

# Demographics and Quality of Life in Unfunded Patients Receiving Regular Emergent Dialysis

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## ABSTRACT

**Introduction:** Patients with End Stage Renal Disease (ESRD) must undergo hemodialysis several times per week for renal dysfunction. Chronic dialysis drastically affects the lifestyles of ESRD patients, as it is time-consuming and uncomfortable. A high number of unfunded ESRD patients present to the Emergency Department (ED) at Parkland Hospital for dialysis. These patients accounted for over 7300 ED visits in 2009. Providing emergent dialysis via the ED has been shown to be more costly than providing scheduled dialysis. To date, all psychometric analyses of demographics and quality of life in chronic dialysis patients focus on insured patients in traditional dialysis centers. This study attempts to acquire and analyze such data on the emergent dialysis population at Parkland Hospital. Data will ultimately be compared to control patients from the Parkland system.

**Methods:** A demographic survey developed at UT Southwestern and the established “Kidney Disease Quality Of Life (KDQOL(TM)) Instrument” were presented to ESRD patients seeking dialysis in the Parkland ED. A comprehensive list of 165 suitable patients was obtained from Parkland Nephrology. With a goal of 80% recruitment of those identified, patients were recruited upon presentation 24 hours a day, 7 days a week for a 4-week period beginning on July 8, 2013. In total, 55 data points from each patient were aggregated.

**Results:** Of 101 chronic dialysis patients approached during the initial 4 weeks, 88 completed the survey. Although 39% of listed patients were not surveyed by the end of the 4 weeks, raw data collection has recently been completed. Demographic data reveal a predominantly male, Hispanic, middle-aged, undocumented, and uninsured ESRD patient population seeking dialysis in the Parkland ED. The KDQOL data indicate a majority of surveyed patients rate their current health negatively, while only 9% do so positively. Additional data quantifying the impact of chronic dialysis on patient lifestyles await analysis.

**Discussion:** The demographic data reveal that 68% of the chronic dialysis patients thus surveyed have lived in the USA for more than 5 years, yet only 15% received a diagnosis requiring dialysis over 5 years ago. This finding seems to contradict the currently accepted idea that the need for dialysis is the primary motivating factor bringing most of these patients to the USA. Quality of life data remains to be compared between the unfunded emergent population and the Nephrology clinic population. Descriptors for the emergent patients are expected to be more negative, or at best equivalent to those for the scheduled patients. Considering the higher cost of emergent dialysis, the results of this comparison are expected to support an argument for providing scheduled dialysis for unfunded ESRD patients.

## INTRODUCTION

Patients with End-Stage Renal Disease (ESRD) must undergo dialysis 1 to 3 times per week to compensate for critically insufficient kidney function. Chronic dialysis drastically affects the lives of ESRD patients, as it is a time-consuming and uncomfortable procedure. As the symptoms of ESRD—nausea, vomiting, muscular pain, shortness of breath, pruritus, and fatigue—worsen, the need for dialysis becomes more frequent, demanding a greater number of healthcare visits each week. Parkland Memorial Hospital receives a high number of unfunded ESRD patients who present to the Emergency Department (ED) requesting hemodialysis when their symptoms reach unbearable levels. On moral and legal grounds, the institution practices a policy of “compassionate” dialysis for those meeting criteria for emergent treatment despite the significant associated cost. These patients accounted for more than 7300 ED visits in 2009 alone. Weaver, et al. determined that a case manager-based approach to scheduling dialysis for unfunded patients would be more cost-effective than the current model of providing emergent dialysis (Weaver, et al., 2010). Upon presentation in a highly symptomatic state, the typical emergent ESRD patient must endure a lengthy wait time for lifesaving dialysis treatment. To date, all documented psychometric analyses of quality of life in chronic dialysis recipients have focused solely upon insured patients receiving scheduled therapy in traditional dialysis centers.

