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Quality of service and treatment adherence in individuals with end stage renal disease

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QUALITY OF SERVICE AND TREATMENT ADHERENCE IN INDIVIDUALS WITH END STAGE RENAL DISEASE

A Project

Presented to the

Faculty of

California State University,

San Bernardino

In Partial Fulfillment

of the Requirements for the Degree

Master of Social Work

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by

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ABSTRACT

End Stage Renal Disease (ESRD) is a growing problem for Americans. Many individuals with ESRD are on dialysis for many years. Treatment adherence greatly influences positive outcomes, however non-adherence is common. This study focuses on the patients' attitudes about their treatment. Specifically, this study is interested in exploring the relationship between the quality of service dialysis patients are receiving and their treatment adherence. There were no significant correlations found, but there was a trend that indicated an influence.

ACKNOWLEDGMENTS

I would like to thank Dr. Vang for her assistance with this project; she is an excellent professor and an even better research advisor. I would also like to thank Timothy Thelander for his assistance with formatting.

DEDICATION

I would like to dedicate this project to my parents, who have always encouraged and supported my higher education. Also my girlfriend, who has been very patient with me these last few years; I love you very much.

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CHAPTER ONE

INTRODUCTION

Problem Statement

Treatment non-adherence is a problem that is present in a variety of medical settings; however it is the source of much concern in dialysis clinics since treatment non-adherence leads to poor treatment outcomes. Unlike regular treatments in which patients are only on for a limited and specific duration, patients can be on dialysis indefinitely. It is life sustaining renal replacement therapy that involves a complex treatment, medication, and dietary regimen. Patients' failure to follow their treatment exactly as prescribed puts them at a higher risk of mortality. Understandably, most dialysis patients are not one hundred percent adherent to their treatment, however they often find themselves hospitalized as a result. There have been a number of studies that focus on interventions to improve treatment adherence, but they only focus on interventions directed at patients, and not the dialysis clinics and treatment teams.

Kidney Failure

Kidney failure is a growing problem, affecting more than 20 million Americans. The kidneys filter waste and extra water out of the blood and keep the body in balance. There are five stages of kidney failure. When an individual is in the fifth stage, they are said to have End Stage Renal Disease (ESRD), which means that their kidney function is down to approximately 10-15 percent, and is no longer removing the waste and extra water from their blood. The most sought after treatment for ESRD is kidney transplantation, however due to the high number of individuals with ESRD and the low numbers of available kidneys, most people are on dialysis for many years. There are approximately 350,000 Americans on dialysis and according to the United Network of Organ Sharing, approximately 17,000 kidney transplants done last year.

There are two types of dialysis, hemodialysis, and peritoneal dialysis (PD). With hemodialyis, an individual's blood is pumped out of their body via a catheter, fistula, or graft, and is cleaned by a dialyzer and pumped back in. The process takes about four hours and needs to be done several days a week. With PD, a catheter is placed into an individual's abdomen so a

fluid solution can be poured into the peritoneal membrane. The fluid, which filters the blood, can be exchanged manually throughout the day or at night with use of a machine while the individual sleeps.

In both types of dialysis, the individual has to make several life changes. The treatment plan is a full time commitment that includes dietary restrictions, a medication regimen, and time sensitive treatment and appointments. For the average person, changing only one aspect of their life is difficult; individuals with end stage renal disease on dialysis are asked to make several. If an individual is not following every component of their treatment plan they are generally thought of to be noncompliant, or non-adherent. Non-adherence to the dialysis treatment plan is a serious problem because it results in increased morbidity.

As a member of a multidisciplinary team consisting of nephrologists, dietitian, and nurses, it is a part of the social workers role to address non-adherence. There are several psychosocial concerns that contribute to non-adherence that renal social workers intervene with daily; from financial difficulties, to transportation problems, or just forgetfulness or lack of motivation.

The renal social worker can counsel, educate, and advocate for the patient so they have what they need to comply with treatment. However, the patient's beliefs and attitude about their treatment are more difficult to deal with. If a patient does not believe that their treatment will benefit them, or that their dialysis team is not helping them, then they will not likely comply with treatment (Dijk, Scharloo, Kaptein, Thong, Boeschoten, & Grootendorst, 2009; Hailey & Moss, 2000).

Purpose of the Study

There is a certain stigma attached to dialysis that makes it an undesirable form of treatment. Individuals on dialysis may feel dependent and vulnerable. In addition, hospitals and dialysis clinics can be an unwelcoming and intimidating place. A person's belief about their treatment will influence how well they adhere to it (Dijk, Scharloo, Kaptein, Thong, Boeschoten, & Grootendorst, 2009). Where most studies seek to find way of intervening with clients to improve their treatment adherence, this study focuses on modifications that can be made on the agency side. Specifically, this study seeks to understand if the patient's perception of the

quality of service they are receiving impacts their treatment adherence.

