, other users of the forum appeared to understand the reference. Usually the use of "they" was made discernible through context; for example, when "they created the fistula" it is presumed that the surgeons were responsible as the only profession with the authority. However, at times context was insufficient; for example, when a user stated that "'they" are taking their water away". While it can be presumed that "they" are a representative of the healthcare system, who they are talking about is not as obvious.

Use of 'My' and 'The'. At times, posts would refer to their providers as *the* nurse and *the* doctor, in contrast to the comments that more frequently used the possessive *my*. These were inconsistent across the posts collected, with some users even flipping between the two within their narrative; however, this pattern was still noted with enough frequency to be highlighted. One post asks the forum if he should inform "the doctors" of a concern, while another states that "the doctor" continually insisted that their condition would improve. In contrast, some posts speak about "my dialysis/healthcare team", "my doctor", and "my nurses". Some even used 'we', stating for example that "we had to add a day" to their dialysis schedule and "we looked into a fistula", in reference to their collaborative decision-making.

Of note, while 'we' in the posts would most often refer to the patient and their healthcare team, 'we' in the comments could refer to either their healthcare team or the dialysis community as a whole. For example, some comments stated that "we are all in the same boat" and that "we

dialysis patients" must support each other. Original posters may even respond to these comments using 'we' as well, as a user did by saying "thank you … we got this".

Discussion

Findings from the selected posts on the r/dialysis subreddit were viewed through a macro lens of power, in accordance with the FDA approach. The iterative process of analyzing each post uncovered multiple overarching discursive categories, which were then filtered to focus on those most relevant to our study. Patient-provider relationships were frequently observed to both shape and be shaped by the discursive power that influences their development. Further analysis revealed the significant role of peer-to-peer interactions within the forum in shaping these relationships. The unique dynamics between posts and their comments provide valuable insights into how patients develop frameworks and concepts during their transition into hemodialysis. Our analysis therefore explores not only findings that speak directly to the patient-provider relationship, but also those on the quality and influence of their relationships with their peers. We have divided the theme of *Creation through Discourse* into three sections: *Creating an Impression, Creating a Community,* and *Creating a Framework.*

Creating an Impression

The first impression plays a crucial role in establishing the foundation of a relationship (Cone et al., 2017). As a result, the way a user presents themselves in their post can reveal pre-existing frameworks and underlying intentions, both deliberate and subconscious. Goffman's dramaturgical model describes self-presentation as a key aspect of self-identity, where the actor displays practices and behaviors to a specific audience to create and manage their impressions (Goffman, 2023). Online forums have created a novel context in which this management occurs, due in part to the anonymity and disinhibition that is afforded with this distance (Shelton et al.,

2015). The rise of the internet in the 1980s spurred the proliferation of virtual communities centered around diverse interests and purposes. In the 1990s, scholars recognized these platforms as spaces for connection, empowerment, and even the subversion of traditional power structures, while also acknowledging their potential to foster alienation (Wilson & Peterson, 2002). As we progress further into the 21st century, especially in the wake of the COVID-19 pandemic, these early observations continue to hold true as society increasingly shifts its interactions to cyberspace (Adams, 2024). Scholars are discovering that traditional theories, such as Goffman's, can be adapted to meet these changes.

On the r/dialysis forum, novice patients were observed to portray an agreeable persona to their peers and establish a novice status. This amiable nature is discursively emphasized through mechanisms such as emojis, humor, and punctuation. While punctuation has traditionally been used to convey emotion through text, written language has evolved to incorporate emojis as a way to convey the prosodic (affective) component of speech. Emojis can moreover serve purposes beyond emotion, also helping to convey a stance, indicate intentions, and apply emphasis (Schneebeli, 2017). Notably, the use of emojis has been found to play a significant role in how recipients perceive both the message and its sender, with emoji use linked to increased social attraction, credibility (Beattie et al., 2020), and warmth (Boutet & Collin, 2021). The first use of the smiling emoticon in 1982 was used to convey an inside joke, which then transformed into emojis a decade later to symbolize a wider variety of meanings. Further, while initially used almost exclusively in casual settings, they have become pervasive across business and formal settings as well (Lebduska, 2015). They often work in tandem with humor, a well-established mechanism that contributes to warmth in impression management (Bitterly, 2018). In this context, dialysis patients create an impression of a friendly beginner through their use of emojis,

inviting more experienced individuals to engage, whether for community, advice, or emotional support.

