Title

Working for the Weekend: The Effect of Cognitive Functioning, Social Support, and the Interdialytic Interval on Disease Self-Management Among Patients on Hemodialysis

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UNIVERSITY OF CALIFORNIA,
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Working for the Weekend: The Effect of Cognitive Functioning, Social Support, and the Interdialytic Interval on Disease Self-Management Among Patients on Hemodialysis

DISSERTATION

submitted in partial satisfaction of the requirements
for the degree of

DOCTOR OF PHILOSOPHY

in Psychology and Social Behavior

by

Shayna Lynn Henry

Dissertation Committee:
Professor Larry Jamner, Chair
Professor Madeleine Pahl
Associate Professor Ilona Yim

2014

for adale, the first and the second

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ACKNOWLEDGEMENTS

A debt of gratitude is owed my committee chair and advisor, Larry Jamner, for his encouragement and guidance throughout my graduate training and his contributions to this dissertation. True to his word, he never told me what to do, but provided me with the tools and resources to develop an expertise in social behavior and its consequences. I am enormously grateful for the experiences I have had working for Professor Jamner and I know they will be echoed in my future work.

I would also like to thank my remaining committee members, Sarah Choi, Ilona Yim, and especially Karen Rook and Madeleine Pahl. Each of them has brought a different perspective to the current project and I am thankful for the opportunity to work with this interdisciplinary team toward this culminating research effort. A huge thanks to Professor Rook, whose encouragement to reach out to faculty in medicine, feedback in the early phases of the project, and support in the drafting of the dissertation proposal were critical in the development of this study. Finally, my heartfelt appreciation to Dr. Pahl, who took the time to answer an email from some graduate student she didn't know in a department she had never worked with, and set in motion an invaluable collaborative relationship. Dr. Pahl's enthusiasm for this project and my work has been heartening and her willingness to offer up her clinical resources and expertise was critical in the success of this project.

Additionally, I would like to thank the staff of the UC Irvine Medical Center Hemodialysis Unit, especially Miguel Hernandez, Karen Luker, and Pat Croft, who graciously gave of their tables and chairs, their keys, their records room, and endless other resources, as well as the patients and their families, who kindly volunteered their time and without whom this effort would not have been possible. Thanks also to the faculty and fellows of the UC Irvine Division of Nephrology and Hypertension for being kind to myself and our team as we repeatedly got in their way, even though we probably never adequately explained how we are different from social workers.

Another big thanks to David Busse, who went above and beyond the call of duty as a colleague and was enormously influential in the development of this project. His input and perspective were hugely helpful as we got the study out of the lab and into the clinic.

Finally, I am tremendously grateful for the support and encouragement of my husband, Brad, and my daughter, Adale, who have suffered and celebrated right along with me throughout my training and who did their best to accommodate the demands of my work and the dissertation project. I know it took more than a couple of years (sorry honey) and I know my friends will not call me doctor but they are my biggest champions and I am hugely thankful for their confidence in me and my career.

Generous financial support for this dissertation was provided by the UC Irvine Institute for Clinical and Translational Sciences Dean’s Triumvirate Award, via the National Center for Research Resources and the National Center for Advancing Translational Sciences, National Institutes of Health, through Grant UL1 TR000153. Funding was also provided in support of this dissertation project by the American Psychological Foundation/Council of Graduate Departments of Psychology Graduate Research Scholarship, a Golden Key International Honour Society Research Grant, and the UC Irvine School of Social Ecology Dean’s Dissertation Writing Fellowship.

CURRICULUM VITAE

SHAYNA LYNN HENRY

EDUCATION

PhD, University of California, Irvine **2014**

Major Area: Health Psychology
Minor Area: Psychopathology
Dissertation: *Working for the Weekend: The Effect of Cognitive Functioning, Social Support, and the Interdialytic Interval on Disease Self-Management Among Patients on Hemodialysis*

MA, California State University, Sacramento **2008**

Major Area: Psychology
Thesis: *Optimism and Social Anxiety in Students with Acne*

BA, University of California, Davis **2002**

Major Area: Psychology
Minor Area: Physical Anthropology

RESEARCH INTERESTS

Chronic disease; disease burden & treatment adherence; social support, social control, and social undermining; ecological momentary assessment; social anxiety, loneliness, & isolation; risky health behaviors

HONORS & AWARDS

Dean's Dissertation Writing Fellowship, UC Irvine School of Social Ecology ($10,000) **2014**

Awarded to exemplary senior graduate students in the final phases of dissertation research

Graduate Student Mentoring Award, UC Irvine School of Social Ecology **2013**

Awarded for Excellence in Mentorship of Undergraduate Students

Dean's Triumvirate Grant, UC Irvine Institute for Clinical and Translational Science ($15,000) **2012**

Awarded in support of the dissertation project; the Triumvirate Grant is awarded by the UC Irvine School of Medicine to foster the development of new collaborations among scientists of different disciplines.

Golden Key International Honour Society Research Grant ($1,000) **2012**

Awarded in support of the dissertation project

American Psychological Foundation/Council of Graduate Departments of Psychology Graduate Research Scholarship ($1,000) **2012**

Awarded in support of the dissertation project

Graduate Student Mentoring Award, UC Irvine School of Social Ecology ($200) **2009**

Awarded for Excellence in Mentorship of Undergraduate Students

Second-Year Project Award, UC Irvine Department of Psychology & Social Behavior ($200) **2009**

Awarded to the Graduate Student with the Most Outstanding Second-Year Thesis

UC Irvine School of Social Ecology Research Fellowship ($10,000) **2007**

Graduate Student Research Funds, UC Irvine Department of Psychology and Social Behavior ($500) **2007**

RESEARCH EXPERIENCE

Graduate Student Researcher **2011-2013**

UNIVERSITY OF CALIFORNIA, IRVINE, PROGRAM IN NURSING SCIENCE, IRVINE, CA.
FACULTY ADVISOR: SARAH E. CHOI, PHD, RN, FNP

Assisted with data analysis and manuscript preparation for a University of California, Irvine Institute for Clinical and Translational Science Community Collaboration Research Grant awarded to the Faculty Advisor.

Graduate Student Researcher **2011-Present**

UNIVERSITY OF CALIFORNIA, IRVINE, SCHOOL OF SOCIAL ECOLOGY, IRVINE, CA.
FACULTY ADVISOR: KAREN ROOK, PHD

Assisted with data analysis and manuscript preparation for “Mind-Body Interactions in Management of Type 2 Diabetes” (NIA 5-R01-AG024833-05; PI Mary Ann Parris Stephens, Kent State University).

Graduate Student Researcher **2007-Present**

CONSORTIUM FOR INTEGRATIVE HEALTH STUDIES
UNIVERSITY OF CALIFORNIA, IRVINE, SCHOOL OF SOCIAL ECOLOGY, IRVINE, CA.
FACULTY ADVISOR: LARRY JAMNER, PHD

Assisted with research participant recruitment, consent, and participation for “Behavioral Ecology and Hostility & Cardiac ANS Control” (NHLBI 5-R01-HL072057; PI Richard Sloan, Columbia University). Provide support for “Cognitive Behavior Therapy for Depression Enhanced with a Mobile Therapy” (NIMH 1-R01-MH086028; PI Larry Jamner, UC Irvine). Train, supervise, and mentor approximately 10-12 undergraduates each quarter.

Graduate Research Assistant **2004-2007**

CALIFORNIA STATE UNIVERSITY, SACRAMENTO, DEPARTMENT OF PSYCHOLOGY, SACRAMENTO, CA.
FACULTY ADVISOR: REBECCA CAMERON, PHD

Assisted with laboratory organization as well as data analysis. Supervised and mentored 3-4 undergraduates each semester.

Graduate Research Assistant **2005-2006**

CALIFORNIA STATE UNIVERSITY, SACRAMENTO, DEPARTMENT OF PSYCHOLOGY, SACRAMENTO, CA.
FACULTY ADVISOR: GREG KIM-JU, PHD

Collection and organization of data for "Daily Social Interactions" Ethnic Identity study and ensured that research subjects received credit for their participation. Trained, scheduled, and supervised 10-15 undergraduates each semester.

Staff Research Associate **2002-2007**

UC DAVIS CENTER FOR HEALTH AND TECHNOLOGY, SACRAMENTO, CA.

April 2004 – August 2007

Grant application writing and research program support for Peter M. Yellowlees, MD, Professor of Psychiatry and Director, Academic Information Systems.

November 2002 – September 2006

Staff coordination for Enhancing Mental Health Services to Children with Autism in Rural Communities: The Promise of Technology (NIMH 1-R21-MH067363; PI Thomas S. Nesbitt, MD, MPH).

August 2003 – April 2005

Program evaluation for Integrating Mental Health and Primary Care (Funded by The California Endowment; PI Speranza Avram, MPA). Contracted with Northern Sierra Rural Health Network, Nevada City, CA (now the Health Alliance of Northern California).

Student Assistant **2002**

UC DAVIS DEPARTMENT OF PSYCHIATRY, SACRAMENTO, CA
SUPERVISOR: DONALD M. HILTY, MD

Project coordination for "A randomized trial of telepsychiatry versus usual care for depression in rural primary care clinics" (Funded by the Hibbard E. Williams, MD Research Fund).

Student Intern **2001-2002**

UC DAVIS MOOD DISORDERS AND HEALTH SERVICES RESEARCH PROGRAM, SACRAMENTO COUNTY MENTAL HEALTH TREATMENT CENTER, SACRAMENTO, CA.
SUPERVISOR: DONALD M. HILTY, MD

Research and staff support; recruitment of treatment center patients to clinical studies; examination of medical records for research data. Compliance with research protocol.

Student Assistant **1999-2001**

UC DAVIS DAIRY GOAT RESEARCH FACILITY, DAVIS, CA

SUPERVISORS: JAMES D. MURRAY, PHD & STEFANIE OPPENHEIM, PHD

Care of transgenic dairy goats and student supervision; compliance with research protocol.

TEACHING

INSTRUCTOR OF RECORD

Teaching Associate, UC Irvine Department of Psychology & Social Behavior **2012-2014**

Responsibilities included independently planning and teaching an undergraduate course, including preparation of syllabi, exams, and written assignments.

Courses: *Human Stress* (Spring 2013, Spring 2014); *Health Psychology* (Summer 2013)

Psychology Instructor, Irvine Valley College **2013-2014**

Responsibilities included independently planning and teaching an undergraduate course, including preparation of syllabi, exams, written assignments and classroom activities.

Course: *Introductory Psychology* (Fall 2013)

Psychology Instructor, Rio Hondo Community College **2011-2012**

Responsibilities included independently planning and teaching five sections of an undergraduate course, including preparation of syllabi, exams, written assignments and classroom activities.

Course: *Introductory Psychology* (Fall 2011; Spring 2012; Summer 2012)

Teaching Associate, CSU Sacramento Department of Psychology **Spring 2006**

Responsibilities included independently and cooperatively planning and teaching an undergraduate course.

Course: *Introductory Psychology: Individual and Social Processes*

TEACHING ASSISTANT

Teaching Assistant, UC Irvine School of Social Ecology **2007-Present**

Responsibilities included holding office hours, conducting exam review sessions, tutoring students, and grading written assignments and exams; for certain courses, duties included independently teaching weekly discussion sections, mentoring students in development of field research, and providing extensive feedback on coursework to students (marked with *).

Courses: *Abnormal Behavior (Winter 2008; Fall 2008; Fall 2009; Winter 2011; Fall 2012; Fall 2013; Professor Larry Jamner, PhD)*
Naturalistic Field Research (Winter 2009; Professor Mona Lynch, PhD)*
Health Psychology (Spring 2009; Instructor Dan Graham, MA)
Behavioral Medicine (Fall 2010; Winter 2013; Professor Larry Jamner, PhD)

Teaching Assistant, CSU Sacramento Department of Psychology 2004-2005

Responsibilities included holding office hours, conducting exam review sessions, preparing exam materials, tutoring students, and grading written assignments and exams.

Courses: *Abnormal Psychology (Fall 2004; Professor Rebecca Cameron, PhD)*
Introductory Psychology (Fall 2005; Professor Emily Wickelgren, PhD)

OTHER TEACHING & MENTORING EXPERIENCE

Instructor, Telemedicine Learning Center at UC Davis 2003-2007

Responsibilities included developing and teaching a short course for health professionals and administrators starting new telemedicine programs in rural communities.