Since this study focuses on the quality of dialysis treatment, patients' beliefs will be the source of data. Patients will be asked via questionnaire how much their quality of service affects their treatment adherence. It is hypothesized that patients will attribute a portion of their treatment adherence to a warm, supportive, trustworthy treatment team. Conversely, it is hypothesized that patients will attribute a portion of their non-adherence to a cold, unwelcoming, dismissive team and environment. The results of this study may suggest a need for a higher quality of service when working with individuals with ESRD.

Significance of the Project for Social Work

This study is necessary to evaluate two of the core values of the social work profession in the renal social work setting: service, and dignity and worth of the person. This is not to say that it is felt that dialysis patients are being mistreated in anyway, it is just that there may be areas for improvement in terms of quality of service. For example, with hemodialysis, patients share a

room with twenty or more others lined up in their chairs with no barriers in between them. Many hemodialysis patients have reported that they feel depressed sitting in the rooms with others because they can see how sick the others look.

Similarly, in some agencies there is a high caseload, with at times a hundred patients to one social worker. Though the social worker may be skilled, the quality of service can be hindered by the sheer number of patients. This study aims to provide an increased awareness of the importance of service, with the hope of increasing the service provided.

CHAPTER TWO

LITERATURE REVIEW

Introduction

This chapter provides a review of past dialysis literature. It will cover treatment adherence and psychosocial factors that contribute to non-adherence. Also it will discuss the theoretical perspective and rational for this study.

End Stage Renal Disease

An individual has End Stage Renal Disease when their kidneys fail to function, and they require renal replacement therapy to remove the toxins, wastes, and excess fluid from their blood (Hailey & Moss, 2000). In the United States, diabetes, hypertension, glomerulonephritis, and polycystic disease are the primary contributors to ESRD (Ramezani et al., 2007). According to the United States Renal Data System, in 2009 there were 572,569 individuals with ESRD. The rates of ESRD are expected to increase due to the rising rates of obesity and type-two diabetes (Glassock, 2004).

There are two types of renal replacement therapy; dialysis and kidney transplantation (Ypungmee &

Evangelista, 2010). With kidney transplantation the kidney can come from a living donor or a cadaver. According to the United Network for Organ Sharing, in 2009 there were 28,463 kidney transplants in America. Due to the high number of individuals with ESRD and the low number of available kidneys the wait period to receive a cadaver kidney can be more than fifteen years. Even if an individual with ESRD has a friend or family member who has chosen to donate their kidney to them, it can take as long as a year due to the amount of testing that is required.

Hemodialysis is the most common form of treatment for ESRD (Ypungmee & Evangelista, 2010). Hemodialysis is the process of circulating and cleaning the blood through a dialyzer. Individuals that are on this form of dialysis have to clean their blood three to four times a week, with a process that takes about four hours (Durose, Holdsworth, Watson, & Przgrodzka, 2004). Individuals on hemodialysis require much medication, and must follow a intricate diet that monitors potassium, sodium, phosphorus, and fluid intake (Durose et al., 2004).

For some individuals with ESRD, peritoneal dialysis is a preferred treatment because it allows more

flexibility (Ellam & Wilkiw, 2007). Unlike hemodialysis, an individual does not have to be connected to a machine for multiple hours a day. Instead, an individual exchanges a dialysate solution into their peritoneal cavity throughout the day (Ellam & Wilkiw, 2007). On average, there are four, two-liter solution exchanges in a day (Ellam & Wilkiw, 2007).

Dialysis and Treatment Adherence

Treatment non-adherence, when medical advice is not followed, can result in terrible outcomes such as infection, cardiac complications, and death (Chilcot, Wellsted, Vilarl, & Farrington, 2010). There are different types of non-adherence. Patients are required to follow a dialysis schedule, control what they eat and drink, and take medication (Hailey & Moss, 2000). The likelihood that a patient will skip a dialysis treatment or medication, or eat something they are not suppose to is high (Hailey & Moss, 2000). Treatment non-adherence can be self reported, or measured by weight gains and lab results, or by observable resistance (Baines, Hamilton, & Jindal, 2000).