## OBJECTIVE

This study attempts to determine demographic data and quantitatively assess quality of life among the population of ESRD patients presenting to Parkland Hospital for emergent dialysis. These data will be compared to age- and sex-matched control patients who receive scheduled, funded dialysis in the Parkland System’s Nephrology clinics. The results are expected to support an argument against the current system of providing emergent dialysis through the ED by demonstrating that the current system is more costly and does not hold any advantage in terms of patient quality of life. Additional trends elucidated from the data will hopefully assist physicians and policymakers in making decisions on the care and coverage of unfunded chronic dialysis patients.

## MATERIALS AND METHODS

A demographic survey developed in house at UT Southwestern and the well-established, statistically validated “Kidney Disease Quality of Life (KDQOL™) Instrument” developed by the RAND Corporation’s Social Policy Department were selected to be administered to ESRD patients presenting for dialysis in the Parkland Hospital ED. A list of all known chronic dialysis patients was obtained from the Parkland Nephrology Department and was narrowed down to 165 eligible individuals by removing patients who were minors or prisoners. With a goal of surveying 80% of the listed individuals, patients were recruited 24 hours a day, 7 days a week for a 4-week period beginning July 8, 2013 to account for every ESRD patient seeking dialysis during that time. While data after the initial 4 weeks has not yet been incorporated into the present analysis, raw data collection has recently been completed.

Upon presentation in the ED, each patient was asked to complete both the demographic and KDQOL surveys in either English or Spanish depending upon preference. The vast majority of patients preferred to have the survey read to them and provided verbal responses to each question. Infrequently, extenuating circumstances, such as blindness or illiteracy, combined with acute medical situations, such as the use of a nebulizer and mask, prevented willing patients from completing the survey on a particular visit.

Every effort was taken to maintain the confidentiality of the patients’ responses. All electronic transmissions containing data were encrypted. Complete paper surveys were maintained in locked storage prior to data entry. Before analysis, each survey was disassociated from the patient’s name and Medical Record Number (MRN) and assigned a random tracking number. 20 possible data points from each demographic survey and 36 possible data points from each quality of life survey were aggregated for analysis in tabular and graphical formats. If a patient chose not to complete or marked multiple answers for a given question, the corresponding data point was omitted from analysis.

After data for the remaining emergent dialysis patients has been compiled and scheduled dialysis patient data is obtained from Parkland Nephrology clinics, appropriate statistical analyses will be used to compare quality of life data between these two populations.

## RESULTS

Descriptor	Number of Patients	Percentage of Surveyed Patients
Hispanic Origin	82 (of 83)	99%
Undocumented Status	65 (of 83)	78%
>5 years in United States	57 (of 84)	68%
>5 years since ESRD Diagnosis	15 (of 79)	19%

Table 1. Immigration Status and History of ESRD Diagnosis Among Parkland Hospital’s Emergent Dialysis Patient Population.

## RESULTS

Of 101 chronic dialysis patients approached during the initial 4-week period of data collection, 88 agreed to complete the survey. Although approximately 39% of patients previously identified by Parkland’s Nephrology Department (64 of 165) had not been surveyed at the time of present analysis, raw data collection for these patients has recently been completed. General trends regarding the immigration status of the chronic dialysis patient population are summarized in *Table 1*. These data reveal that the majority of emergent dialysis recipients presenting to the Parkland ED are Hispanic immigrants (99%), the majority of whom (78%) are undocumented. 68% of patients report having resided in the United States for more than 5 years. Only 19% of patients surveyed thus far first received a diagnosis of end stage renal disease more than 5 years in the past.