Course: *Program Evaluation and Assessing Satisfaction*

Guest Lecturer

"Obsessive-Compulsive Disorder," California State University, Sacramento Department of Psychology: Abnormal Psychology; October 21, 2004.

"Comorbid Anxiety Disorders & Substance Use Disorders," University of California, Irvine, School of Social Ecology: Health Psychology; June 1, 2009.

School of Social Ecology Honors Program Mentor 2009-Present

Department of Psychology and Social Behavior, UC Irvine

Students Mentored: *Beatriz Bello, Cynthia Canfield, Meril Dagher, & Reveka Shteynberg (2009-2010)*
Benjamin Latham-Bryman (2012-2013)

Undergraduate Research Opportunities Program (UROP) Mentor 2008-Present

Department of Psychology and Social Behavior, UC Irvine

Students Mentored: *Beatriz Bello, Nicole Shoraka, Robyn Wellerstein & Peria Zandi (2008)*
Beatriz Bello, Meril Dagher, Ein Ho, Nicole Shoraka (2008-2009)
Audrey Nguyen & Christine Ta (2009-2010)
Erin Kang (2010-2011)
Benjamin Latham-Bryman & Amanda Tan (2011-2012)
Alexandria Tong (2012-2013)
Aiko Jin (2013-2014)

Competitive Edge Summer Research Program Graduate Peer Mentor **Summer 2013**
University of California, Irvine Graduate Division
Students Mentored: Amanda Acevedo, BA & Karina Corona, BA

Supplemental
Completed PSYC 283, *Teaching of Psychology*, California State University, Sacramento. Professor: Emily Wickelgren, PhD.

PUBLICATIONS

Choi, S. E., Rush, E. B., & **Henry, S. L.** (2013). Psychological environment and risk for type 2 diabetes among Korean immigrants. *The Diabetes Educator, 39*, 679-688.

Henry, S. L., Rook, K. S., Stephens, M. A. P., & Franks, M. M. (2013). Spousal undermining of older diabetic patients' disease management. *Journal of Health Psychology, 18*, 1550-1561.

Choi, S. E., Rush, E., & **Henry, S.** (2013). Health literacy and risk for type 2 diabetes among Korean immigrants. *Journal of Immigrant and Minority Health, 15*, 553-559.

Henry, S. L., Jamner, L. D., & Whalen, C. K. (2012). I (should) need a cigarette: Adolescent social anxiety and cigarette smoking. *Annals of Behavioral Medicine, 43*, 383-393.

Marks (Henry), S. L., Wegelin, J. A., & Bourgeois, J. A. (2010). Anxiety disorders in rural primary care: use of the MINI to estimate prevalence in the medical population. *Journal of Health Care for the Poor and Underserved, 21*, 680-690.

Marks, S. L., Shaikh, U., Hilty, D. M., & Cole, S. L. (2009). Weight status of children and adolescents seen in a pediatric telepsychiatry clinic. *Telemedicine and e-Health, 15*, 970-974.

Yellowlees, P. M., Burke, M. M., **Marks, S. L.**, Hilty, D. M., & Shore, J. (2008). Emergency telepsychiatry: Past experiences and future directions. *Journal of Telemedicine and Telecare, 14*, 277-281.

Yellowlees, P., **Marks, S.**, Hilty, D., & Shore, J. (2008). Using e-health to enable culturally appropriate mental health care in rural areas. *Telemedicine and e-Health, 14*, 486-492.

Yellowlees, P. M., **Marks, S. L.,** Hogarth, M., & Turner, S. (2008). Open-source electronic health record systems: A desirable future for the U. S. health industry. *Telemedicine and e-Health, 14*, 195-199.

Yellowlees, P. M., Hilty, D. M., **Marks, S. L.,** Neufeld, J., & Bourgeois, J. A. (2008). A retrospective analysis of a child and adolescent eMental Health program. *Journal of the American Academy of Child and Adolescent Psychiatry, 47*, 103-107.

Yellowlees, P. M., Cook, J. N., **Marks, S. L.**, Wolfe, D., & Mangin, E. (2008). Can virtual reality be used to conduct mass prophylaxis clinic training? A pilot program. *Biosecurity and Bioterrorism: Biodefense Strategy, Practice, and Science, 6*, 36-44.

Hilty, D. M., **Marks, S. L.**, Wegelin, J., Callahan, E. J., & Nesbitt, T. S. (2007). A randomized, controlled trial of disease management modules, including telepsychiatric care, for depression in rural primary care. *Psychiatry, 4*, 58-65.

Yellowlees, P. M., & **Marks, S. L**. (2007). Problematic Internet use or Internet addiction? *Computers in Human Behavior, 23*, 1447-1453.

Yellowlees, P. M., & **Marks, S. L**. (2006). Pedagogy and educational technologies of the future. *Academic Psychiatry*, *30*, 439-441.

Hilty, D. M., **Marks, S. L.,** Bourgeois, J. A., & Yellowlees, P. M. (2004). Hypochondriasis. *eMedicine Journal* [http://www.emedicine.com/MED/topic3122.htm]: Updated October 6, 2004.

Hilty, D. M., **Marks, S. L.**, Urness, D., Yellowlees, P. M., & Nesbitt, T. S. (2003). Clinical and educational applications of telepsychiatry: a review. *Canadian Journal of Psychiatry, 49*, 12-23.

Hilty, D. M., Liu, W., **Marks, S. L.**, Callahan, E. J., & Nesbitt, T. S. (2003). The effectiveness of telepsychiatry: a brief review. *Canadian Psychiatric Association Bulletin, 35*, 10-17.

Hilty, D. M., Nesbitt, T. S., **Marks, S. L.**, & Callahan, E. J. (2002). Effects of telepsychiatry on the doctor-patient relationship: communication, satisfaction, and relevant issues. *Primary Psychiatry, 9*, 29-34.

Coss, R. G., **Marks, S.**, & Ramakrishnan, U. (2002). Early environment shapes the development of gaze aversion by wild bonnet macaques (*Macaca radiata*.) *Primates, 43*, 217-22.

MANUSCRIPTS UNDER REVIEW

Henry, S. L. (Under review). Loneliness and risk factors for cardiovascular disease: A prospective analysis.

MANUSCRIPTS IN PREPARATION

Henry, S. L., Rook, K. S., Stephens, M. A. P., & Franks, M. M. (*in preparation*). Factors that predict social undermining among spouses of diabetic patients.

Henry, S. L., White, M. L., Westmaas, J. L., & Jamner, L. D. (*In preparation*). Social support, gender, and 24-hr ambulatory blood pressure.

Henry, S. L., Jamner, L. D., & Whalen, C. K. (*in preparation*). Alcohol use among socially anxious adolescents: The role of the social context.

Jamner, L. D., **Henry, S. L.**, Wellerstein, R., & Whalen, C. K. (*in preparation*). Do or Diaries: Participant adherence to experience sampling protocols.

Jamner, L. D., Lett, H., Shapiro, D., **Marks, S. L.** (*in preparation*). Relationship of defensiveness and blood pressure on brain volume and cognitive decline in aging persons.

Jamner, L. D., Epstein, E., **Henry, S. L.** (*in preparation*). Effects of the repressive coping style on heart rate variability.

PRESENTATIONS

COLLOQUIA

Henry, S. L. (28 November 2012). Social and Cognitive Functioning and Disease Self-Management Among Hemodialysis Patients. Presented at the Department of Psychology and Social Behavior Health Psychology Colloquium Series, University of California, Irvine, Irvine, CA.

Henry, S. L. (17 November 2010). Loneliness and risk factors for cardiovascular disease: A prospective analysis. Presented at the Department of Psychology and Social Behavior Health Psychology Colloquium Series, University of California, Irvine, Irvine, CA.

Marks, S. L. (1 June 2009). I (should) need a cigarette: Adolescent social anxiety and cigarette smoking. Presented at the Department of Psychology and Social Behavior Colloquium Series, University of California, Irvine, Irvine, CA.

PAPER PRESENTATIONS

Henry, S. L., White, M. L., Westmaas, J. L., & Jamner, L. D. (*19 May 2013*). Social support, gender, and 24-hr ambulatory blood pressure. Paper presented at the American Psychological Association Work, Stress and Health 2014: Protecting and Promoting Total Worker Health, Los Angeles, CA.

POSTER PRESENTATIONS

Henry, S. L. & Jamner, L. D. (23 March 2013). Disentangling Reciprocal Relationships between Daily Affective Experiences, Stress Physiology, and Quality of Sleep. Poster presented at the Annual Meeting of the Society of Behavioral Medicine, San Francisco, CA.

Henry, S. L. (27 April 2011). Loneliness and Risk Factors for Cardiovascular Disease: A Prospective Examination. Poster presented at the Annual Meeting of the Society of Behavioral Medicine, Washington, D. C.

Marks, S. L., Jamner, L. D., & Whalen, C. K. (23 May 2009). Using Ecological Momentary Assessment to Examine Social Fear and Adolescent Smoking. Poster presented at the Annual Meeting of the Association for Psychological Science, San Francisco, CA.

Marks, S. L., Jamner, L. D., & Whalen, C. K. (13 March 2009). Using Ecological Momentary Assessment to Examine the Relationship Between Subclinical Social Phobia and Alcohol Use in Adolescents. Poster presented at the Annual Meeting of the Anxiety Disorders Association of America, Albuquerque, NM.

Figueroa, W. S., Chavez, D. M., Sharif, M., Maddi, S. R., & **Marks, S. L.** (13 April 2008). Hardiness and achievement in transfer vs. non-transfer students. Poster presented at the Western Psychological Association Annual Conference, Irvine, CA.

Burke, M. M., **Marks, S. L.**, Cameron, R. P., & Sanftner, J. (4 May 2007). Mutuality, social support, and coping style. Poster presented at the Western Psychological Association Annual Conference, Vancouver, BC.

Marks, S. L., Burke, M. M., Cameron, R. P., & Sanftner, J. (4 May 2007). Ethnic differences in parental relationships, social support, and mutuality. Poster presented at the Western Psychological Association Annual Conference, Vancouver, BC.

Marks, S. L., Saldanha, M., Marquez, A. P., Simmons, A. L., LaPilusa, J. A., Kim-Ju, G., & Meyers, L. S. (28 April 2006). The influence of ethnic composition on the attitudes and emotions of White Americans. Poster presented at the Western Psychological Association Annual Conference, Palm Springs, CA.

WORKSHOPS

Henry, S. L. (5 December 2012). Moderation and Mediation in SEM. UC Irvine Department of Psychology & Social Behavior “Stats ‘n’ Snacks” Statistical Workshop Series.

PROFESSIONAL ACTIVITIES & SERVICE

Professional Affiliations

- American Psychological Association
  - APA Division 38 (Health Psychology)
  - APA Division 2 (Teaching of Psychology)
- Western Psychological Association
- Association for Psychological Science
- Society of Behavioral Medicine
- American Heart Association

Ad Hoc Reviewer

Nicotine & Tobacco Research

Honors Societies

- Psi Chi, the National Honor Society in Psychology
- The Honor Society of Phi Kappa Phi
- Golden Key Honour Society

University Service

Peer Mentor, Competitive Edge Summer Research Program 2013

UC Irvine Graduate Division

Competitive Edge, sponsored by the U.S. Department of Education, is designed to support entering doctoral students who plan to pursue an academic career. Peer mentors support and advise incoming students as they transition into graduate studies and complete a research project.

Departmental Service

Mentor, Graduate Student Mentor-Mentee Program 2012-2013

UC Irvine Department of Psychology & Social Behavior

Met quarterly with two junior graduate students to advise their progress in the program and help with navigating Department and School requirements and deadlines.