Non-compliance can be due to psychosocial concerns such as depression, finances, or transportation issues (Baines, Hamilton, & Jindal, 2000; Cukor, Rosenthal, Jindal, Brown, & Kimmel, 2009). However, the patients representation of their ESRD and treatment also contribute to non-adherence (Dijk, Scharloo, Kaptein, Thong, Boeschoten, & Grootendorst, 2009)

Attitudes and Beliefs

Given the degree of their illness, and the tedious and invasive treatment, individuals with ESRD tend to have a low quality of life (Krespi, Bone, Ahmad, Worthinton, & Salmon, 2004). The patients' negative perceptions of ESRD and dialysis treatment influence non-adherence (Ypungmee & Evangelista, 2010). Someone will have little buy in with their treatment if they do not perceive it to be working, and even less if they are receiving low standards of care. Future advances in medicine may prove to facilitate better dialysis treatment options and better renal outcomes for ESRD. However, in the meantime different options need to be explored to increase patient attitudes and beliefs (Hailey & Moss, 2000).

Organizational change is necessary to achieve the best results (Proehl, 2001, Ch 1). Though it may not be possible to improve the quality of dialysis any time soon, it may be possible to improve the quality of service to develop better treatment and illness perceptions. According to Proehl (2001), outcomes can be improved through organizational modifications (p. 13). By attaining the patient's values and incorporating them into a higher quality of service, it may be possible to facilitate a better treatment environment (Proehl, 2001, Ch 1); and in doing so improve on the two social work values in question, service, and dignity and worth of the person.

Theories Guiding Conceptualization

The Theory of Reasoned Action has been used in a variety of studies to explain how attitudes interact with behavior. In short a persons' behavior is greatly influenced by their attitudes toward that specific behavior (Ajzen & Fishbein, 1980). Dialysis tends to carry a particularly negative stigma. Due to the nature of the treatment it is life altering and is frequently perceived as a burden. As a result, patients tend to have

negative attitudes of their dialysis treatment. This can be compounded by the quality of care they are receiving at their dialysis clinic.

This study operates under the assumption that, if a patient has a negative attitude or perception of his or her dialysis treatment then he or she will not likely adhere to treatment. It is believed that by this student that the quality of care a patient receives greatly affects their attitudes of their treatment. If this is the case, the task should be to develop batter practices to reduce the stigma of dialysis, and improve on the negative attitudes and perceptions.

Summary

This chapter gave background information on End Stage Renal Disease. It stressed the importance for the development of interventions to increase patient treatment adherence. It also stated that patients' attitudes about their treatment must be addressed to better increase their adherence.

CHAPTER THREE

METHODS

Introduction

This chapter discusses the purpose of the current study, and the methods by which the data was collected and examined. It covers who was surveyed in the study, how they were surveyed, and how the data was analyzed. The study was conducted to test the hypothesis that the quality of dialysis treatment received effects treatment adherence.

Study Design

The purpose of this quantitative study is to explore the relationship, if any, between the quality of service dialysis patients receive, and their treatment adherence. It is thought by this student that patients attitudes of their dialysis treatment are influenced by the quality of care they receive. Data was collected through surveying individuals with end stage renal disease (ESRD) who have been receiving either hemodialysis or peritoneal dialysis. It is hypothesized that individuals receiving dialysis treatment will attribute a portion of their

success or failure in treatment adherence to the quality of care they receive.

Sampling

Dialysis clinics within Riverside and San Bernardino counties were explored to serve as potential study sites, however this graduate student was unsuccessful in gaining access to these locations. As a result, participants were recruited online through dialysis support groups and forums. Participants were required to be at least 18 years of age, and currently receiving either hemodialysis or peritoneal dialysis. The sample is made up of 11 hemodialysis, and 14 peritoneal dialysis patients, who have been receiving treatment for at least one year. There were 13 males and 12 female who participated in this study with ages ranging from 25 to 67 years old.

Data Collection and Instruments

Data was collected to explore the relationship between the quality of care dialysis patients receive (independent variable), and their adherence to their treatment (dependent variable), i.e., dietary restrictions, medication compliance, and treatment schedule. The quality of care provided by the facility

and the level of adherence was self reported by the study participants though a survey.

The quantitative survey (Appendix A) was made up of questions regarding the quality of care that the participants are receiving at their dialysis clinic, and how well they have adhered to the medication, treatment, and various dietary restrictions that accompany dialysis. Five of the questions pertained to the quality of care the patients are receiving. There were also five questions regarding their treatment adherence. The answers to the questions were collected via Likert style scale (strongly agree, agree, unsure, disagree, strongly disagree)(always, very often, sometimes, rarely, never). The answers were scored and added up. Demographics were collected to determine if there were differences in the results be age, gender, dialysis type, years on dialysis, or race/ethnicity.

Procedures

Patients receiving hemodialysis and peritoneal dialysis treatment for their end stage renal disease were asked to participate in the current master's thesis project through several message posts at the following

online groups: Dailystrength, Mdjunction, Davita, and Imedix. Volunteers were assured that their treatment would not be affected in any way by agreeing or refusing to participate in the study. Also, they were informed that their information and participation is anonymous, and handled with standards that would insure confidentiality. The study was explained to the participants and they were given informed consent. The data was collected between February and March of 2011.