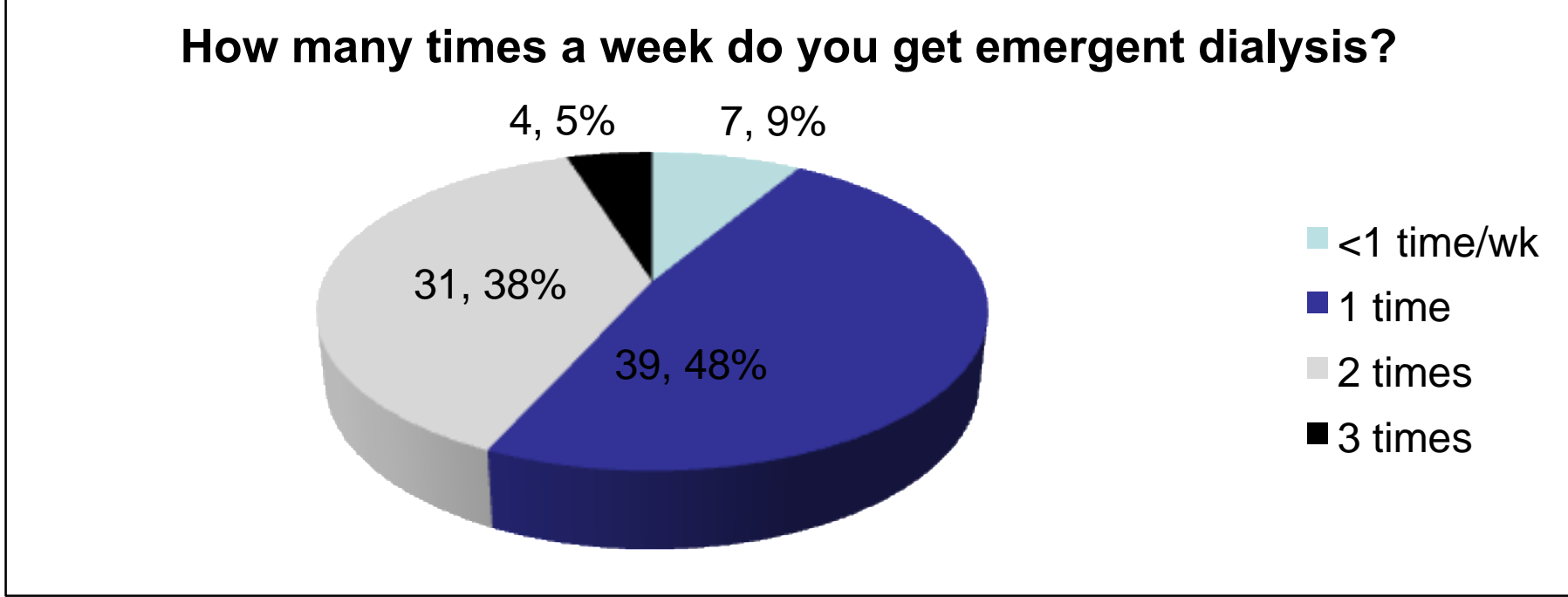


Figure 1. Frequency of ED Visits For Emergent Dialysis as Reported by Parkland Hospital’s Emergent Dialysis Patient Population