Graduate Student-Faculty Liaison 2012-2013

UC Irvine Department of Psychology & Social Behavior

Coordinator, "Stats 'n' Snacks" Statistical Workshop Series 2012-2013

UC Irvine Department of Psychology & Social Behavior

Coordinator, Health Psychology Specialization Colloquium Series 2011-2012

UC Irvine Department of Psychology & Social Behavior

Co-organizer, UC Irvine Psychology & Social Behavior Colloquium Series 2008-2009

Volunteer Service

UC Davis Department of Psychiatry	2002-2005
Sacramento County Mental Health Treatment Center	2002-2003

ABSTRACT OF THE DISSERTATION

Working for the Weekend: The Effect of Cognitive Functioning, Social Support, and the Interdialytic Interval on Disease Self-Management Among Patients on Hemodialysis

By

Shayna Lynn Henry

Doctor of Philosophy in Psychology & Social Behavior

University of California, Irvine, 2014

Professor Larry Jamner, Chair

End-stage renal disease is a chronic, terminal condition in which the kidneys retain less than 5% of their normal capacity for filtering wastes and fluids from the bloodstream. Kidney failure represents a significant and costly public health problem, especially for Hispanic patients. While there are no known direct psychosocial causes of kidney failure, sociobehavioral factors play a crucial role in determining the capacity for survival for the end-stage renal disease patient; in addition to taking on dialysis treatment, in which an artificial kidney filters waste products from the body, patients must take dozens of medications and monitor and restrict their diet and fluid intake, resulting in high disease burden, high cognitive demand, and high risk for morbidity and mortality. Additionally, changes in cognitive and psychosocial functioning over the course of the dialytic cycle may be crucial in determining treatment outcomes for these patients. The purpose of the present study was to examine the interrelationships between cognitive functioning, general and disease-specific social support, and the length of the interdialytic interval on adherence to treatment in a sample of patients on hemodialysis. The study was the first to explore these relationships using a sophisticated electronic diary system.

Participants included 22 (female n = 11; Mean age 44 years) English- and Spanish-speaking, primarily Hispanic patients being treated for kidney failure at the UC Irvine Medical Center. Overall, levels of social support in this sample were high, and reports of cognitive dysfunction were minimal. Some aspects of social support, particularly diet-related support, were associated with improved adherence to treatment, but in general, support did not substantially influence engagement in behaviors of disease self-management. Additionally, contrary to hypotheses, cognitive functioning was greater over two-day interdialytic intervals than shorter one-day intervals, and was not found to mediate the relationship between length of the interdialytic interval and disease self-management. Likewise, the effect of cognitive functioning on treatment adherence was not buffered by social support. Such findings provide some limited support for an osmotic theory of cognitive dysfunction resulting from hemodialysis, but should interpreted with caution pending recruitment of a larger sample and a higher degree of compliance with the ecological momentary assessment protocol.

CHAPTER ONE

INTRODUCTION

Kidney failure, or end-stage renal disease (ESRD), is a degenerative, chronic condition in which the ability of the kidneys to filter wastes and fluids from the body is compromised (NKUDC, 2007). As of 2008, more than 500,000 individuals in the U.S. were receiving treatment for ESRD (United States Renal Data System, 2010), and nearly 90,000 ESRD patients die annually. While the incidence of ESRD is declining in the United States (USRDS, 2013), Southern California is home to one of the highest rates of ESRD nationwide, and kidney failure continues to represent a significant public health problem. This is especially true for Hispanic/Latino patients, for whom the rate of ESRD is rising, especially among younger age groups; in 2007, 12.6% of incident ESRD cases were Hispanic patients, while in 2011, 14% of new ESRD patients were Hispanic, and the overall rate of ESRD among Hispanics remains more than 50% greater than the prevalence among non-Hispanic groups.

The etiology of kidney failure is assumed to be purely biological, with social factors playing no direct role in the causation of ESRD (Furr, 1998). However, diabetes and hypertension – two chronic conditions in which social and behavioral factors are acknowledged to play an important role in the onset of these diseases – are the primary causes of ESRD (Hailey & Moss, 2000; Sumiyoshi, Kawata, Shikata, & Makino, 2010). Approximately 44% of incident ESRD cases result from diabetes, and an additional 28% are caused by high blood pressure (USRDS, 2013). While the rate of ESRD cases caused by diabetes is falling (USRDS, 2013), diabetes-caused kidney failure rates vary considerably by age and ethnic group. In particular, rates of diabetes- and hypertension-caused ESRD are growing among young Hispanic patients. While the sociobehavioral factors directly related to the etiology of ESRD are currently unknown, these factors may contribute to preclinical states and other chronic upstream illnesses, such as hypertension and diabetes, that eventually give rise to ESRD. The incidence rate of ESRD in the U.S. is currently declining (USRDS, 2013). However, the rate of diabetes has been steadily increasing over the past 30 years, even when adjusting for age (CDC, 2013). While it is impossible to know exactly how this increase in diabetes cases will impact the rate of ESRD, it is likely that rates of kidney failure will increase in coming years as a consequence of the rise in rates of diabetes and hypertension and, further upstream, epidemic rates of obesity (CDC, 2008a, 2008b; Geiss, et al., 2006).

Finally, in addition to the significant physiological morbidity associated with kidney failure, including elevated blood pressure and cardiovascular disease, the incidence of psychological problems among ESRD patients is much greater than in the general population (Chilcot, Wellsted, & Farrington, 2010; Kimmel, 2002; Kimmel, Thamer, Richard, & Ray, 1998; Siegal, Calsyn, & Cuddihee, 1987) and possibly higher than the rate of other chronic disease patients. Understanding the determinants of morbidity and mortality in this population is critical to developing more effective policies about the prevention and treatment of kidney failure (Plough & Salem, 1982).

For individuals in kidney failure, refusing or withdrawing from treatment or failing to faithfully adhere to the treatment regimen is essentially life-ending – as wastes and fluids build up in the body, blood pressure increases, cardiovascular and respiratory function decreases, body systems rapidly begin to shut down, with death following in only a few days or weeks. For this reason, in 1973, Medicare took over all payment for treatments related to end-stage renal disease for all persons in the U.S. (Plough & Salem, 1982) and continues to pay 80% or more of the cost of treating ESRD (Hailey & Moss, 2000; USRDS, 2010). In 2011, 44% of incident hemodialysis patients had only Medicare coverage, 14% had both Medicare and Medicaid, and 16% were covered by a Medicare HMO (USRDS, 2013); the annual cost of ESRD to public and private payors is estimated to be more than $39 billion. Treatment options for ESRD include some form of dialysis, a procedure in which artificial means are used to filter the blood and remove waste products and excess fluids, or kidney transplantation. Because of the shortage of appropriate donor tissue (Christensen, 1997), the vast majority of patients in treatment for kidney failure undergo regular dialysis, with approximately 65% of those patients receiving in-center hemodialysis (USRDS, 2010), traveling to a clinic or hospital several times a week to spend several hours per session hooked up to a machine which filters the blood. Dialysis is the only available option for individuals with end-stage renal disease to survive without transplantation (Ekelund & Andersson, 2010), and the number of dialysis patients is growing; in 2011, the number of patients on dialysis increased 3.2%, a 52% larger patient population than in 2000 (USRDS, 2013). Although transplant may be the treatment of choice for patients, families, and providers, nearly all patients with kidney failure must go on dialysis at some point in the course of their disease (Christensen, 1997).

Dialysis works by using an artificial kidney machine to remove excess fluids, toxins, and metabolic end products from the bloodstreams of individuals with renal failure (National Kidney and Urologic Disorders Clearinghouse, 2007; Cummings, Becker, Kirscht, & Levin, 1982). More than 65% of kidney failure patients in the U.S. and nearly all ESRD patients in Europe currently receive hemodialysis (Denhaerynck, et al., 2007). Hemodialysis is one of the safest and most efficient treatments for kidney failure, but leads to a very restricted life for patients (Boyer, Friend, Chlouverakis, & Kaloyanides, 1990). Dialysis is not a complete substitute for failed kidneys (Cummings, et al., 1982), replacing around 10% of kidney functioning (Loghman-Adham, 2003). Patients on dialysis often suffer a number of disease complications, including thyroid abnormalities, anemia, heart disease, and hypertension, that negatively impact their quality of life (USRDS, 2013; Tell, et al., 1995) and health risk factors. Only around 30% of patients survive five years on dialysis treatment. The remaining kidney function not restored by dialysis must be preserved by restricting diet and fluid intake and taking up to 12 different medications to maintain health (Cummings, et al., 1982; Denhaerynck, et al., 2007).

The behavioral demands of hemodialysis

End-stage renal disease is unique among chronic illnesses in some ways because of the extreme level of dependence on a machine for survival, and for the enormous burden of the prescribed self-management regimen (Christensen, 1997; Christensen & Ehlers, 2002). Currently, only about half of hemodialysis patients in the U.S. are still surviving after three years of ESRD treatment (USRDS, 2013), and although dialysis can restore a portion of renal functioning, annual mortality rates among patients with end-stage renal disease range up to 20% (McClellan, Stanwyck, & Anson, 1993). Adherence to restrictions in diet and fluid intake is critical for survival among patients with kidney failure treated by dialysis (Vlaminck, Maes, Jacobs, Reyntjens, & Evers, 2001). Even slight nonadherence to treatment protocols can result in serious, immediate medical complications and dramatically increased mortality risk. As a result, a large degree of the success of dialysis treatment depends on the patient’s capacity for disease self-management (Cummings, et al., 1982). Self-care among individuals on dialysis began in earnest in the 1970s (Richard, 2006); since then, patients on dialysis have been expected to adhere to a strict regimen of diet and fluid restrictions, medication taking, as well as care for their vascular access site. Dialysis patients must restrict their intake of foods high in potassium (Matteson & Russell, 2010), sodium (Welch, Bennett, Delp, & Agarwal, 2006), and phosphorus (Oka & Chaboyer, 1999), which eliminates many fresh and prepared foods and severely constrains their diet. Patients must also strictly limit their intake of water and other fluids to only 500-1000mL, the equivalent of no more than four cups of fluid, per day (Denhaerynck, et al., 2007; Molaison & Yadrick, 2003; O'Brien, 1980). This restriction includes foods high in water content like many fruits and vegetables (NKUDC, 2008). The medication regimen can involve taking up to 12 different medications at various intervals (Denhaerynck, et al., 2007). For example, phosphate binders must be taken with each meal or snack, while other medications to control blood glucose, blood pressure, or regulate cardiac function may be taken at other times.

Strict adherence to treatment regimens can prolong the lifespan of patients with end-stage renal disease for up to 20 years (Bame, Petersen, & Wray, 1993). In contrast, nonadherence is the direct cause of death in up to 18% of kidney disease patients (McGee, Rushe, Sheil, & Keogh, 1998). In one study of 40 adults on hemodialysis, “dietary indiscretion” was the leading cause of death, contributing to 27% of deaths in this sample (Plough & Salem, 1982). In another study, participants who were nonadherent to dialysis sessions had a 69% increased risk of mortality (Unruh, Evans, Fink, Powe, & Meyer, 2005); the mortality risks for those nonadherent to phosphorus and potassium were 59% and 50% greater, respectively. Of note, patients who skip even one dialysis session have a 25% greater chance of mortality than those who do not skip sessions, and each skipped session is associated with a 10% increase in mortality risk (Hailey & Moss, 2000).

High interdialytic weight gain (IWG), or the body weight increase resulting from fluid accumulation between dialysis sessions, has been associated with 35% mortality risk, and increased phosphate levels have been associated with 13% greater mortality. Overall, the one-year survival of dialysis patients is around 78%; the 5-year survival rate is only 32% (Matteson & Russell, 2010). It is reasonable to assume that nonadherence may be responsible for a sizable proportion of these deaths, and as the complexity of a treatment regimen increases, the rate of adherence tends to decrease. Simply put, strict adherence with treatment is crucial for the continued health and survival of patients with ESRD.

The problem of nonadherence to treatment is common among patients on dialysis (Christensen, 1997). Nonadherence estimates range from 30% (Khechane & Mwaba, 2004; Kutner, Zhang, McClellan, & Cole, 2002) to more than 50% (Christensen, et al., 1992) with up to 94% of patients (Brady, Tucker, Alfino, Tarrant, & Finlayson, 1997) nonadherent in at least one domain of self-management. However, the reported rates of nonadherence vary considerably from one study to the next, largely due to the differences in adherence to different aspects of the ESRD self-management regimen. For example, in one study, 58.1% of patients reported nonadherence with diet restrictions, and 68.1% of patients reported nonadherence with fluid restrictions (Kara, Caglar, & Kilic, 2007). In another, while 91% of patients were adherent on the protein measure and 98% were adherent on the potassium measure, only 50% of patients were adherent on the phosphorus or fluid measure (Bame, et al., 1993). In their 2008 study, O’Connor and colleagues found that though participants demonstrated adequate knowledge of kidney disease, 70% were nonadherent to fluid restrictions, 55% were nonadherent to phosphate binders, and 16% were nonadherent to potassium or dietary adherence, and the levels of adherence to the three different domains were not correlated with one another (O'Connor, Jardine, & Millar, 2008). In one review, the prevalence of self-reported nonadherence to fluid restriction ranged from 30-74%, while objectively measured fluid nonadherence rates, as reported by IWG values, ranged from 10-60% (Denhaerynck, et al., 2007). For potassium intake, nonadherence estimates ranged from 2-39%; for phosphorus, nonadherence estimates ranged from 19-57%.