Protection of Human Subjects

All conceivable methods were used to protect the study participants' confidentiality and anonymity. Survey completion was conducted on a voluntary basis, and included informed consent (Appendix B) along with a debriefing statement (Appendix C). No data involving the study participants' identities were used for this study, and the individual surveys remain anonymous and are treated as privileged information.

Data Analysis

The quantitative survey used in this study measured the independent variable quality of service, and the dependent variable treatment adherence. The statistical

software SPSS was used to compute the data and a correlation between the ordinal IV and the DV was determined using Spearman's Rs.

Summary

This chapter explained the design, procedures, and sample the current study used to determine if there is a correlation between the quality of care dialysis patients receive and their treatment adherence. The results of this study can potentially be helpful in the development of higher standards of care when treating individuals with ESRD.

CHAPTER FOUR

RESULTS

Introduction

This Section covers the findings of the current thesis. It describes the demographics of the sample, and how they reported and scored on their treatment adherence and the quality of service they receive. Finally it explains the relationship between the two variables.

Presentation of the Findings

The current study solicited individuals with end stage renal disease currently receiving hemodialysis or peritoneal dialysis to see if their treatment adherence is influenced by the quality of service they receive. There were total of 25 participants (represented by Table 1), 52 percent were males, and 48 percent were females. 64 percent of the sample was individuals currently receiving peritoneal dialysis, and 36 percent received hemodialysis. At 60 percent diabetes was the primary cause of kidney failure among the sample, followed by hypertension at 20 percent, 8 percent glomerulonephritis, and 4 percent polycystic kidney disease respectively. Four percent of the sample listed causes other than the

above as the cause of their renal failure. At 40 percent, the most common age range of the sample was 35-45 years, followed by 56-65 years making up 24 percent of the sample, 46-55 years at 16 percent, 18-25 and 25-35 years each 8 percent, and 66-75 years 4 percent (Appendix D).

Table 1. Sample Characteristics

	All	Hemodialysis	Peritoneal Dialysis
Gender of participants			
Male	13	4	9
Female	12	5	7
Cause of Kidney Disease			
Diabetes	15	4	11
Hypertension	5	1	4
Glomerulonephritis	2	2	0
Polycystic	1	1	0
Other	2	1	1
Age of participants			
18-25 years	2	0	2
26-35 years	2	0	2
36-45 years	10	6	4
46-55 years	4	1	3
56-65 years	6	1	5
66-75 years	1	1	0

Treatment adherence is used in this thesis to describe an individual's ability to follow their treatment as recommended by their treatment team. It was self-reported and measured by the first five questions of the survey. As represented by table 2 below, the participants reported that they were adherent to their treatment; scoring highest in "always" or "very often" at 94.4 percent. Though, this survey did note that participants had the most difficulty adhering to their dietary and fluid restrictions.

Table 2. Treatment Adherence

Question	Always	Very often	Sometimes	Rarely	Never
1	0.056	0.096	0.048	0.000	0.000
2	0.120	0.080	0.000	0.000	0.000
3	0.200	0.000	0.000	0.000	0.000
5	0.152	0.048	0.000	0.000	0.000
	Strongly agree	Agree	Unsure	Disagree	Strongly disagree
4	0.176	0.016	0.000	0.008	0.000
Total	0.704	0.240	0.048	0.008	0.000

The quality of service the participants received was again self-reported. It was measured by the last five questions of the survey. As shown by table 3, the

majority of the participants believed that they received a relatively good quality of service; scoring 88 percent in the first two columns. However, there were a few individuals who reported that they were not comfortable in their dialysis clinic (3.2 percent), that their dialysis team was not helpful (3.2 percent), and that their needs were not addressed (4 percent).

Table 3. Quality of Service

Question	Strongly agree	Agree	Unsure	Disagree	Strongly disagree
6	0.128	0.640	0.008	0.000	0.000
7	0.136	0.640	0.000	0.000	0.000
8	0.136	0.024	0.032	0.008	0.000
9	0.112	0.056	0.024	0.008	0.000
10	0.088	0.072	0.024	0.016	0.000
Total	0.600	0.280	0.088	0.032	0.000

A Pearson's correlation crosstabulation appears in Appendix E. Cross tabulations between the participants' treatment adherence and the quality of service they receive, showed a 0.436 level of significance. Though this thesis could not significantly confirm a relationship between an individual's treatment adherence and the quality of service they receive the data did

Table 4. Treatment Adherence and Quality of Care

Participant Number	Treatment Adherence	Quality of Service
1	7	12
2	7	13
3	5	6
4	6	9
5	6	9
6	6	7
7	5	14
8	9	7
9	9	14
10	11	14
11	8	10
12	5	6
13	6	5
14	5	5
15	6	5
16	5	5
17	5	5
18	7	5
19	7	5
20	8	5
21	9	7
22	9	9
23	7	5
24	5	5
25	7	7
Total	170	194

suggest a trend (see table 4). Though most of the participants reported good treatment adherence (94.4 percent) and good service (88 percent), some reported less the perfect adherence (5.6 percent) and a lacking quality of service (12 percent).