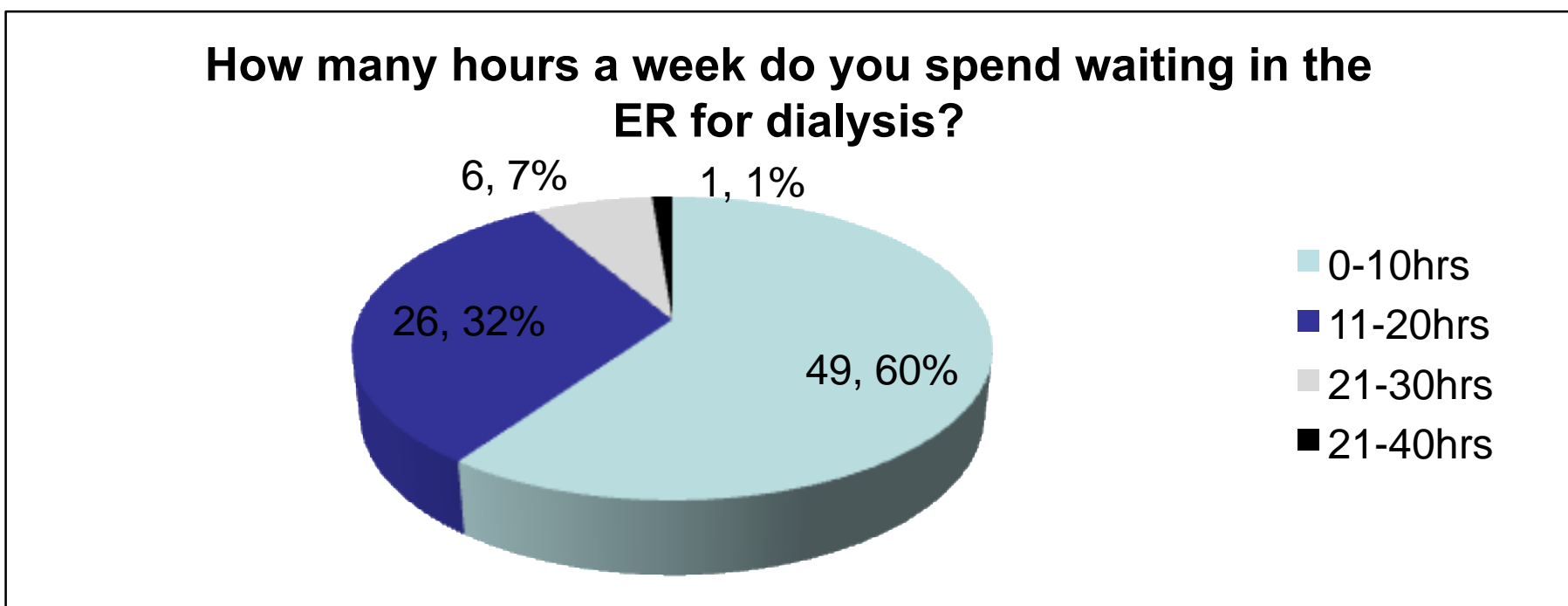


Figure 2. Cumulative Time Spent Waiting for Emergent Dialysis as Reported by Parkland Hospital’s Emergent Dialysis Patient Population

*Figure 1* illustrates the frequency with which the ESRD patients visit the Parkland ED each week to receive emergent dialysis. *Figure 2* expounds upon this data by demonstrating the total amount of time these patients spend waiting to receive life-saving dialysis each week. These data suggest approximate wait times up to 10 hours per ED visit before receiving emergent dialysis. These numbers exclude the time each patient spends being dialyzed.