By positioning themselves as novices, these users further shape a power dynamic between themselves and their intended audience, the veteran patients. Through their posts, they exert technologies of self as a form of impression management, situating themselves within the forum's hierarchy and opening themselves up to others. One user, for example, rhetorically asks if death is "any worse than [life on dialysis]???" This comparison between death and dialysis suggests that dialysis removes what gives their life meaning, and is framed as the less desirable option. The concept of death, with its permanence, evokes fear and a vivid visualization of the user's perceived lack of control. This display acts as a sign of vulnerability from the novice patient, reinforcing the power dynamic while also inviting others to connect and form trust. As Huckaby (2011) suggests, relations of vulnerability and power occur both simultaneously and inseparably – as the user navigates the dynamics of power in the forum, they also must confront their vulnerabilities. A state of vulnerability "demands our attention and calls for response" (Gilson, 2011, p. 309), serving as a necessary condition for change and transition. Users are thus observed to leverage this by inviting advice and emotional support from their veteran peers.

As a continued form of impression management, novice patients were observed to engage in self-discipline. They apologized for "incoherent rants" and expressed that they "should" maintain a more positive outlook, both in their initial posts and in the dialogue within the comments. Despite the presence of moderators on the forum, they did not intervene or comment on any of the selected posts. This lack of direct oversight suggests a classic panoptic setting, where individuals regulate themselves without overt coercion, in line with Foucault's (2020) concept of technologies of the self. This raises the question of who, exactly, the inspector is in

this context – could it be their peers, who have the power to exclude them from the community if they present dissenting views? Or is it a larger societal force imposing the discursive ideal of being a fighter? The use of warfare imagery in relation to disease has been extensively documented, particularly in the field of oncology, and is deeply ingrained in societal discourse. Military metaphors have appeared in medical contexts for centuries, first entering Western thought in the mid-seventeenth century and becoming dominant in the 1800s (Hansen, 2018). This discourse has persisted into the present day and likely shapes how dialysis patients view their own experiences throughout their treatment journey. Prior interactions with peers and the patterns they observe in the forum may also begin to influence their self-presentation. Unspoken norms and shared, subconscious narratives can hold significant power, even when these rules are never explicitly defined.

Creating a Community

The r/dialysis forum presents itself as a space where patients can ask questions about kidney failure and dialysis, as well as share personal experiences related to kidney issues (www.reddit.com/r/dialysis). It positions itself as an inclusive community, open to anyone who engages with good intentions. According to Foucauldian theory, the sustainability of any community – regardless of its focus – relies on subtle power dynamics that naturally give rise to a dominant discourse (Philo, 2019). The interactions between peers in the forum serve to both include and exclude certain narratives, thus preserving the integrity of the communal space.

The use of pronouns such as “they,” “we,” and “my” can be interpreted as indicators of where an individual is situated within both personal and communal hierarchies. When patients refer to providers as “they” or “them,” they position their providers on the outskirts of their social circle. Conversely, referring to providers as “we” brings them closer to the center,

implying a more integrated relationship. The use of "my" and "the" have similar implications, where the former is more personal and the latter more distancing. This movement of the provider between layers of inclusion may reflect the evolving nature of patient-provider relationships over time. For example, novice patients were often observed using "the" and "they," while veteran patients in the comments were more likely to use "my" and "we." This pattern mirrors existing understandings of chronic disease patients, who, through frequent interactions with the healthcare system, develop unique relationships with their providers (Drossman & Ruddy, 2020). These relationships, built over time, begin with providers positioned on such an external layer of the sphere that they can even be seen as anonymous extensions of the healthcare system ("they"). When patients discursively position providers as part of "the system," the power associated with them is situated as immense and institutional. Novice patients, with their limited knowledge, experience a greater power imbalance than their peers. However, with the rise of online forums and increased access to information, patients can shift this power dynamic and gradually separate the provider from the system. As a result, providers become distinct entities with which positive relationships can be built, and the previously conflated sources of power are separated in the patient's worldview.