Summary

The sample was composed of 25 participants, almost evenly male and female, with an age ranging from 18 to 67. Most of the participants receive peritoneal dialysis, and the primary cause of kidney failure was diabetes. The majority of the participants reported that they were adherent with their treatment plan. Similarly, the majority of the participants reported that they receive a good quality of service from their dialysis clinic. Unfortunately, this thesis did not produce any results that were significant.

CHAPTER FIVE

DISCUSSION

Introduction

This chapter extrapolates on and examines the results. It argues the relationship between treatment adherence and quality of service. Also, it covers the limitations of the thesis, and discusses potential areas for improvement in renal social work and the dialysis setting.

Discussion

As previously mentioned, treatment adherence is closely monitored with dialysis because non-adherence is associated with increased hospitalizations, and a higher mortality rate. Depression, language barriers, and cultural differences are a few factors that are associated with non-adherence; this thesis sought to identify an additional area. The attempt at establishing a relationship was done by measuring levels of adherence and quality of service.

The sample self reported an unusually high level of treatment adherence. This in inconsistent with other studies such as Kuther (2002), who found that at least

half of hemodialysis patients are non-adherent, and one third of peritoneal dialysis patients skip treatments. There are two possible explanations; either the participants were dishonest, or they do not consider their behaviors to be non-adherent. Since the sample was anonymous and they had no reason to be anything other than honest, this student believes the latter to be true. However, this could indicate that there is a discrepancy in how patients define treatment adherence, and how healthcare providers define it.

Though little non-adherence was reported by the sample at all they did express the most difficulty attaining to their dietary restrictions, which is consistent with the findings of Lam, Twinn, and Chan (2010). The sample reported less difficulty adhering to their medication and treatment regimen. When a new patient begins dialysis they receive equal education in the two areas; the only difference is that they are adding medication and their dialysis treatment to their routine, while with dietary restrictions they are asked to modify what they have been doing their entire life.

Quality of service was broken down into three categories; supportiveness, communication, and treatment

environment. Overall, the participants felt they received good service, but there are a few areas for improvement. Some participants expressed that they were not comfortable in the clinic. Moreover some reported that they were not comfortable asking questions. Though they were not heavily reported, it is still a cause for concern. If patients do not understand what they are being told, and are not comfortable enough to clarify, then they will leave confused.

Quality of service has been grossly overlooked and continues to be undervalued. The centers for Medicare and Medicaid divide the U.S. into 18 Networks; Southern California is in the eighteenth network. The networks primary responsibility it to regulate and enforce the standards of practice for dialysis centers. They insure "quality care", in that every clinic has everything a patient will medially need; as opposed to quality of service, which they do not concern with. Furthermore, Medicare has an ESRD Quality Initiative, but again it focuses only on providing access to medical needs.

This thesis did not provide evidence of a significant relationship between treatment adherence and quality of service. The majority of the participants

reported that they were adherent with their treatment so there was few non-adherent participants to examine. The participants that did report a less than perfect level of adherence showed a trend consistent with the hypothesis. Even though a relationship between treatment adherence and quality of service was not established, it should not be completely rejected; there were several limitations of this thesis.

Limitations

Since the incidence and precedence of End stage renal disease is on the rise in America, dialysis clinics in high demand. Unfortunately, this does not necessary mean that there is a sufficient number of staff working at the dialysis clinics. As such, local clinics were too overwhelmed with heavy caseloads to participate during the data collection phase of this thesis. As a result, there were several constraints and inadequacies, otherwise known as limitations with this thesis.

The first and primary limitation of this study was a lack of access to individuals with end stage renal disease currently receiving dialysis treatment. Much time was spent preparing to meet with and interview the study

sample; however the opportunity was never there. Since data was collected and participants were recruited collected online, further extrapolation other then surveyed responses were not possible.

The use of a survey alone was inadequate to measure the variables. Participants may have rated their treatment adherence better or worse than it actually is. A more accurate method, and the originally proposed, would be to examine their protein, KV/T, phosphorus, calcium, and parathyroid laboratory results. Similarly, when measuring the quality of service the participants receive, a qualitative approach may have been more effective then the quantitative approach used. There may have been areas in which the participants felt lacked in service other than those that were covered by the survey.