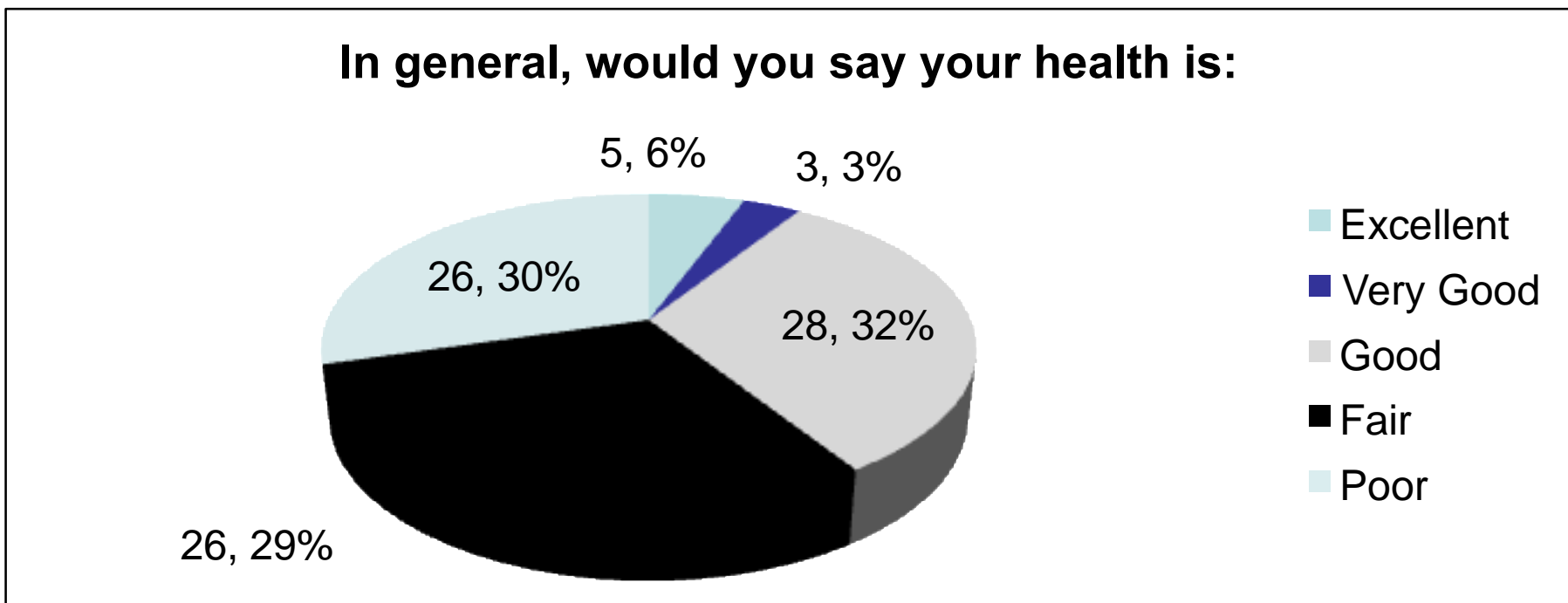


Figure 3. General Health Status Descriptors as Reported by Parkland Hospital’s Emergent Dialysis Patient Population

As seen in *Figure 3*, data from the quality of life survey indicate that 60% of currently surveyed patients rate their current state of health either “Passable” or “Bad.” Only 9% of patients rate their health “Good” or “Very Good.”