Foucault links his concept of 'othering' closely with technologies of power and knowledge (Philo, 2019). Communities are built on divisions that emphasize the strengths of the 'in-group' while exposing the flaws of the 'out-group.' While this process can be overt, it is more often manifested through subtle mechanisms (Adlam & Scanlon, 2010). For example, certain knowledge can be made visible, or specific language repeatedly used, to establish a dominant discourse that circulates within the community. Users reinforce these ideas over time, shaping them into accepted truths. This dynamic is both an exercise of power and a form of

resistance against external discourses, as the in-group unites against what they perceive as an unfair narrative (Essex, 2022). These mechanisms are visible in the dialysis forum. Veteran patients, for example, often refer to the community as a team, with statements like "we dialysis patients must stick together." Discourses emphasizing positivity, perseverance in the 'fight,' and the empowerment of asking questions are frequently reiterated. Certain experiences are seen as "just the way things are," becoming normalized as part of the dialysis experience, while others are flagged as problematic. What is considered 'normal', and what is 'not', is thus collectively determined by the group.

Interactions between peers and the self-discipline exercised by users also reveal the need to 'silence' what is deemed an 'incorrect' discourse. Users are often observed apologizing for their complaints and negativity, either proactively or in response to others' comments. Some comments even explicitly encourage them to "be more positive." As users start to refer to the community as "we" and "us," they begin to 'other' those outside their circle who "don't understand" the dialysis experience. This process fosters a dependence on the inner circle for knowledge, as users express a preference to "only trust... those with personal experience." The advice from veteran patients is regarded as equally, if not more, valuable than that from healthcare providers. This is not to suggest that these patients devalue their providers – on the contrary, veteran users are more likely to refer to their "dialysis team" as "we," asserting a shared decision-making process shaped through their interactions. In this way, providers become part of the dialysis community's "in-group", despite not participating in the r/dialysis forum itself. This shift may be supported by the accumulation of shared experiences, mutual understanding, and knowledge gained over time. Sharing becomes a crucial factor in forming what Belk (2013) describes as an "aggregate extended self," where collective experiences help

create an imagined community. As self-identity work increasingly shifts to online spaces, the forum provides users with a platform to form connections and build their “extended selves.” This ongoing process may also lead users to become more accepting of the discourses circulating within their shared space.

Foucault emphasizes a “bottom-up approach” to analyzing discursive power and highlights the importance of the “fringes of society,” where institutional power filters down to the micro-level (Foucault, 2020). In the case of the r/dialysis forum, peer-to-peer interactions function as spaces of both power and active resistance, existing alongside the broader dynamics between patients and the healthcare system. Traditionally, the healthcare system has exerted institutional power through providers who act as intermediaries (Cody, 2003). However, novice patients, by engaging with their peers, can reclaim power by gaining knowledge and support from each other. Veteran patients hold authoritative power within the communal hierarchy due to their extensive lived experiences, shaping the dominant discourse present in the forum. Despite the potential for resistance, observations of the forum suggest that novice patients often embrace, and even perpetuate, these power dynamics. The readiness with which they accept peer opinions without questioning point to a marked difference in quality between patient-provider and peer-to-peer relationships. As one patient noted, many “only trust those with personal experience,” signaling the elevated credibility placed on peers over providers. This may reflect a broader societal shift in how healthcare providers are perceived, as counter-discourses around healthcare become prominent. Peer communities have historically been studied to develop counter-narratives as forms of resistance (Essex, 2022), creating an alternative discourse grounded in shared dissatisfaction with the existing system. In this way, the forum becomes a space where power dynamics are re-negotiated by the participants who engage in it.