Last of all, the size was much too small. Though the internet allowed for a potentially a wide and diverse sample, not many people participated. The minimum target amount was 40 participants; however this student was only able to obtain 25. Had there been more participants there might have been significant results.

Recommendations for Social Work Practice, Policy and Research

Treatment non-adherence is addressed by each member of the treatment team; it is not just the responsibility of the social worker. However, typical interventions are solely directed at the patient, in which they are educated about what they need to do, and why they need to do it. Instead, this thesis focused on one area the clinic and treatment team could themselves change in a way that would improve treatment adherence in their patients. It did not produce any significant results indicating a relationship between treatment adherence and quality of service, but it did display a trend indicating certain areas that could be improved on.

To begin with, the number of patients that are assigned to the social worker and dietitian is too high. There are several nephrologists and nurses but typically only one social worker and one dietitian per clinic. Being that the participants of this thesis indicated that they had the most difficulty adhering to their dietary restrictions; it would be beneficial to have additional dietitians so they can spend more time with their patients. Similarly, if there were additional social

workers, they would be able to allocate more time to their patients, and work on underlying factors that may influence treatment non-adherence such as depression.

Furthermore, some participants expressed a disconnection in communication. Whether they do not understand what is being said to them due to the medical jargon, or they are not comfortable asking question; a patient centered approach should be taken by each discipline to insure comfort, understanding, and adequate communication.

Lastly, there is a need to revamp hemodialysis clinics. Hemodialysis patients have to go to their clinic to receive treatment three to four days a week for three to four hours each day, which is difficult in itself but not the area of concern. The concern is with how the patients receive their treatment. They receive their dialysis in a shared open area. There are as many as thirty people receiving their treatment at the same time and they can all see each other, which eliminates privacy and creates a depressing environment. Better ways of facilitating hemodialysis need to be explored. Small changes such as creating barriers in between patients can make a big difference.

Making the clinic a pleasant place to be will make the treatment that much tolerable. However, good service is difficult to enforce. A set standard of service needs to be developed, and consistently monitored. Patients themselves can randomly and anonymously rate the service provided.

Conclusions

Nearly all of the participants reported that they were adherent with their treatment. As such, there was no evidence linking non-adherence with a low quality of service from treatment centers. However there were areas identified that can be improvement. When interacting with patients it is crucial to insure they fully understand what is being said. Also, they should feel comfortable enough in the dialysis setting so that they are confident to address their concerns with the treatment team. Additional emphasis should be added on insuring a high quality of service; equally as much as quality of care.

APPENDIX A

QUESTIONNAIRE

Demographics

(Please circle the following)

Current Treatment Modality:

Hemodialysis
Peritoneal Dialysis

Gender:

Male
Female

Cause of Renal Failure:

Hypertension
Diabetes
Polycycstic
Glomerulonephritis
Other

Age: _____

Survey

(Please circle one)

1. I follow all of my dietary and fluid restriction
   1. Always 2. Very Often 3. Sometimes 4. Rarely 5. Never

2. I take all of my medication as prescribed
   1. Always 2. Very Often 3. Sometimes 4. Rarely 5. Never

3. I show up to my dialysis appointments on time
   1. Always 2. Very Often 3. Sometimes 4. Rarely 5. Never

4. I never skip a dialysis treatment
   1. Strongly Agree 2. Agree 3. Unsure 4. Disagree 5. Strongly Disagree

5. I follow my treatment
   1. Always 2. Very Often 3. Sometimes 4. Rarely 5. Never

6. My dialysis clinic is clean
   1. Strongly Agree 2. Agree 3. Unsure 4. Disagree 5. Strongly Disagree

7. My dialysis team is helpful
   1. Strongly Agree 2. Agree 3. Unsure 4. Disagree 5. Strongly Disagree

8. I feel I can ask my dialysis team anything
   1. Strongly Agree 2. Agree 3. Unsure 4. Disagree 5. Strongly Disagree

9. I am comfortable at my dialysis clinic
   1. Strongly Agree 2. Agree 3. Unsure 4. Disagree 5. Strongly Disagree

10. All of my needs and concerns are addressed by my treatment team
    1. Strongly Agree 2. Agree 3. Unsure 4. Disagree 5. Strongly Disagree

Survey was created by Kyle Fraga

APPENDIX B

INFORMED CONSENT

INFORMED CONSENT

You have been selected to participate in this study, with the purpose of further exploring dialysis adherence. Treatment adherence is important because it is linked with treatment outcomes. There are many factors that influence treatment adherence; however this study is focusing on the quality of service dialysis patients receive. This study is being conducted by Kyle Fraga, a graduate student in the Masters of Social Work program at California State University San Bernardino, under the supervision of Assistant Professor Pa Der Vang. Approved by the School of Social Work Sub-Committee of the CSUSB IRB.