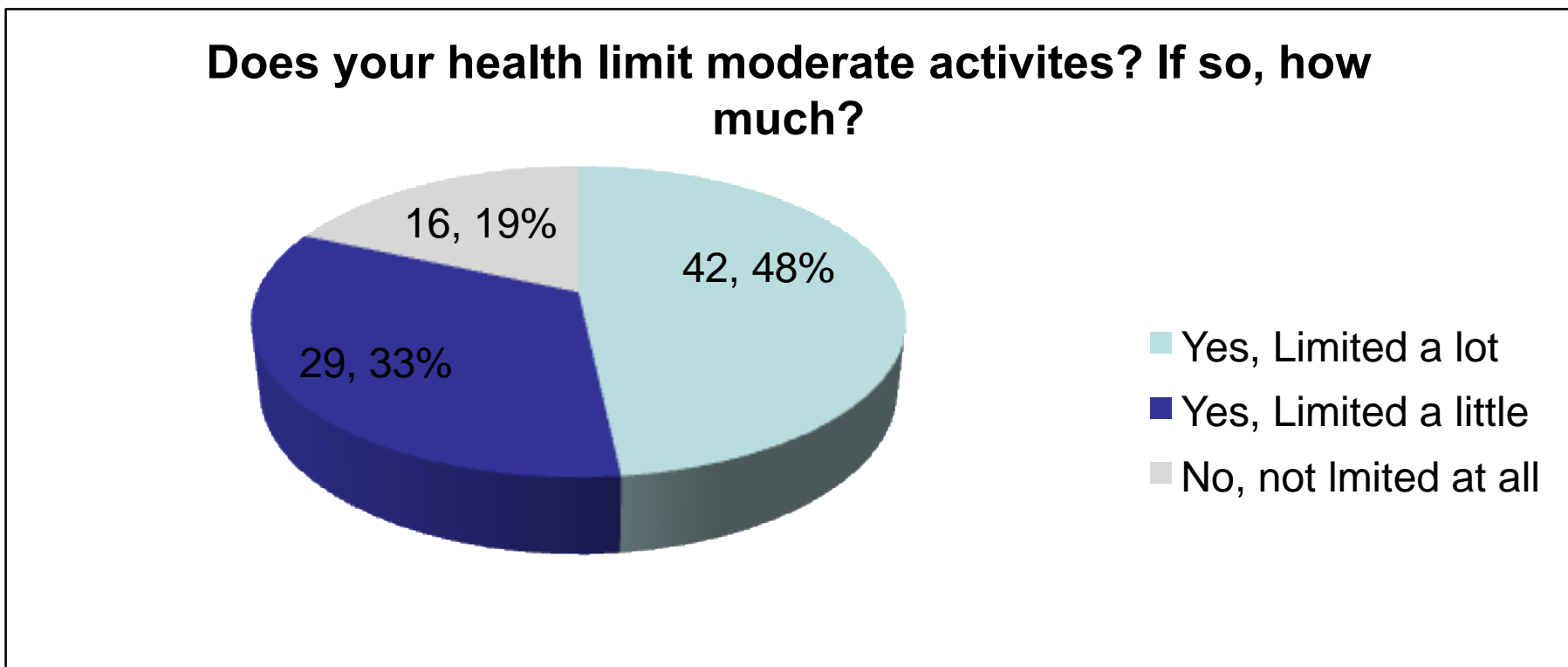


Figure 4. Impact of Patient’s Health on Ability to Perform Moderate Activities as Reported by Parkland Hospital’s Emergent Dialysis Patient Population

## RESULTS

*Figure 4* demonstrates that 81% of patients report that their condition (ESRD) limits their ability to perform moderate activities (such as domestic chores) in some capacity.