Creating a Framework

As novice patients engage with posts and comments in the r/dialysis forum, their perceptions of what it means to be a 'good' patient, the role of providers, and the nature of the patient-provider relationship start changing. While numerous factors influence this framework, including those outside the peer and provider relationship, the advice and stories shared by peers hold significant weight. The r/dialysis community places a strong emphasis on the shared experiences of hemodialysis patients, sometimes cultivating an 'us vs. them' mentality that distinguishes dialysis patients from others. In this environment, novice patients start adopting these discourses, aligning themselves with the perspectives of more experienced peers and shaping their own views based on the collective experiences shared in the comments.

Dialysis patients may experience a tension between the narratives shared by their healthcare providers and those endorsed by the dialysis community. As they transition into their new identity as dialysis patients, they can be seen internalizing certain aspects of the healthcare system, particularly through the adoption of medicalized terminology. Medicalization refers to the framing of non-medical issues within a medical context, or the transfer of self-determination and decision-making from individuals to the medical profession for the purpose of social control (Van Dijk et al., 2019). By adopting medicalized terminology, patients internalize the medical gaze, a concept Foucault describes as the process through which the body is constructed and understood through clinical observations and discourse (Greenhalgh, 2001). This gaze starts from the moment the patient enters the healthcare system and can influence the way the patient views themselves. It objectifies them, reducing them to clinical terms and concepts, such as fluid volumes. Using this medicalized language is powerful, as, in Foucault's (2002) words: "The eye that knows and decides, [is] the eye that governs" (p. 88-89). Over time, patients may start to see

themselves in the way their providers view them. This can lead to a conflict between their internalized medical identity and the self-concept shaped by their peers within the r/dialysis forum. The dialysis community, with its emphasis on shared lived experience, offers an alternative framework that can be at odds with the clinical lens.

As expectations grow for patients to actively participate in their care, the internet has become a valuable space for empowerment through the exchange of knowledge. Online forums like r/dialysis have created a space for dialysis patients around the world to engage in a discourse that centers on empowerment and resistance to the medicalized system. Foucault discusses how knowledge can become a site of resistance, where power structures are contested and challenged (Medina, 2011). Subjugated knowledge, or knowledge suppressed by dominant discourses, is often rendered invisible over time but can be reclaimed as a tool for resistance (Foucault, 1980). Historically, it was challenging to combine and strengthen such counter-knowledge, but the rise of online forums has eased the process. Patients sharing experiences that were once overlooked are now empowered by their peers to mobilize this knowledge. This dynamic is evident in the r/dialysis forum, where the supportive and protective nature of the community fosters empowerment and collective resistance. Comments may urge the novice patient to "BE CONCERNED" and ask more questions, or encourage them to speak up and "fight it hard!" In many cases, patients become advocates for their own care, using their accumulated knowledge to challenge the traditional medical narrative. One patient, for example, thanks the forum for suggesting they get a second opinion, and explains that they advocated for more than a simple fistulogram: "… if he had done that, my steal syndrome would be even worse." Scholars have coined the term "expert patients" to describe this phenomenon, a concept that has sparked both support and criticism from medical professionals (Tattersall, 2002). Despite modern movement

towards patient autonomy and empowerment, discursive transformation is rarely smooth. Patients may be perceived to be demanding, unreasonable, or subversive in their use of medical terminology to assert authority in their decision-making (Shaw & Baker, 2004). These strategies challenge the passive role traditionally assigned to them by the medical gaze in an effort to enact change.

Veteran dialysis patients, in particular, promote the idea of “control” and actively encourage others to ask providers for information and clarity. This shift from being passive recipients of care to active participants marks a significant challenge to the traditional power dynamics between patients and providers. The repeated reinforcement of these ideas within the forum contributes to the broader movement of patient empowerment, which continues to grow as patients take a more active role in their healthcare decisions (Johansson et al., 2021). Foucault’s concept of resistance encompasses everything from small, personal acts – such as asking a provider specific questions about care options – to large-scale movements that aim to challenge institutional norms (Fage-Butler, 2021). Through these individual and collective acts of resistance, patients in forums like r/dialysis may be reimagining their roles and agency within the healthcare system.