Patients appear to be more adherent to medication taking and dialysis session attendance than to other aspects of the treatment regimen; only around 30% of medications are not taken as prescribed (Horne & Weinman, 1999), and the rate of skipping dialysis ranges from 1-10% of dialysis patients (Obialo, et al., 2008). The most persistent problem in treating patients on dialysis is fluid nonadherence and excess weight gain between dialysis sessions (Streltzer & Hassell, 1988), with "severe" and "very severe" nonadherence more common for fluid than diet restrictions (Kara, et al., 2007). Overall, patients appear to be much more adherent with diet than with fluid restrictions (Bame, et al., 1993). This may be because while forbidden foods can be substituted with other foods, nothing can be substituted for fluids (O'Connor, et al., 2008). Patients in kidney failure often complain of thirst, and report that remaining adherent to their fluid restrictions is the most difficult part of their treatment regimen (Christensen, 2000; Christensen & Ehlers, 2002; McGee, et al., 1998; Schneider, Friend, Whitaker, & Wadhwa, 1991). In one recent qualitative study of patients' perceptions of fluid restriction, respondents indicated feelings of significant ambivalence about drinking fluids, an activity which had been a non-issue for most patients before dialysis (Tovazzi & Mazzoni, 2012).

While all aspects of treatment adherence can be regarded as a major source of stress for ESRD patients (Gurklis & Menke, 1995; Kimmel, 2000), fluid restriction in particular can be considered both a physiological and a psychological stressor for patients on dialysis (Pang, Ip, & Chang, 2001). Indeed, patients in Tovazzi and Mazzoni's study remarked that while dietary and other changes were a fairly straightforward shift in behavior, fluid restrictions were nearly unbearable (Tovazzi & Mazzoni, 2012). Respondents in this study described themselves as "addicts", fighting against the urge to drink fluids when thirsty, and commented that fluid restriction was the most difficult aspect of their treatment. Feelings of thirst were described as "terrible", "tragic", and "crazy". In another study, patients reported being obsessed with their need for liquid (Denhaerynck, et al., 2007). In one recent report of patient preferences regarding fluid restriction, researchers found that nearly half of their sample of hemodialysis patients indicated that, even though many find dialysis unpleasant, they would be willing to extend their dialysis sessions by up to 15 minutes if it meant they could drink more fluids during the interdialytic period (Flythe, Mangione, Brunelli, & Curhan, 2014). As a result of this fluid-related stress, patients may misrepresent their adherence, or experience denial or avoidance on the subject of fluid restriction. Ultimately, more needs to be learned about the factors that influence diet and fluid adherence in this population (Christensen, 1997). A better understanding of the social and contextual factors responsible for morbidity and mortality among patients with kidney failure could improve health dramatically in this population.

Issues related to the assessment of nonadherence to ESRD treatment

There are numerous methods of assessing treatment adherence, and the strategy used can vary widely from one study to another, making drawing concrete conclusions about the factors underlying adherence difficult. For instance, in one early study, patients were most adherent to medication, and least adherent to diet restrictions when assessed using self-reported adherence (Cummings, et al., 1982). In contrast, biological markers of adherence in that same sample indicated that only 30% of patients were adherent to their medication regimen, while 86% were adherent to their diet, and 59% were adherent to fluid restrictions. Objective measures of treatment adherence among patients on hemodialysis include measures of serum levels of phosphorus and potassium, minerals which must be restricted in the diet because of the kidneys' compromised ability to clear them from the bloodstream, the number of dialysis sessions which are skipped or cut short, and the interdialytic weight gain (IWG), or the change in body weight between dialysis sessions due to the inability to evacuate fluids from the body (Christensen & Ehlers, 2002). These markers are considered to be direct reflections of behavioral adherence, although there is some evidence that non-behavioral factors may play a role in elevating mineral and fluid levels in some patients (Vlaminck, et al., 2001). Though most studies of adherence to treatment among patients in kidney failure use at least one, if not all, of these objective measures of adherence, there is little consistency in what constitutes "adherent" levels of fluid weight gain or serum mineral levels; the criteria for what determines adherence are often unstandardized, and, interestingly, are not always associated with clinical outcomes (Loghman-Adham, 2003). Because there is no gold standard for acceptable IWG, potassium, or phosphorus values, the clinical significance of the currently used cutoffs is not clear, and there is little correlation between self-reports of dietary adherence and serum phosphorus or potassium levels (Denhaerynck, et al., 2007).

Self-report measures of treatment adherence among dialysis patients vary just as broadly. In one study, patients rated their degree of compliance with diet, fluid restriction, and medication taking each on a seven-point scale from poor to excellent (Cummings, et al., 1982). In another, compliance was defined as 75% or more of the expected answers on an assessment questionnaire (Thomas, et al., 2001). Standardized instruments of adherence in this population are limited, though a few are available, such as the Dialysis Diet and Fluid Non-Adherence Questionnaire (DDFQ; Vlaminck, et al., 2001). Questions on the DDFQ include "How many days during the past 14 days didn't you follow your diet guidelines?" "To what degree do you deviate from your diet guidelines?" "How many days during the past 14 days didn't you follow your fluid guidelines?" and "To what degree do you deviate from your fluid guidelines?" However, although there appears to be consistency between the DDFQ and biological markers of adherence for patients on dialysis, this is not the norm for objective and subjective reports of treatment adherence in this population. Additionally, given that adherence revolves around food and drink intake, activities which necessarily take place in the context of the home and family, further research is needed on who purchases the food for the home, who prepares food, and how food is consumed by a patient's family (Boyer, Friend, Chlouverakis, & Kaloyanides, 1990; Isenberg & Trisolini, 2008) to understand the factors which contribute to behavioral adherence for patients undergoing treatment for kidney failure.

Demographic factors associated with adherence to ESRD treatment

Relatively few demographic factors have been consistently linked to measures of treatment adherence among patients with ESRD. Although some studies have found that no demographic variables were significant predictors of adherence (Christensen, Moran, Lawton, Stallman, & Voigts, 1997), the majority indicate that younger patients are more likely to be nonadherent than older patients (Hailey & Moss, 2000; Oka & Chaboyer, 1999). However, the relationship between age and adherence varies depending on the aspect of adherence being measured. Age has been significantly associated with better fluid adherence (Bame, et al., 1993; Christensen, et al., 1997; Christensen, Wiebe, Edwards, Michels, & Lawton, 1996). Additionally, older patients have demonstrated better phosphate binding adherence (Bame, et al., 1993; Christensen, Wiebe, Benotsch, & Lawton, 1996) and more compliance with protein restrictions (Bame, et al., 1993).

Psychosocial & environmental determinants of adherence to treatment & disease self-management

Though certainly there may be physiological or practical reasons for nonadherence – taking medications that stimulate thirst, for example – a number of psychosocial factors have been implicated in treatment nonadherence in this population. Many early studies of psychosocial factors associated with adherence were focused on identifying predictors of successful treatment because of a limited number of available dialysis slots, so many of the studies were exclusively descriptive (Cummings, et al., 1982). However, as dialysis technology and procedures have improved and our understanding of the ways in which psychosocial factors influence our health and wellbeing has increased, more has been learned about the contextual and environmental factors that affect patients on dialysis and their adherence to treatment.

Contrary to demographic factors, numerous psychosocial factors have been associated with treatment adherence among patients with ESRD. Factors such as depressive symptoms and perceived well-being may be associated adherence with treatment recommendations (Kimmel, 2002; Kimmel, Emont, Newmann, Danko, & Moss, 2003; Kimmel, Peterson, et al., 1998). Cognitive factors, such as locus of control, may also play a role in adherence. In one study, researchers found that individuals who attributed their fluid restriction adherence to their own efforts were more likely to remain adherent to fluid restrictions in the long term (Friend, Hatchett, Schneider, & Wadhwa, 1997). In another, cognitive factors, including locus of control and perceived adherence, accounted for 42% of the variance in fluid adherence, while emotional factors (depressive symptoms, trait anxiety, and anger) only accounted for 4% (Schneider, et al., 1991). Although other researchers have not found that health locus of control to be related to self-reported or objective markers of adherence (Brown & Fitzpatrick, 1988), they have found that factors such as resourcefulness and self-control were all associated with improved fluid adherence, indicating that fluid adherence is more a cognitive task than an emotional one.

Personality factors may also play a role in adherence; in one study, neuroticism was significantly, positively correlated with serum phosphorus levels, and conscientiousness was significantly, negatively correlated with serum phosphorus (Christensen & Smith, 1995). In another, although there was no significant main effect for conscientiousness serum phosphorus, participants high in both conscientiousness and high in disease severity beliefs had the poorest adherence to phosphorus treatment, while those high in conscientiousness but low in disease severity beliefs had the best adherence to phosphorus treatment (Wiebe & Christensen, 1997). Stress may influence adherence as well; not only do patients experience stress related to ESRD treatment itself, but also related to the consequences of their altered lifestyle. Numerous studies have described the huge social losses experienced by patients on dialysis, with up to 70% of dialysis patients experiencing moderate to severe levels of stress related to their impaired health, social relationships, and employment (Wolcott, Nissenson, & Landsverk, 1988). In one sample, the second most commonly identified stressor of dialysis was a decrease in social life (Lok, 1996). Even minor stresses may lead to disregard of the diet and fluid restrictions imposed on dialysis patients; in one study, minor weekly hassles were found to be associated with potassium and protein levels, such that greater stress was predictive of poorer adherence (Hitchcock, Brantley, Jones, & McKnight, 1992). In another, as the number of daily stressful events increased, so did IWG values (Everett, Brantley, Sletten, Jones, & McKnight, 1995).

Finally, depression has historically been the common psychological complication associated with dialysis (Kimmel, 2002; Levy, 1984). In one early study, researchers reported that up to a quarter of patients on dialysis experience elevated symptoms of depression, and major depression has been diagnosed in up to 22% of dialysis patients (Craven, Rodin, Johnson, & Kennedy, 1987). In another study, 70% of those presenting with depression had experienced their first depressive episode after the onset of kidney failure. However, there does not appear to be a consistent relationship between adherence and depressive symptoms (Khalil & Frazier, 2010).

Social support and ESRD

No dialysis patient is an island, but rather is a member of a family, a community, and a particular dialysis unit (Isenberg & Trisolini, 2008; Kimmel, 2000). One psychosocial factor that has consistently been associated with improved health behaviors and outcomes among individuals with a wide variety of chronic diseases is social support. Social support is the perception that an individual is part of a wider network of persons who can provide assistance and tangible and emotional resources (Wills, 1991). In the case of patients with ESRD, those who have greater levels of social support may have more help with the practical aspects of treatment for kidney failure, such as transportation to medical appointments, help with medication taking, and meal preparation (Kimmel, 2000). However, ESRD can be exceptionally isolating as a result of the time patients must spend on dialysis and in activities of disease self-management. In one qualitative study of the experiences of patients with ESRD, some participants reported feeling ostracized, abandoned, or alienated by colleagues, friends, and family members, and many patients reported receiving support only from other patients on their dialysis unit (Tong, et al., 2009). In another, patients reported that roles, social relationships, and activities of daily living were all impacted by dialysis (Yu & Petrini, 2010). Still, availability of support in this population appears to be high, with reports that more than 75% of participants in one sample had someone to help them with their diet, usually a family member (Thomas, et al., 2001), and support from family and friends has been found to be a common coping strategy for patients struggling with the demands of ESRD (Clarkson & Robinson, 2010).