You will be asked questions regarding you treatment adherence (how well you follow your treatment, dietary restrictions, and medication), and the quality of care you receive at you dialysis clinic. The survey will take about 5 minutes and is completely anonymous. Your name or any identifiable information will not be collected at any time. There are no foreseeable risks to taking part and no personal benefits involved in this study

By marking below, you agree that you have been fully informed about this survey, are volunteering to take part, and are at least 18 years old.

Mark _____ Date _____

APPENDIX C

DEBRIEFING STATEMENT

DEBRIEFING STATEMENT

Thank you for your participation in this study. The study was done to determine if there is a relation between the quality of care dialysis patients receive and their treatment adherence. This study was conducted by Kyle Fraga, a graduate student in the Masters of Social Work program at California State University San Bernardino, under the supervision of Professor Pa Der Vang.

If you have any questions or concerns about this study you can contact Dr. Vang at CSUSB, (909) 537-3775. The results of this study will be available at the John M Pfau Library after September 10th, 2011.

APPENDIX D

FREQUENCIES

Frequency Table

Participant Age

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00	1	4.0	4.0	4.0
	25.00	1	4.0	4.0	8.0
	26.00	1	4.0	4.0	12.0
	27.00	1	4.0	4.0	16.0
	37.00	1	4.0	4.0	20.0
	38.00	1	4.0	4.0	24.0
	39.00	1	4.0	4.0	28.0
	40.00	1	4.0	4.0	32.0
	42.00	1	4.0	4.0	36.0
	43.00	1	4.0	4.0	40.0
	44.00	2	8.0	8.0	48.0
	45.00	2	8.0	8.0	56.0
	50.00	2	8.0	8.0	64.0
	53.00	1	4.0	4.0	68.0
	55.00	1	4.0	4.0	72.0
	56.00	1	4.0	4.0	76.0
	57.00	1	4.0	4.0	80.0
	58.00	1	4.0	4.0	84.0
	60.00	1	4.0	4.0	88.0
	61.00	1	4.0	4.0	92.0
	65.00	1	4.0	4.0	96.0
	67.00	1	4.0	4.0	100.0
	Total	25	100.0	100.0	

Participant Gender

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	male	13	52.0	52.0	52.0
	female	12	48.0	48.0	100.0
	Total	25	100.0	100.0	

Cause of Kidney Disease

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	hypertension	5	20.0	20.0	20.0
	diabetes	15	60.0	60.0	80.0
	polycystic	1	4.0	4.0	84.0
	glomerulonephritis	2	8.0	8.0	92.0
	other	2	8.0	8.0	100.0
	Total	25	100.0	100.0	

Treatment Modality

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	hemodialysis	9	36.0	36.0	36.0
	peritoneal dialysis	16	64.0	64.0	100.0
	Total	25	100.0	100.0	

Frequency Table

Q1

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	always	7	28.0	28.0	28.0
	very often	12	48.0	48.0	76.0
	sometimes	6	24.0	24.0	100.0
	Total	25	100.0	100.0	

Q2

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	always	15	60.0	60.0	60.0
	very often	10	40.0	40.0	100.0
	Total	25	100.0	100.0	

Q3

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	always	25	100.0	100.0	100.0

Q4

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	strongly agree	22	88.0	88.0	88.0
	agree	2	8.0	8.0	96.0
	disagree	1	4.0	4.0	100.0
	Total	25	100.0	100.0	

Q5

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	always	19	76.0	76.0	76.0
	very often	6	24.0	24.0	100.0
	Total	25	100.0	100.0	

Q6

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	strongly agree	16	64.0	64.0	64.0
	agree	8	32.0	32.0	96.0
	unsure	1	4.0	4.0	100.0
	Total	25	100.0	100.0	

Q7

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	strongly agree	17	68.0	68.0	68.0
	agree	8	32.0	32.0	100.0
	Total	25	100.0	100.0	

Q8

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	strongly agree	17	68.0	68.0	68.0
	agree	3	12.0	12.0	80.0
	unsure	4	16.0	16.0	96.0
	disagree	1	4.0	4.0	100.0
	Total	25	100.0	100.0	

Q9

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	strongly agree	14	56.0	56.0	56.0
	agree	7	28.0	28.0	84.0
	unsure	3	12.0	12.0	96.0
	disagree	1	4.0	4.0	100.0
	Total	25	100.0	100.0	

Q10

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	strongly agree	11	44.0	44.0	44.0
	agree	9	36.0	36.0	80.0
	unsure	3	12.0	12.0	92.0
	disagree	2	8.0	8.0	100.0
	Total	25	100.0	100.0	