Conclusion

Ultimately, as patients progress in their renal journey, their perception of the patient-provider relationship evolves, alongside shifting power dynamics and peer influence. In the early stages, patients rely heavily on the discourse endorsed by their providers, often perceiving them as extensions of the larger healthcare system. When questions or concerns arise, they may bring them to their peers, whose shared experiences lend credibility that providers may not possess. A strong sense of community forms quickly as patients connect over common struggles and

emotions that are difficult to express to those outside the group. As novice patients continue to interact with veterans, they begin to adopt the perspectives and frameworks of their more experienced peers, often fueled by disenchantment with the healthcare system (Thorne & Robinson, 1988). This shift in perception can lead to a sense of camaraderie among patients and a shared desire to resist the medical institutional discourse. Despite this, a healthy patient-provider relationship can still develop when the provider is seen as distinct from the larger healthcare system. This shift allows for a more individualized relationship to develop, where trust and collaboration can emerge over time.

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Chapter 5: Conclusion

In this study, I investigated the patient-provider relationship through the lens of patients transitioning into hemodialysis. By applying Foucauldian Discourse Analysis to a social media dataset, I revealed key insights into how discourse is influenced through peer-to-peer interactions and how the healthcare system, providers, and patients are interconnected. This analysis has significant implications, including a shift in understanding of the patient experience, changing dynamics between patients and providers, and the application of similar methodology in future research studies.

5.1 The Patient Experience

The peer-to-peer interactions observed in the r/dialysis subreddit emphasized the pivotal role of community in shaping patients' perceptions during their transition into hemodialysis. The three overarching themes identified were all significantly influenced by peer perspectives: in *Creating an Impression*, patients positioned themselves as vulnerable dialysis novices to navigate the hierarchy within the forum; in *Creating a Community*, linguistic strategies reinforced a discourse that embraced the 'in-group' while marginalizing the 'out-group' who lacked dialysis experience; and in *Creating a Framework*, patients adopt the perspectives of their peers in defiance of the medical discourses imposed by the broader healthcare system. As online forums continue to expand and make it easier for individuals to connect, the influence of peer relationships is likely to become even stronger.

These insights highlight the significant impact each actor has on others within the healthcare network. Under the right circumstances, words exchanged between a provider and patient on hemodialysis can ripple through the larger peer network, be reiterated over time, and enter the dominant discourse. As such, the interactions within a single patient-provider dyad are

crucial, not only for that individual's experience but also for the broader patient community. In practical terms, this means providers must be mindful at every interaction and recognize the far-reaching effects that even small, micro-level actions or words can have. The use of medicalized language or 'fighter' metaphors, for example, may have consequences, particularly for patients who are still in the process of forming their own framework and may be more vulnerable to provider influence. While the current study examined snapshots of patients new to hemodialysis, the long-term impact remains unexplored. Further research is needed to identify specific actions and phrases with influence, alongside their long-term consequences.

This study helped clarify the role of providers in the new patient experience, revealing how providers are initially perceived as indistinguishable from the healthcare system. Newer patients were observed to position their providers at the periphery of their social circle and blur the lines between provider and system, referring to both as a generalized 'they'. This finding is significant in understanding how patients perceive providers and the institutional power they represent, offering insights into the potential formation and impacts of patient-centered care. As providers are separated from the system, they are no longer seen as mere conduits of power; instead, they have the opportunity to build meaningful relationships and offer personalized care that supports shared decision-making. However, the question remains: how can providers shift their role from the periphery to the core, and transform from being seen as 'they' to being seen as 'we'? Future research is needed to explore the mechanisms that facilitate this transition, including the roles of both peers and providers in this process.