End-stage renal disease patients experience considerable needs for social support and help from their partners, friends, and family, particularly tangible or instrumental support, to cope with the demands of their illness (Isenberg & Trisolini, 2008; Symister & Friend, 2003). Investigations of the role of social support in hemodialysis outcomes go back more than 30 years; Dimond (1979) assessed the relationship between various sources of social support and morale and social functioning among dialysis patients, and to examine the relationship between social support and adaptation to hemodialysis in a sample of 36 dialysis patients. He found that social support was positively correlated with morale, and more family cohesiveness and availability of a confidant were associated with less change in social functioning following onset of dialysis. In another early study of 150 adults on home hemodialysis, patients higher in social support were less anxious, depressed, and less introverted (Burton, et al., 1983). Additionally, social support appeared to reduce the effects of dialysis-related stress on disease progression. Helpfulness of friends and family members and frequency of contact with social network members have been shown to be related to better psychological adjustment to kidney failure (Siegal, et al., 1987).

Kidney failure patients higher in social support have reported less anxiety, less introversion, and less depression, and demonstrated a greater likelihood to adhere to their treatment regimen, particularly in the diet domain (Furr, 1998). Conversely, patients who were more isolated and evidenced greater family disorganization and poorer family involvement in dialysis have had poorer health outcomes. Social support may also be important in determining how an individual will react to being placed on dialysis and coping with the demands of chronic treatment (Gregory, Way, Hutchinson, Barrett, & Parfrey, 1998). In one study, social support was significantly poorer among individuals who developed severe infections at the site of their dialysis catheter than among those who did not (Tovbin, et al., 2001). In other investigations, however, social support has not been found to be a significant predictor of any adherence domain (Kutner, et al., 2002). Additionally, in at least one study, individuals who had better social support and social adjustment were *less* adherent to diet restrictions, possibly because those who are more social may be more likely to eat out (Sensky, Leger, & Gilmour, 1996) or because more social individuals are more likely to be tempted to eat foods not on their diet plan by friends or family around them eating more desirable foods.

Compared to evidence for a general relationship between social support and improved functioning, however, evidence for a relationship between social support and positive health behaviors, including adherence to treatment, among patients on dialysis has been mixed (Cukor, Cohen, Peterson, & Kimmel, 2007; Hailey & Moss, 2000). In some studies, greater family support has been associated with better diet and fluid adherence (Cohen, et al., 2007; Kara, Caglar, & Kilic, 2007). In one early study, however, social support was not strongly associated with adherence to treatment (Cummings, et al., 1982). In another, serum potassium levels were significantly negatively associated with patients' perceptions of support, while serum phosphorus levels were significantly, negatively associated with families' actual provision of support (Boyer, et al., 1990). In one study of 739 hemodialysis patients, investigators found that emotional support, tangible support, affectionate support, and positive social interaction levels were slightly lower, though not significantly so, among individuals nonadherent to dialysis sessions, phosphorus restriction, and potassium restriction (Unruh, et al., 2005).

Social support appears to operate differently for different parameters of adherence (Christensen, et al., 1992). For example, in some studies, but not others, social support has been found to be correlated with serum levels of potassium and phosphorus, markers of diet and medication adherence among dialysis patients (Kimmel, 2000). In two studies by Kimmel and colleagues, social support was weakly associated with decreased serum phosphorus levels, but with no other markers of adherence (Kimmel, Peterson, Weihs, Simmens, Boyle, Cruz, et al., 1995; Kimmel, Peterson, Weihs, Simmens, Boyle, Verme, et al., 1995). Others have shown similar results; for instance, in one study, the only environmental factor that was significantly associated with compliance was “My family doesn’t help me follow my diet”, which was more often the case for non-compliant patients (Thomas, et al., 2001). In another study, dietary behavior was significantly, positively correlated with family and with healthcare provider support, and family support was the strongest predictor of diet adherence (Oka & Chaboyer, 1999). However, in another study, after controlling for diabetes, there was no relationship between family support and diet adherence (Christensen, et al., 1992). Others have similarly found that social support was not significantly, independently associated with dietary behavior among patients on dialysis (Sumiyoshi, et al., 2010). Although social support may have a limited influence on diet adherence, it has been more consistently associated with fluid adherence; patients with better family support have evidenced improved fluid adherence, but not diet adherence, compared to those with less family support (Brown & Fitzpatrick, 1988; Christensen, et al., 1992). Satisfaction with social support has been shown to be a significant predictor of IWG, such that patients low in social support gained more weight between dialysis sessions (Pang, et al., 2001). More recently, researchers have shown that patients who report greater dissatisfaction with family time and with family support were 18-27% more likely to demonstrate excessive interdialytic weight gain, a marker of poor fluid restriction adherence (Untas, et al., 2011). Adherence to dialysis session attendance may differ still; greater perceived social support was found to be weakly but significantly correlated with improved attendance at dialysis clinic, but was not associated with cutting dialysis sessions short (Kimmel, et al., 1998).

Evidence for the effect of social support on broader outcomes, including mortality rates, in this population has been somewhat more consistent. In one study of 126 adult dialysis patients, 88 patients took part in support groups (Friend, Singletary, Mendell, & Nurse, 1986). After 10 years, 30 patients were surviving; 22 of those were group participants, and 8 were non-participants. Although the groups were similar in sociodemographic and illness profiles at baseline, group participants experienced significantly greater survival over 10 years than did non-participants. None of the sociodemographic variables were significantly related to survival; those who engaged in support group activities simply demonstrated significantly better survival over 10 years than those who did not. Other studies have shown similar positive effects of support on survival among patients with ESRD. In one, family support was predictive of survival, such that a 1-point increase in the family support score was associated with a 13% decrease in mortality risk (Christensen, et al., 1994). In this sample, the mortality rate among ESRD patients low in family support was 52%; among patients high in family support, the mortality rate at 44 months follow-up was 18%. In another study, after controlling for age, illness severity, protein metabolism, and dialyzer type, social support was associated with better survival, such that a one standard deviation increased in perceived social support scores was associated with a 20% decrease in mortality risk over one year (Kimmel, et al., 1998). In another sample, for every one-point increase in social support scores, there was a 0.6% decrease in mortality risk over a 12-month follow-up period (Szeto, et al., 2008). Survival for those in the lowest quartile of perceived social support was 57.1%, whereas for the highest social support quartile, survival over 12 months was 88.6%. Participants high in family support in one investigation had significantly greater survival at 60 months follow-up than did patients low in family support, such that a one-point increase in Family Environment Scale score was associated with a 13% decrease in risk of mortality (Christensen, et al., 1994). Five-year mortality rates were three times higher among patients low in family support compared to those high in family support in this sample. Nevertheless, the specific mechanisms by which social support influences survival and mortality are not presently known (Kimmel, 2000; Kimmel, et al., 1998).

Social support has also been shown to have an impact on other important aspects of living with a chronic, degenerative condition such as ESRD. In one study, social support was significantly, positively related to increased perceived quality of life (Patel, Shah, Peterson, & Kimmel, 2002). In another, social support was significantly, positively related to overall quality of life, as well as health-functioning, socioeconomic, psychological, and family quality of life (Rambod & Rafii, 2010). Social support has been shown to be associated with ESRD patients' symptoms of depression as well as their self-esteem levels and optimism (Symister & Friend, 2003). Social support has been shown to be significantly associated with social function, fatigue, emotional well-being, employment status, and healthcare satisfaction, as well as better functioning in the areas of pain and emotional well-being, among patients with ESRD (Vazquez, et al., 2005).

Support may also be associated with adherence to treatment and to outcomes in patients with kidney failure by way of its interaction with other psychosocial, behavioral, and environmental factors. For example, in one study, researchers found that social support type and locus of control appeared to interact to predict depressive symptoms among individuals on dialysis for kidney failure (Gencoz & Astan, 2006). Specifically, among those participants with an internal locus of control, perceived availability of support, but not satisfaction with received support, was significantly, negatively associated with depressive symptoms, while among participants with an external locus of control, satisfaction with received support, but not perceived availability of support, was significantly, negatively associated with depressive symptoms. Personality factors may also moderate the relationship between social support and physiological or psychological outcomes among patients in treatment for kidney failure. In one study, agreeableness moderated the relationship between social support and depressive symptoms among individuals with chronic kidney disease, highlighting the fact that individual difference variables should be considered alongside social support in examining its relationships with disease outcomes (Hoth, Christensen, Ehlers, Raichle, & Lawton, 2007). Agreeable patients may be more likely and willing to elicit help from others in managing their disease, while less agreeable patients may find social support unhelpful. In another study, social support was associated with fluid adherence, but such that increased support predicted decreased adherence (Moran, et al., 1997).

Finally, because ESRD is degenerative, as the disease progresses, the treatment demands often become more burdensome, and the demand for support can increase as well (Gurklis & Menke, 1995). It may be the case that the value of social support and relationship quality to disease management and survival among ESRD patients increases as the duration of illness increases (Kimmel, et al., 1996). However, the demands of ESRD symptoms and treatment can fluctuate dramatically even over much shorter periods of time – not just months or years, but hours or days. To date, the potential for subtle shifts in perceived support need or support utilization over the interdialytic interval, and the contribution of such micro-level support, has not been explored.

Cognitive demands of hemodialysis treatment

Given the high level of demands placed on ESRD patients – regular attendance at time-consuming and tiring dialysis sessions, restrictions on diet and fluid intake, and taking multiple medications – individuals in kidney failure take on an enormous cognitive burden in terms of keeping track of their food and water intake, their treatment schedule, and their prescriptions. In one study, participants frequently reported using heuristics and mental shortcuts to make decisions about their health and medication (Williams, et al., 2009). However, they struggled with the amount of information that needed to be kept straight about their illnesses, and often oversimplified health risks when managing their treatment. As a result, patients underestimated the risks of non-adherence, and reported that competing demands on their mental resources and time, such as family commitments and financial concerns, contributed to taking shortcuts with their disease self-management. In fact, poor vision, fatigue, nausea, and memory problems occasionally interfered with treatment adherence in one study (Williams, Manias, & Walker, 2008). Some participants reported that their cognitive processes were cloudy and interfered with their medication dosing, especially first thing in the morning, and many reported forgetting to take medications, especially if they were tired, lived alone, or during times away from home. Healthcare providers reported that the mental health of patients, especially cognitive symptoms like information processing, memory, and motivation were often obstacles to medication adherence.

Indeed, cognitive problems are common among individuals on hemodialysis (Altmann, Barnett, & Finn, 2007; Griva, et al., 2010; Hain, 2008; Harciarek, Biedunkiewicz, Lichodziejewska-Niemierko, Debska-Slizien, & Rutkowski, 2009; Jassal, Devins, Chan, Bozanovic, & Rourke, 2006; Lux, et al., 2010; Madero, Gul, & Sarnak, 2008; Murray, 2008; Nulsen, et al., 2008; Pereira, et al., 2007; Radic, et al., 2010; Song, et al., 2011). Such problems may take the form of memory and attention impairment, reduced psychomotor speed and accuracy, and reduced mental efficiency (Harciarek, et al., 2009). Cognitive dysfunction is a unique predictor of mortality, contributing to a risk of death three times that of individuals without cognitive dysfunction (Griva, et al., 2010). Additionally, cognitive dysfunction persists even when patients are well dialyzed, indicating that there may be aspects of the dialysis process itself that lead to poor cognitive function. In some cases, hemodialysis patients outperform chronic kidney failure patients on measures of cognitive impairment, but dialysis does not appear to return patients to their pre-morbid levels of functioning (Evans, Wagner, & Welch, 2004). Even those patients who have normal scores on the Mini Mental Status Exam (MMSE; Folstein, Folstein, & McHugh, 1975) may still have cognitive deficits (Pereira, et al., 2007); even minor cognitive dysfunction is likely to affect planning, organization, and flexibility, which may in turn influence their ability to engage in daily activities, disease self-management, and treatment adherence (Post, et al., 2010).

Though cognitive decline may just represent a general consequence of declining health, it is possible that such cognitive dysfunction is a byproduct of poorer adherence to treatment, which in turn increases mortality risk (Griva, et al., 2010). Deficits in memory or concentration could result in patients’ forgetting to engage in disease self-management, and reduced cognitive abilities may make it more difficult to follow prescribed instructions and managing a complex treatment regimen (Murray, et al., 2006). Adequate cognitive functioning may be critical to treatment adherence. Evidence for a relationship between cognitive function and adherence is limited, but it is reasonable to believe that such impairments contribute to errors in diet, medication usage, and fluid consumption (Hain, 2008; Radic, et al., 2010). In one study, 58% of those with cognitive dysfunction were treatment non-adherent, with the most common marker of non-adherence being IWG. The results indicate that there may be a link between cognitive dysfunction and greater IWG, and cognitive deficit should be considered a possible risk factor for non-adherence.