APPENDIX E

CROSSTABULATION

Crosstabs

Adherence1 * Qualityservice Crosstabulation

Count

		qualityservce								Total
		5.00	6.00	7.00	9.00	10.00	12.00	13.00	14.00	
adherence1	5.00	4	2	0	0	0	0	0	1	7
	6.00	2	0	1	2	0	0	0	0	5
	7.00	3	0	1	0	0	1	1	0	6
	8.00	1	0	0	0	1	0	0	0	2
	9.00	0	0	2	1	0	0	0	1	4
	11.00	0	0	0	0	0	0	0	1	1
Total		10	2	4	3	1	1	1	3	25

Correlations

		adherence1	qualityservce
Adherence	Pearson Correlation	1	.436*
	Sig. (2-tailed)		.029
	N	25	25
Qualityservice	Pearson Correlation	.436*	1
	Sig. (2-tailed)	.029	
	N	25	25

*. Correlation is significant at the 0.05 level (2-tailed).

REFERENCES

Ajzen, I., & Fishbein, M. (1980). *Understanding attitudes and prediction social behavior.* Englewood Cliffs, NJ: Prentice-Hall.

Baines, L. S., Hamilton, D. N., & Jindal, R. M. (2000). Compliance with hemodialysis and kidney transplantation: A Pyschotherapeutic perspective. *Transplant Proceedings, 33,* 1985-1986.

Chilcot, J., Wellsted, D., Vilarl, E. & Farrington, K. (2009). An association between residual renal Function and depression symptoms in hemodialysis Patients. *Nephron Clinical Practice, 113*(2), 117-124.

Cukor, D., Rosenthal, D.S., Jindal, R.M., Brown, C.D., & Kimmel, P.L. (2009). Depression is an important contributor to low medication adherence in hemodialyzed patients and transplant recipients. *Kidney International,* 75, 1223-1229.

Dijk, S., Scharloo, M., Kaptein, A., Thong, M., Boeschoten, E., Grootendorst, D., et al. (2009). Patients' representations of their end-stage renal disease: relation with mortality. *Nephrology Dialysis Transplantation, 24*(10), 3183-3185.

Durose, C., Holdsworth, M. M., Watson, V., & Przgrodzka, F. (2004). Knowledge of dietary restrictions and the Medical consequences of noncompliance by patients on hemodialysis are not predictive of dietary Compliance. *Journal of the American Dietetic Association, 104,* 35-42.

Ellam, T., & Wilkie, M. (2007). Chronic renal failure: Peritoneal dialysis. *Medicine,* 35(8), 466-469.

Glassock, R. (2004). The rising tide of end stage renal disease: What can be done? *Clinical & Expermental Nephrology, 8*(4), 291-296.

Hailey, B., & Moss, S. (2000). Compliance behavior in patients undergoing hemodialysis: A review of the Literature. *Psychology, Health, & Medicine, 5*(4), 395-406.

Krespi, M. R., Bone, M., Ahmad, R., Worthinton, B., & Salmon, P. (2004). Hemodialysis patients' beliefs about Renal failure and its treatment. *Patients Education & Counseling, 53*(2), 189-196.

Kutner, N.G. (2001). Improving compliance in dialysis patients: Does anything work?. *Seminars in Dialysis*, 14, 324-327.

Lam, L.W., Twinn, S.F., & Chan, S.L. (2010). Self-reported adherence to a therapeutic regimen among patients undergoing continuous peritoneal dialysis. *Journal of Nursing*, 66(4), 763-773.

Proehl, R. (2001). *Organizational change in the human services*. Thousand Oaks, CA: Sage Publications.

Ramezani, M., Ghoddousi, K., Hashemi, M., Khoddami-Vishte, H., Fatemi-Zadeh, S., Saadat, S., et al. (2007). Diabetes as the cause of end-stage renal disease affects the pattern of post kidney transplant rehospitalizations. *Transplantation Proceedings, 39*(4), 966-969.

United Network for Organ Sharing. Transplants in the U.S. by State from 1988-2011. Health Resources and Services Administration, U.S. Department of Health & Human Services. Retrieved February 15, 2011, from www.unos.org

United States Renal Date System. USRDS 2010 Annual Data Report: Atlas of Chronic Kidney Disease and End-Stage Renal Disease in the United States, Incident and Prevalent Counts. Retrieved December 4, 2010, from www.usrds.org/reference

Ypungmee, K.M., & Evangelista, L. (2010). Relationship between illness perceptions, treatment adherence, and clinical outcomes in patients on maintenance hemodialysis. *Nephrology Nursing Journal*, 37(3), 271-280.