The identity work that occurs during the transition period is underscored by the findings of this study. Initially, patient frameworks may be largely shaped by discourses promoted by their providers, but over time they are also influenced by the discourses of peers. The tension

between these two discourses can create conflict within the patient's framework, and may foster a sense of resistance and mistrust. Patients may feel compelled to 'other' as they decide who to include in their community. Providers must recognize the impact of conflicting discourses and find ways to bridge these differences. While counter-narratives often emerge as challenges to dominant societal discourses, aligning with the values of peers can help incorporate providers into the patient community. This may be achieved by leveraging strong relationships with veteran patients, who hold influence within the peer hierarchy, and fostering positive interactions early in a new patient's journey. Small gestures and the use of appropriate terminology are likely key to cultivating individualized relationships that resonate with the empowering discourse prevalent in patient forums. Future studies to support this insight and examine this process in closer detail are needed to assist this identity work.

5.2 Safe Spaces

The r/dialysis forum positions itself as a safe space for patients on hemodialysis to share their stories, seek advice, and find support from their peers. While it appears to achieve this goal, patients were observed moderating their own behavior, exercising self-discipline, and curating their impressions based on the perceived expectations of the community. Additionally, certain discourses were reiterated while others were suppressed. Patients may hesitate to fully express their opinions if they see others being criticized for dissent, leading to apologies and adjusted perspectives. This raises the question of whether such spaces can still be considered safe, and if safe means the absence of all criticism. Foucault reminds us that every society will eventually form a dominant discourse, supported by power structures, that is accepted as truth (Foucault, 1977). As such, peer-to-peer forums may offer a valuable space for patients to form and discuss their own frameworks, independent of direct healthcare influence.

The free expression of concerns by patients is essential for fostering a respectful relationship (Salt et al., 2012). While initial impression management may be unavoidable, the provider's role may be to quickly establish a sense of safety through rapport-building (Dang et al., 2017). In this context, a safe space allows patients to share insights from various sources, discuss them with their provider (Williams et al., 2017), and generally feel empowered to develop expertise as a patient. When patients can ask questions without fear, they may feel better equipped to self-manage (Fox & Chesla, 2008). Such empowerment becomes increasingly crucial as care provision begins to transition from hospital settings to the community (Baxter et al., 2018). Intentionally validating knowledge that may traditionally be subjugated helps prevent further divisions that could be created through counter-discourse. This study highlights the need for a shift in medical discourse regarding patient expertise, challenging the existing reluctance to value patient-driven research and experience. More studies are needed to support this change and encourage patient-provider relationships in which patients feel safe.

Providers have the opportunity to encourage patients to engage with their peers, either through online patient forums or within the physical dialysis unit. As this study suggests, patient frameworks may be largely influenced by community discourse, where narratives, support, and advice are shared. Relationships formed with peers versus providers may inherently hold different values given the relative positions of patients in their social hierarchies, potential shared experiences of kidney disease, and ability to exercise institutional power (Embuldeniya et al., 2013). Clinicians must remain aware of the multitude of power dynamics at play, including those between peers, between patients and providers, between patients and the system, and between providers and the system. Equally important are the overlapping vulnerabilities that accompany these dynamics. While the value of patient-centred care and voice is gaining prominence in

academic circles (Bombard et al., 2018), the anonymity of online spaces and lack of formal moderation may make patients vulnerable to misinformation. Providers may have a role in encouraging patients to critically evaluate the messages they encounter throughout their healthcare journey from both peers and the healthcare system. At the same time, a provider-free safe space may be invaluable to this patient population as they allow free expression without fear of institutional repercussion. Further studies in establishing provider roles outside of the hospital may help clarify patient boundaries and provider involvement.

While this study analyzed nurses and physicians as a unified group of providers, it is important to note key differences between the two disciplines. Renal nurses are likely to engage in more frequent and prolonged conversations with their patients compared to their physician counterparts, providing them with more opportunities to influence the discourse through these interactions. Nursing as a profession may benefit from a deeper understanding of how patients discuss their experiences with them in non-clinical contexts, especially as they develop long-term relationships with patients managing chronic conditions. These relationships may also lead to more blurred boundaries for nurses compared to physicians (Suryani et al., 2023), causing dynamic shifts within the patient's social circle. Further research is needed to explore the nuanced differences in relationship quality with nurses and physicians from the patient's perspective, and how each may be positioned within the patient's broader community.