Cognitive performance has been shown to be poorer for ESRD patients than for chronic kidney disease patients and for the general population (Kurella, Chertow, Luan, & Yaffe, 2004). Adjusting for age, sex, race, education, and comorbidity, dialysis patients still exhibited more cognitive dysfunction than other patient groups. In one study, strict volume control was related to better cognitive performance, which may be related to their better vascular profile (Dogukan, et al., 2009). The decrease in volume between dialysis sessions may have more bearing on cognitive functioning than just reducing blood pressure. Increased volume may be one of the causes of the marked cognitive dysfunction in end-stage renal disease patients. In others, phosphorus (Kurella, Luan, Yaffe, & Chertow, 2004), calcium, and urea levels were somewhat related to cognitive functioning (Griva, et al., 2003). Many have noted that another mechanism may be fluid levels, which shift considerably among hemodialysis patients depending on the time since last dialysis. Such volume instability may be related to cognitive functioning; there may be a role of fluid volume or disrupted metabolic processes in this cognitive decline (Lux, et al., 2010). Additionally, it is possible that accumulation of toxic compounds over the interdialytic interval leads to confusion and cognitive dysfunction (Williams, Sklar, Burright, & Donovick, 2004). The evidence has not been entirely consistent; though cognitive dysfunction has been associated with IWG, in one study, there did not appear to be a substantial relationship between cognitive function and fluid adherence (Evans, et al., 2004). However, one study found that daily dialysis seemed to afford an advantage in cognitive functioning compared to thrice-weekly dialysis (Jassal, et al., 2006). One reason may be the improved fluid clearance in nightly versus thrice-weekly dialysis. Less frequent dialysis may be associated with greater shifts in cognitive functioning which, in turn, impacts adherence.

Cognitive dysfunction and the interdialytic interval

Most hemodialysis patients who dialyze in a clinic come to sessions three times a week, either on Mondays, Wednesdays, and Fridays or Tuesdays, Thursdays, and Saturdays. However, little is known about how the schedule affects adherence to attendance at dialysis (Obialo, et al., 2008). There do appear to be some differences in adherence relative to a patient's clinic schedule; in one study of over 100 hemodialysis patients, Tuesday-Thursday-Saturday participants had higher no-show and shortened dialysis session rates than did Monday-Wednesday-Friday participants. Indeed, the number of skipped sessions was significantly greater on Saturdays than on any other day. Consistent with others' findings, age was associated with better adherence; no-shows were most common among younger (< 50 years) Tuesday-Thursday-Saturday participants than any other age/schedule group. Additionally, the thrice-weekly dialysis schedule means that the interdialytic interval, or the period between dialysis sessions, varies in length over the course of the week. As a result, patients typically have two one-day intervals – either Tuesdays and Thursdays, or Wednesdays and Fridays – of only one day's duration, and one two-day interdialytic interval – Saturday and Sunday for Monday-Wednesday-Friday dialyzers; Sunday and Monday for Tuesday-Thursday-Saturday dialyzers. Given the apparently strong relationship between increasing fluid volume and decreasing cognitive function, it is possible that cognitive dysfunction would increase as a function of time since last dialysis, such that longer, two-day interdialytic intervals would be associated with greater cognitive dysfunction than shorter, one-day intervals.

It appears that patients do, in fact, experience shifts in their cognitive functioning relative to the length of the interdialytic interval. Though cognitive function may be impaired generally among these patients, it appears that in some domains, there is an effect of time since last dialysis on cognitive performance (Lux, et al., 2010). In one study, many patients reported that they were tired and had trouble concentrating on dialysis day (Hays, Kallich, Mapes, Coons, & Carter, 1994). In another, hemodialysis patients showed marked improvement in cognitive functioning from 2 hours before dialysis to 24 hours after (Griva, et al., 2003). Other researchers have concluded that hemodialysis patients show a significant decline in cognitive task performance over the study interval from 1 hour, to 24 hours, to 67 hours after the completion of the preweekend dialysis session (Williams, et al., 2004). Dialysis patients might therefore be increasingly compromised over the course of the interdialytic interval, which could contribute to difficulty achieving adherence to fluid and diet restrictions and medication regimens. Indeed, the timing of testing relative to dialysis may influence the results of cognitive assessments (Madero, et al., 2008). It may be the case that cognitive function peaks around 24 hours after dialyzing, then drops continuously as time increases since the last dialysis session (Murray, 2008; Murray, et al., 2007). However, the literature on this point has not been entirely consistent. Post and colleagues (2010) found that, in their small sample of 27 older male dialysis patients, time since dialysis was not associated with cognitive performance (Post, et al., 2010). Regardless, the existing evidence indicates that fluctuations in cognitive performance as a function of time since dialysis are likely, and that the optimal time in the dialysis sequence to assess cognitive functioning is not known (Kurella, et al., 2004b).

Recent researchers have noted that future work should explore the degree to which cognitive functioning influences adherence and, in particular, explore the mechanisms by which cognitive dysfunction affects mortality (Griva, et al., 2010). It may be the case that any one patient's individual and social factors interact with factors related to the treatment context to produce differences in hemodialysis treatment outcomes (Christensen, 2000). However, this person-by-context interaction has received relatively little attention in the ESRD literature. One issue related to studying the person/context interaction is identifying the appropriate aspects of the treatment context that might be relevant to adherence behaviors – it is not presently known what aspects of the illness and treatments are the likeliest moderators of treatment adherence. In theory, health behaviors and outcomes should be best when the patient's resources match well with the demands and consequences of treatment. In the case of cognitive dysfunction over the interdialytic interval, numerous individual and social factors may influence the degree to which unavoidable cognitive declines affect adherence and, in turn, the health of the patient in kidney failure. One such influence may be the provision of social support from the patient's spouse or other family members.

Family support, cognitive function, and treatment adherence

As noted, ESRD patients have enormous treatment demands and, consequently, high needs for help from their partners, friends, and family (Isenberg & Trisolini, 2008; Symister & Friend, 2003). Although social and family support has not been reliably associated with improved adherence across all treatment domains (Christensen, et al., 1992; Cukor, et al., 2007; Hailey & Moss, 2000; Unruh, et al., 2005), it has been somewhat consistently predictive of fluid adherence in particular (Brown & Fitzpatrick, 1988; Christensen, et al., 1992; Pang, et al., 2001). Since fluid adherence is likely to be most closely associated with progressive cognitive dysfunction over the interdialytic interval (Dogukan, et al., 2009; Jassal, et al., 2006; Lux, et al., 2010), social support – particularly disease-specific support, in the form of reminders and help with treatment tasks, such as monitoring the amount of fluid consumed – may be critical for patients as the time since last dialysis increases. Essentially, the relationship between cognitive function and treatment adherence – diet and fluid restriction and medication taking – may depend on family support, such that individuals reporting greater family support will evidence better adherence at high levels of cognitive dysfunction compared to those with less family support.

Though empirical investigations for such a relationship are unavailable, some researchers have commented that it is likely that social support may play a role in moderating the relationship between cognitive dysfunction and treatment adherence among patients with ESRD. Investigators have speculated that the interplay between social support and treatment complexity and burden may affect adherence, and should be explored in future research (Hain, 2008). Others have suggested that increasing social support could decrease the effects of depression and other cognitive problems on disease management and outcomes among patients with kidney disease (Madero, et al., 2008), and that patients suffering from cognitive dysfunction pre-dialysis may require more support, and may also require more guidance on their healthcare decisions and their medication, fluid, and dietary adherence (Nulsen, et al., 2008). Indeed, in one study, spouses frequently took on the role of reminding or prompting participants to take their medication on schedule (Williams, et al., 2008); in another, 40% of patients received support in the form of help with reminders to restrict fluids and take medication, preparation of the dialysis diet, and helping with medical needs (Gurklis & Menke, 1995). In their 2008 study, Isenberg and colleagues found that family members, especially spouses, were extensively involved in ESRD patients' disease self-management, especially their diet and fluid restrictions and medication taking, with one spouse even indicating that "*'[his] job is to buy the right food and keep tabs on if she wants to eat something that's not right'*" (Isenberg & Trisolini, 2008, p. 52). Family members also remarked that they took responsibility for finding healthy substitutes for patients' favorite unrecommended foods. While it is not known if the frequency of such assistance increases as time since dialysis increases, it is possible that the lack of a consistent interaction between cognitive dysfunction and fluid adherence may be due to family support (Evans, et al., 2004). That is, those patients who evidence better cognitive functioning and better adherence may simply have more support for their activities of ESRD self-management, such as a spouse or other family member keeping track of their food and fluid intake, reminding them to take medication, and helping them with activities of daily living.

While direct evidence of a relationship between social support, cognitive function, and treatment adherence has not been studied among patients on hemodialysis for ESRD, researchers have examined such relationships among patients with diabetes. Diabetes puts similar, though less restrictive, behavioral demands on patients in terms of their diet and medication management. As with kidney failure, poor glycemic control among diabetes patients has been linked to decreased cognitive functioning (Lippa, Klein, & Shalin, 2008; Munshi, et al., 2006), and, like ESRD, it is thought that better treatment adherence can ameliorate such cognitive dysfunction (Nguyen, et al., 2010). Additionally, social support has been shown to improve adherence to behaviors of disease self-management for patients with diabetes (Rosland, et al., 2008). In one study, increased cognitive dysfunction and decreased social support were found to be independent risk factors for mortality among older patients with diabetes (Sampson, Bulpitt,

& Fletcher, 2009). In another, though cognitive dysfunction was related to poorer glycemic control among patients with diabetes, this association was diminished for patients with greater social support (Okura, Heisler, & Langa, 2009). Evidence also indicates that psychological functioning more generally, including cognitive function as well as optimism, self-esteem, and symptoms of depression, among patients with diabetes may be associated with increased social support, which in turn improves glycemic control, chiefly by helping the patient with glucose monitoring (Brody, Kogan, Murry, Chen, & Brown, 2008). Not all studies have shown a positive effect of social support on cognitive functioning and glycemic control among patients with diabetes, however; in their 2009 study, Feil and colleagues found that while cognitive dysfunction was associated with poorer diabetes self-management, the presence of a supporting caregiver predicted *worse* glycemic control over one year follow up (Feil, et al., 2009). In any case, the bulk of the evidence points to a moderating effect of social support on the relationship between cognitive dysfunction and adherence and outcomes among patients with diabetes. Given the similarities in the behavioral and cognitive demands between diabetes and ESRD, it is likely that such a relationship also exists in patients in treatment for kidney failure. The proposed project aims to address this gap in the literature by examining cognitive functioning, demand for social support, and adherence to treatment over the interdialytic interval among ESRD patients in a context-sensitive, ecologically valid framework.

Ecological Momentary Assessment: Using experience sampling to measure health behaviors

A considerable methodological limitation of the research examining the influence of social support or cognitive dysfunction on various aspects of the disease process among individuals on dialysis for ESRD has been the reliance on self-report questionnaires (Piasecki, Hufford, Solhan, & Trull, 2007; Shiffman, Stone, & Hufford, 2008; Stone, Broderick, Shiffman, & Schwartz, 2004; Takarangi, Garry, & Loftus, 2006). Even under the best circumstances, people can be unreliable sources of information about their past behaviors. Some researchers have reported that individuals have difficulty accurately reporting on the details of how well they adhered to their disease management regimen beyond about three days (Dunbar-Jacob, Houze, Kramer, Luyster, & McCall, 2010); others have found that subjective reports of medication-taking behavior were not correlated with objective measures of medication use (Lee, et al., 2007). One way to reduce dependence on one-time, “snapshot” evaluations is to capture behaviors of disease self-management as well as moods and emotional and cognitive experiences as they unfold over time on a moment-by-moment basis. Ecological Momentary Assessment (EMA), also known as experience sampling, is used by investigators to increase the ecological validity of and contextual sensitivity of their research. EMA helps reduce the retrospective bias that is inherent in one-time self-reports seeing to characterize the frequency or intensity of past behaviors, moods, and cognitions (Dunbar-Jacob, et al., 2010; Shiffman, 2007), and is sensitive to temporal effects, social contexts and other environmental influences, as well as capturing dynamic and interpersonal processes. In EMA-based studies, participants respond to questions about their behaviors, feelings, and experiences at repeated intervals over the course of several days, signaled by an alarm or event (Shiffman, et al., 2008). This enables data to be collected from a respondent in as many natural, real-life settings and situations in real time as possible. Instead of trusting respondents to accurately report on their typical behaviors and evaluating behaviors and attitudes at only a single time point, EMA affords an ongoing self-reporting of everyday activities. Additionally, EMA may be more accurate and have greater validity compared to traditional survey methods of collecting information (Shiffman, et al., 2008).