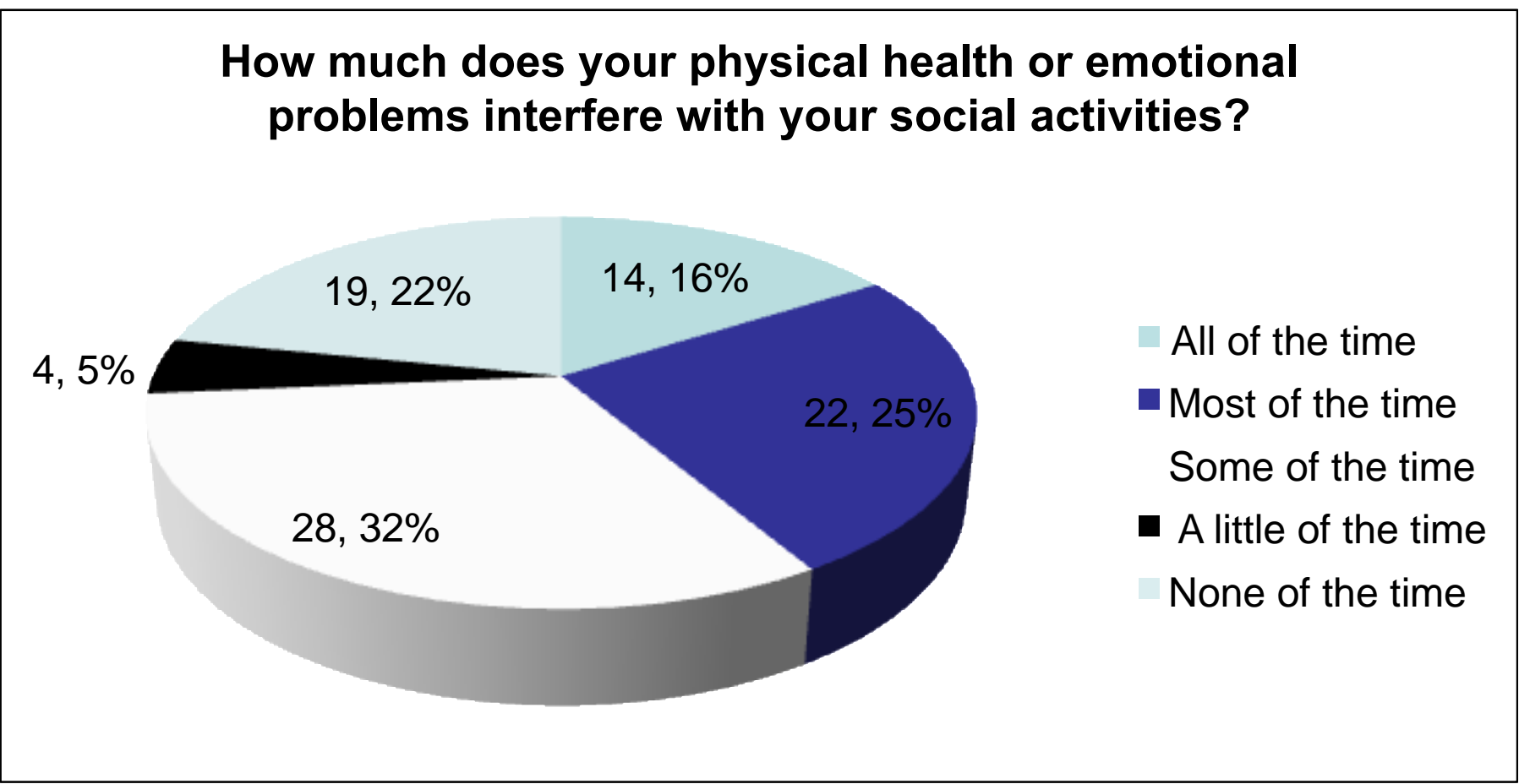


Figure 5. Impact of Patient’s Health and Emotional Problems on Patient’s Social Life Reported by Parkland Hospital’s Emergent Dialysis Patient Population

The data in *Figure 5* show that 78% of patients (68 of 87) find their physical health or emotional problems an impediment to their social lives at least “a little of the time.” Of this fraction, 53% (36 of 68) report that their condition hampers their social lives “most” or “all” of the time.

## CONCLUSION

From the results of the demographic survey, a surprising discrepancy between length of patient residency in the United States and time of ESRD diagnosis can be noted. While 68% of this patient population has resided in the USA for greater than 5 years, fewer than 19% of these patients received a diagnosis mandating chronic dialysis more than 5 years ago. This finding seems to directly contradict the widely accepted idea that most of Parkland’s ESRD patients (and by extension, many unfunded dialysis patients in similar care centers) immigrate to the United States motivated primarily by their ability to receive chronic dialysis.

Further patient enrollment, additional data analysis, and comparison of study patients to age- and sex-matched controls must still be done. Despite the remaining work, currently available data seem to support an argument against the current model of emergent dialysis treatment in the Parkland System. At face value, descriptors for Parkland’s emergent dialysis patients illustrate a predominantly negative quality of life for the majority of these individuals.

After accounting for any biases between the two populations to be compared, emergent dialysis is expected to demonstrate inferiority, or at least equivalence, to scheduled dialysis in terms of the quality of life as perceived by recipients of the treatment. Compared to recipients of scheduled dialysis, the emergent patients appear to spend significantly more time seeking dialysis in highly symptomatic states when seeking treatment in an emergent setting. At best, the quality of life is expected to be equivalent between the two groups in spite of the disparate time commitments between the two avenues of treatment.

Should these hypotheses prove true, serious questions will certainly arise concerning the uncomfortable, time-consuming experience of Parkland’s unfunded ESRD patients considering the lack of a demonstrable cost benefit to providing chronic dialysis via the ED. Hopefully, the data and trends derived from the completed study will be informative to hospital policymakers and lawmakers alike with respect to the care of unfunded chronic dialysis patients.

## REFERENCES

- RAND, and the University of Arizona (2000). Kidney Disease and Quality of Life™ (KDQOL™-36) English Version 1. Kidney Disease Quality of Life Instrument (KDQOL). [www.rand.org/health/surveys\_tools/kdqol.html].
- Weaver, et al. (2010). An Analysis of a Case Manager-Driven Emergent Dialysis Program. Professional Case Management, 17(1), 23-28.