5.3 Methodological Considerations

Beyond its implications for patient and provider populations, this study utilized a unique methodology in analyzing a Reddit forum dataset. Social media, as a relatively new area of healthcare research, presents novel challenges. As more aspects of our lives move into cyberspace, traditional theories, such as those of Foucault and Goffman, must be revisited and

possibly adapted for this digital context. While some researchers have begun this exploration, there remains significant potential for further theoretical development.

One of the key advantages of using online datasets is the sheer volume of data available in each forum. However, this large volume requires considerable time to process, and effective search tools. In this study, the innovative use of *Teleoscope* proved particularly valuable and highlights the potential of such tools for qualitative researchers working with large datasets. Beyond improving efficiency, machine-learning tools enable researchers to conduct more effective searches without relying solely on predefined keywords, offering a broader and more comprehensive sampling. This approach may encourage researchers to tackle what might otherwise seem like a daunting task, promoting the adoption of qualitative research methods in applied settings.

The most valuable insights in this study came from the interactions between posts and their comments. These datasets provide a unique opportunity to capture unfiltered dialogue and power dynamics between parties, along with the reactions of others in real time. This is a significant advantage for qualitative researchers, particularly those focused on exploring discourses and narratives. Discourse analysis applied to social media datasets is an effective approach for understanding patient perspectives and may be extended to a broader range of topics. Traditionally, institutional focus has been on quantitative data in driving change, but with the integration of machine learning tools and these powerful datasets, it may be possible to expand the use of qualitative research.

These datasets present complexities that may need to be considered in potential future research. Given the richness and depth of the data, analysis requires a focused approach that is guided by specific questions or concepts. This study uncovered a wealth of insights that were not

fully explored due to the scope of the thesis, and consequently may have benefited from a narrower scope. At the same time, such expansive analysis offers significant value for exploratory research, offering a higher-level perspective. Other important considerations include the anonymity of posts and the use of post histories, which are central to ongoing ethical discussions around the use of these datasets (Adams, 2022). These approaches should be handled with care, possibly requiring explicit consent from participants if following them over time or investigating a single individual in more depth. The academic community may need to reassess the definitions and boundaries of informed consent, ensuring that ethics reviews are updated to reflect the evolving digital landscape and the increasing use of online platforms for research.

This study, which examines the evolution of patient conceptualizations during their transition into hemodialysis, underscores the importance of providers supporting discourses that resonate with the peer experience. Peers hold substantial influence, as they come together to create communities that uphold specific counter-narratives to challenge dominant medical discourses. Moreover, the interconnectedness of patients, peers, and providers creates a complex web of shared vulnerabilities and power dynamics to navigate. This study's analysis suggests that providers can prioritize the empowerment of their patients by encouraging healthy peer-to-peer connections, fostering open communication and safe spaces, and embracing the need for counter-discourses that may ultimately support more holistic and patient centered care.

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Appendix

Exemption Email from the University of Victoria Human Ethics Board

Dear Su Han Ong,
Thank you for your email. The Vice-chair of the Human Research Ethics Board, Dr. Cindy Holder reviewed your information received via email on September 27, 2024.

We concluded that the research as described, is **exempt** from a UVic human research ethics review under the national ethics policy (TCPS2) and the University of Victoria's human research ethics policy and guidelines:

- Board of Governors research policy (RH8100)
- Board of Governors regulations for research involving humans (RH8105)
- Tri-Council Policy Statement on the Ethical Conduct for Research Involving Humans - TCPS2 (2022)

Reason(s) for exemption:

- The study will be limited to discourse analysis of data/information from publicly available sources, in this case, Reddit posts.

Note
In the event the nature of the project this exemption applies to changes, UVic human research ethics review may be required. Please contact us if you have questions.

Please retain this email for your records. We will do the same.

Best,
Jeta (she/her)

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