EMA has been used probably most widely to track the incidence of negative health behaviors, such as cigarette smoking (Chandra, Scharf, & Shiffman, 2011; Shiffman, et al., 2002; Whalen, Jamner, Henker, & Delfino, 2001) and alcohol use (Piasecki, et al., 2011). Additionally, many studies of the factors associated with chronic disease outcomes have used EMA to collect richer, more context-sensitive data. Notably, EMA has been used extensively to explore the psychosocial and environmental factors associated with blood pressure, as well as the affective and cognitive effects of subtle shifts in blood pressure over the course of a typical day. For example, in a series of studies on the effects of workplace stress on blood pressure reactivity and mood, researchers recorded participants' blood pressure using an ambulatory monitor, and asked them to concurrently report their moods and activities in a diary over the course of several work- and non-workdays (Goldstein, Jamner, & Shapiro, 1992; Jamner, Shapiro, Goldstein, & Hug, 1991; Shapiro, Jamner, & Goldstein, 1993, 1997; Shapiro, Jamner, Goldstein, & Delfino, 2001). The investigators found that workplace stress was associated with increases in both waking and sleeping blood pressure levels, and also found a direct relationship between negative mood and increased blood pressure, particularly overnight diastolic blood pressure, as well as an interactive relationship between negative mood, workplace stress, and blood pressure levels. Of particular note for the present investigation, in one EMA study of blood pressure and cognitive function, researchers found that even modestly increased blood pressure levels and increased variability in blood pressure was associated with attentional and memory deficits among normotensive adults (Goldstein, Shapiro, La Rue, & Guthrie, 1998). Despite the low mean blood pressure in their sample (120/72 mmHg), Goldstein and colleagues found that an average increase in systolic or diastolic blood pressure of only 5 to 7 mmHg was associated with significant drops in performance on the Digit Span (Wechsler, 1945, 1981), Auditory Consonant Trigrams (Peterson

& Peterson, 1959; Stuss, et al., 1985), and the Benton Visual Retention Test (Benton, 1974; Sivan, 1991), suggesting that individuals with elevated or poorly controlled blood pressure could suffer even more dramatic declines in cognitive performance. In more recent years, researchers have also used EMA in studies of patients with asthma (Juth, Smyth, & Santuzzi, 2008; Nazarian, Smyth, & Sliwinski, 2006), diabetes (Helgeson, Lopez, & Kamarck, 2009; Mulvaney, et al., 2011), and obesity (Carels, Douglass, Cacciapaglia, & O'Brien, 2004; Dunton, Liao, Intille, Spruijt-Metz, & Pentz, 2011; Goldschmidt, et al., 2011; Salvy, et al., 2008). Such findings indicate that more ecologically valid assessments of the psychosocial context of health and symptoms of illness are warranted, particularly in chronically ill samples where even minor fluctuations in health status can have a dramatic impact on morbidity and mortality.

To date, however, very few published studies have used EMA in the context of hemodialysis treatment (Abdel-Kader, et al., 2014; Riis, et al., 2005). Additionally, only a small number of these have focused on using experience sampling to track or improve adherence. A few studies have used a medication event monitoring system (MEMS), in which medication bottles are outfitted with an electronic device that detects when and how often the bottle has been opened, to track medication adherence in patients on hemodialysis, two in adults (Curtin, Svarstad, Andress, Keller, & Sacksteder, 1997; Curtin, Svarstad, & Keller, 1999) and one in adolescents (Blowey, et al., 1997). Each found adherence to oral medications to be well below the desired level of medication adherence. In another study, Sevick and colleagues (Sevick, et al., 2005; Sevick, et al., 2008) employed a personal digital assistant (PDA)-based food tracking program, in concert with a diet improvement intervention, in their study on reducing sodium, potassium, and phosphorus intake in a sample of adult hemodialysis patients. Researchers found that the PDA program was useful in collecting information about participants' dietary intake in real time and in efficiently informing dieticians about their patients' consumption over the course of the interdialytic interval. Unfortunately, published findings from the study reflect only the results from a small pilot sample and one more detailed case study, and the program used to collect information about participants' diet (BalanceLog®, Microlife USA, Inc., Clearwater, FL) was designed to collect information about nutrition goals for weight management, and not specifically for dialysis patients. As a result, the program did not track data on the sodium, potassium, or phosphorus content of the respondents' consumed foods, or specifically address the issues of food and fluid restriction in this population.

Most studies that employ EMA methodologies, including the present study, use an electronic diary presented on a palmtop computing device or PDA which both alerts the participant that it is time to make a diary entry and presents the data collection instrument to the participant (Shiffman, et al., 2008). Using electronically-enabled EMA to assess activities of disease management, particularly adherence to treatment regimens, has increased considerably in recent years (Dunbar-Jacob, et al., 2010). Electronic diaries can constrain as well as record the time that diary reports are made; with most electronic EMA protocols, participants are not able to see their responses to previous questions or to go back and change previous answers, and the diary program marks each entry with a "time stamp" to ensure entries were made at the time they were requested (Shiffman, et al., 2008). Such practices reduce retrospective reporting bias as well as sampling bias that may occur if participants are allowed to make entries on their own schedule. In the context of adherence to treatment, electronic monitoring allows investigators to compute the ratio of desired adherence events to the number of adherence events that actually take place. Additionally, ecological momentary assessment of disease management can enable researchers to explore the contexts of success and failure in adherence, which can in turn help promote strategies to improve adherence to treatment (Dunbar-Jacob, et al., 2010). However, there is still much to be learned about the day-to-day experiences of patients in kidney failure, and EMA may be a particularly powerful tool with which to examine the associations between social support, cognitive functioning, and disease self-management, particularly adherence to fluid restrictions, among dialysis patients.

The present investigation

Even subtle shifts in cognitive and psychosocial functioning may have disastrous consequences for ESRD patients' health. While researchers have posited that social support could buffer the effects cognitive decline on activities of disease self-management in this population (Madero, et al., 2008), and that ESRD may also need more help with their health behaviors as the next dialysis session approaches (Nulsen, et al., 2008), to date, there are few empirical studies to support these claims. If it is the case that cognitive function declines and demand for and utilization of social support increases in predictable ways over the interdialytic interval, particularly over the two-day interval, it is plausible that social support plays a role in moderating the relationship between cognitive dysfunction and treatment adherence among patients with ESRD. Associations between cognitive function and treatment adherence, and between cognitive function and disease outcomes, may depend on social support, such that those highest in support will demonstrate better subjective and objective rates of treatment adherence, even at high levels of cognitive dysfunction. The present study addressed a number of knowledge gaps in the literature concerning the intricate relationships between cognitive functioning, social support, and adherence to treatment among patients with end-stage renal disease over the course of the interdialytic interval.

The overarching aim of this study was to leverage the strengths of the ecological momentary assessment approach to test specific predictions on the relationship between disease self-management, particularly adherence to fluid restrictions, cognitive dysfunction, length of the interdialytic interval, and family support, especially from a spouse or partner, among patients on hemodialysis for end-stage renal disease. The specific aims of the present investigation were as follows:

Specific Aim 1: To examine the relationship between social support and objective and subjective markers of fluid, diet, and medication adherence.

Hypothesis 1: Patients higher in perceived social support would demonstrate better self-reported adherence to fluid and diet restriction and medication taking, reflected by lower IWG, serum phosphorus, and serum potassium levels compared to those patients lower in perceived support.

Specific Aim 2: To examine the relationship between time since the last dialysis session – the interdialytic interval – and cognitive functioning.

Hypothesis 2: Cognitive function (i.e., memory, concentration, decision-making) would decline as a function of time since last dialysis, such that two-day interdialytic intervals would be associated with greater cognitive dysfunction compared to one-day intervals. In particular, functioning on day two of the two-day interval was expected to differ significantly from the one day interval, as well as from day one of the two-day interval.

Specific Aim 3: To examine the relationship between cognitive functioning and objective and subjective markers of fluid, diet, and medication adherence.

Hypothesis 3: Cognitive dysfunction was expected to be positively related to greater IWG, greater serum potassium, and greater serum phosphorus levels.

Hypothesis 4: Cognitive dysfunction was also expected to be associated with greater discrepancies in self-reported adherence compared to biological markers of adherence.

Hypothesis 5: Cognitive function would mediate the relationship between the length of the interdialytic interval and subjective and objective reports of adherence to treatment.

Specific Aim 4: To explore the interaction between cognitive functioning, treatment adherence, and family support.

Hypothesis 6: Family support would moderate the relationship between cognitive function and adherence, such that individuals reporting greater family support would evidence better adherence at high levels of cognitive dysfunction compared to those with less family support.

Secondary Aims

The present study also made some exploratory assessments of the role of individual difference factors, including personality factors and health locus of control, on declines in cognitive functioning, social support, and adherence. Given the established relationships between neuroticism and conscientiousness on biological markers of adherence, particularly phosphorus levels (Christensen & Smith, 1995; Wiebe & Christensen, 1997), and especially the effects of the interaction between conscientiousness and other individual-level psychosocial factors on adherence markers, personality traits were assessed and included as potential covariates and moderators in the proposed study. Additionally, though it has not consistently been associated with all subjective markers of adherence, locus of control has been shown to account for a substantial portion of the variance in fluid adherence (Schneider, et al., 1991), and was explored as a potential contributor to the relationship between cognitive functioning, social support, and subjective and objective measures of adherence to treatment. The conceptual model for the present study is illustrated in Figure 1.

CHAPTER TWO

METHOD

Participants

Participants included 32 (Female n = 15, Male n = 17) English- and Spanish-speaking adults being treated at the University of California, Irvine Medical Center for end-stage renal disease or other serious kidney failure. The mean age of participants in the complete sample was 44.8 years (SD = 20.0 years). The majority of participants were Hispanic or Latino (n = 22, 68.8%); other respondents were Asian or Pacific Islander (n = 4, 12.5%), White (n = 2, 6.3%), Native American (n = 2, 6.3%), African American (n = 1, 3.1%), or Other (n = 1, 3.1%). Seven participants were Spanish speakers; the remaining 25 respondents were English speakers. Thirteen respondents (40.6%) were currently married. Eight participants (25.0%) had completed less than a high school degree, ten (31.2%) had completed high school, seven (21.9%) had attended some college, and seven (21.9%) had completed college or beyond. In terms of employment status, only six participants (18.8%) remained in the workforce, and two (6.3%) were in school. The remaining participants were disabled (n = 9, 28.1%), unemployed (n = 10, 31.2%), or retired (n = 4, 12.5%). One participant declined to state her employment status.

Participant recruitment. Participant recruitment was conducted at the UC Irvine Medical Center Hemodialysis Unit. The outpatient dialysis clinic is home to 20 hemodialysis stations, used for the treatment of ESRD among adults, and staff on site include physicians, nurses, technicians, and nutritionists. The majority of outpatients are seen three times each week – either Monday, Wednesday, and Friday or Tuesday, Thursday and Saturday – during one of four daily “shifts” – early morning, mid-day, afternoon, or evening. Permission for and assistance with participant recruitment was arranged with the chief of the Division of

Nephrology and Hypertension. Recruitment for this study was both active and passive. Flyers advertising the study were placed at the registration counter in the dialysis clinic, as well as at individual dialysis stations. Additionally, the principal investigator, trained research assistants, and clinic staff, including attending physicians, nurses, and medical social workers, approached eligible patients to notify them of the opportunity to participate in the study. A number of patients also heard about the study from other participating patients via word of mouth and contacted members of the research team either directly during their visits to the clinic or indirectly via clinic staff. Potential participants were informed of the basic study requirements and procedures, the tasks they would undertake as part of the study, and the compensation available for participating.

Procedures

Participants began the informed consent process at the time of enrollment. Once participants had the study tasks explained to them and provided their consent to participate, they completed the battery of self-report instruments, detailed below, as well as a brief survey of sociodemographic information. Participants were given the option of completing the forms on their own, either during dialysis or at home, or having the instruments read to them as an interview. Approximately half of participants opted to respond to the self-report items in an interview. The self-report packet consists of around 350 items. Completed on paper, the battery took 45 to 60 minutes to complete. Administered as an interview, the battery took 60 to 120 minutes to complete, depending on the respondent's abilities. After the self-report instruments were completed, a researcher administered a number of assessments of cognitive functioning. The administration of the cognitive measures took approximately 10 to 15 minutes.

Participants in this study also engaged in approximately one week of ecological momentary assessment via a smartphone-based electronic diary system. Participants were outfitted with a smartphone equipped with the diary program or, if they owned a smartphone capable of running the system, the diary program was installed on their phone. Only one participant had a smartphone compatible with the electronic diary program. Around five times each day, the program signaled participants to enter information about their location, activities, social context, moods, whether or not they consumed any food, fluids, and/or medications, their current level of cognitive functioning, whether anyone helped them with their activities of disease management since the last diary entry, and what type of help they received.

Finally, participants' health records were examined to collect information about biological markers of treatment adherence. Participants' phosphorus, potassium, and interdialytic weight gain values from three months before study enrollment and three months after study enrollment were recorded. Additionally, the recorded causes of participants' ESRD were collected, as well as a list of their prescribed medications and recommended mineral and fluid levels, when available. Records of transplant or transfer to another facility were examined, as well. One enrolled participant received a kidney transplant about four weeks after completing study tasks. Finally, because mortality rates are elevated in this population, information about mortality, in addition to morbidity, was abstracted from patients' health records. One enrolled participant expired during the course of the study. The participant had not completed any study tasks.

Participants were then trained to use the electronic diary system and were instructed on the proper procedures to follow should the smartphone device or the diary program malfunction during their study participation. This training session took approximately 30 minutes. At this session, participants received detailed instructions on how to use the smartphone-based diary that recorded information about daily activities, moods, and social interactions approximately five times each day over seven days. Each time it signaled, the diary prompted participants to enter information about what they were doing, where they were, whom they were with, and how they felt, as well as about information specific to their kidney disease, such as whether they ate any foods on their meal plan, any foods not on their meal plan, an estimate of their fluid consumption, whether they had taken any medication, and whether they had received any help from others for their activities of disease self-management. Participants were given a Diary Manual to take home that reviews diary procedures and the intended meanings of the diary items. Participants were also shown how to open a copy of the diary manual on their smartphone device. Selected contents of the diary are presented in the Appendix. During the training session, participants were given the opportunity to practice using the smartphone device and have any questions about using the diary program answered. Following the diary training session, participants began their week-long monitoring period.

Participants were enrolled and the psychosocial and cognitive instruments administered during one or more of their regularly scheduled dialysis sessions. Participants were trained to use the smartphone diary system during the next dialysis session. Each dialysis session is three to four hours long, during which patients are typically restricted in their movements, and must remain in a chair next to the dialysis machine. Although most studies of psychosocial factors among patients on dialysis administer study materials to participants during the dialysis session (cf. Kimmel, Emont, Newmann, Danko, & Moss, 2003; Wiebe & Christensen, 1997), there is considerable disagreement as to the best point in the dialysis session to make such assessments (Kurella, et al., 2004). In some cases, it appears that cognitive functioning is worst at the very beginning of a dialysis session (Murray, 2008). Others have found that dialysis patients appear to experience a drop in cognitive function and may be confused during dialysis (Murray, et al., 2007). The timing of testing relative to dialysis may influence the results of cognitive assessments (Madero, et al., 2008) as well as other psychosocial assessments. As a result, consistent with Cormier-Daigle and Stewart (1997), all measures and training materials were administered to participants approximately one to two hours after they began their dialysis session.

On average, participants took three sessions to complete all study interview and training tasks. The order in which the long and short interdialytic intervals took place during the week of at-home assessment varied between participants, with some patients presenting with a short interdialytic interval first, followed by a long interval; others with a two-day IDI followed by two one-days, and so on. A sample timeline for one participant is illustrated in Figure 2.

Participants who enrolled in the study were compensated for their time with an Android® wireless tablet computer, valued at approximately $85. If participants were not interested in receiving the tablet computer as compensation for their time, they could request a gift card for the same value to a local department store. Only one participant elected to receive the gift card in lieu of the tablet computer. Participation in the present study was voluntary. All study activities, including informed consent, administering cognitive assessments, psychosocial instruments, abstracting health records, and maintaining data safely and confidentially were carried out by the principal investigator or a trained research assistant.

All study procedures were approved by the University of California, Irvine Institutional Review Board (HS# 2012-9049).

Study instruments. Participants were administered a battery of study instruments in a number of domains, including adherence to ESRD treatment, social support, cognitive functioning, and relevant covariates, including depressive symptoms, health locus of control, and personality traits. Study instruments were translated into Spanish by three volunteer research assistants who were native speakers of Spanish and bilingual in English. Double translation was used to translate all measures. Each measure was translated first from English into Spanish by one reader, then back-translated into English by a second reader. English versions were compared against one another by the principal investigator. Spanish-language measures were checked for fluency by a third reader and any discrepancies corrected. The measures are described below and illustrated in Table 1.

Measures of adherence and health functioning. A number of instruments were administered to assess subjective reports of adherence, including self-reported diet, fluid, and dialysis adherence. The End-Stage Renal Disease Adherence Questionnaire (ESRD-AQ; Kim, Evangelista, Phillips, Pavlish, & Kopple, 2010) is a relatively new scale that assesses the degree to which patients on dialysis adhere to dialysis attendance, medication use, fluid restriction, and their recommended diet. The ESRD-AQ contains 46 items in five sections, evaluating general information about respondents' kidney disease, how long they have been on dialysis, and whether they have ever had a kidney transplant, and information about treatment adherence behaviors. Items in the adherence subscales are rated with a mix of yes/no and Likert-type rating scales, and include questions such as "How much difficulty have you had following your dietary recommendations?", "How important do you think it is to weigh yourself daily?", and "During the last month, how many times have you shortened your dialysis time?". Although the instrument is new and has not been cited extensively, the ESRD-AQ has demonstrated adequate validity and reliability, with a mean item-level content validity index value of 0.99 and test-retest reliability values ranging from .83 to 1.00.

Whereas the ESRD-AQ measures how well respondents follow their dialysis treatment schedule and medical recommendations (Kim, et al., 2010), the Renal Adherence Attitudes Questionnaire (RAAQ) and Renal Adherence Behaviors Questionnaire (RABQ; Rushe & McGee, 1998) assess patients' attitudes toward their dialysis-related dietary and fluid limitations, how such restrictions influence their lives, as well as their perceived adherence to treatment recommendations in the various domains of self-management activities. The RAAQ consists of 26 items, rated on a 5-point Likert-type scale ranging from 1 (Strongly Disagree) to 5 (Strongly Agree); the RABQ consists of 25 items, rated on a 5-point Likert-type scale ranging from 1 (Never) to 5 (Always). The RAAQ assesses adherence attitudes in four domains: Social, Well-Being, Self-care/Support, and Acceptance. The RABQ assesses perceived adherence to treatment in five domains: fluid, potassium/phosphate, self-care, adherence in times of particular difficulty, and sodium. The validity of the RABQ was determined by comparing the findings with patients' serum potassium levels, phosphate levels, IWG, and with a 7-day food diary. Sample items on the RAAQ include "My diet fits into my lifestyle", "My diet has no impact on my social life", and "Restricting fluid prevents enjoyment". Items on the RABQ include "I cannot resist forbidden food", I weigh myself regularly", and "Breaking my diet makes no difference for me".

In one qualitative study of attitudes toward diet and fluid restrictions, the RAAQ and the RABQ were criticized for measuring the level of difficulty experienced by patients in adhering to their treatment recommendations, but ignoring the kind or quality of the obstacles encountered by patients with ESRD (Krespi, Bone, Ahmad, Worthington, & Salmon, 2004). However, despite this minor critique, and although the instruments have not been cited extensively, both the RAAQ and RABQ have demonstrated adequate reliability (Rushe & McGee, 1998). Cronbach's alpha values for the four subscales of the RAAQ are acceptable, with a value of 0.77 for Well-being, 0.86 for Acceptance, and 0.88 for Social. Only the Self-care/Support subscale of the RAAQ demonstrated somewhat weak reliability with a Cronbach's alpha level and a test-retest reliability value of 0.68. However, as with the KDQOL-SF (Hays, et al., 1997; Hays, et al., 1994), because support for self-care behaviors were measured extensively using reliable, valid measures of general and disease-specific social support, and because support from family or other important others was assessed in the electronic diary (described below), the weak performance of the RAAQ support subscale was not expected to pose a concern. Cronbach's alpha levels for three of the five subscales of the RABQ demonstrated adequate reliability, including adherence to fluid restrictions ($\alpha = 0.80$), adherence to potassium and phosphate restrictions ($\alpha = 0.70$), and adherence to overall self-care ($\alpha = 0.78$). However, with Cronbach's alpha levels of 0.56 and 0.68, respectively, the adherence in times of difficulty and adherence to sodium restrictions subscales performed somewhat less well. Although self-report measures of adherence behaviors among patients on dialysis are inconsistently correlated with objective measures of adherence, such as weight gain and serum mineral levels (Cummings, et al., 1982; Denhaerynck, et al., 2007; Vlaminck, et al., 2001), the RABQ has been validated against biochemical and dietician-rated markers with a fair degree of success (Rushe & McGee, 1998).

A modified version of the Kidney Disease Quality of Life Scale-Short Form (KDQOL-SF; Hays, et al., 1994) was administered to assess participants' perceptions of the degree to which their health affects their functioning in other areas of their lives. The original KDQOL consists of 82 items grouped into 24 questions or subscales, and includes self-report measures of respondents' symptoms or problems, effects of kidney disease on their daily life, burden of kidney disease, employment status, cognitive function, quality of their social interactions, sexual functioning, and sleep, as well as subscales assessing social support, support from dialysis staff, and life satisfaction. The KDQOL-SF is based on the SF-36 (Ware & Sherbourne, 1992), an extensively-used and well-validated measure of physical and mental functioning. As a result, the original KDQOL-SF contains a series of items that assess respondents' depressive symptoms. However, many physical symptoms of depression, such as lacking energy or feeling fatigued, overlap with symptoms of kidney failure, and many researchers have noted that including physical symptoms of depression in assessments of ESRD patients' mood or emotional functioning may be misleading and inflate the number of reported depressive symptoms and rates of suspected depression (Kimmel, 2000; Kimmel, Weihs, & Peterson, 1993; Smith, Hong, & Robson, 1985). In the present investigation, the subscale of depressive symptoms was removed, though symptoms of depression were measured using the Cognitive Depression Inventory, detailed below.

Sample items in the KDQOL-SF include "How much does kidney disease bother you in your personal appearance?", "How much does kidney disease bother you in your ability to travel?", and "During the past four weeks, to what extent were you bothered by shortness of breath?". The KDQOL-SF has demonstrated acceptable validity and reliability (Hays, et al., 1994), with Cronbach's alpha levels ranging from 0.76 to 0.94 on the full version and from 0.84 to 0.90 on the short form (Hays, et al., 1997). Two subscales on the short form have demonstrated less than adequate reliability, however; three items assessing quality of social interactions evidenced an alpha level of only 0.61, and three items assessing cognitive functioning demonstrated an alpha level of 0.68. Because the aims of the proposed investigation center heavily on cognitive functioning and social relationships among patients on dialysis, these constructs were measured with other tools, including both standard self-report instruments, neuropsychological tests, and experience sampling measures, so the potential instability of these constructs in the KDQOL-SF was not expected to pose a methodological concern.

Measures of social support. Two instruments were administered to assess participants' perceived general and disease-specific social support. The Multidimensional Scale of Perceived Social Support (MSPSS; Zimet, Dahlem, Zimet, & Farley, 1988) is a 12-item instrument that assesses respondents' perceived availability of general social support across multiple domains rated on a 7-point Likert-type scale ranging from 1 (Strongly Disagree) to 5 (Strongly Agree). The MSPSS has demonstrated excellent validity and reliability, with an overall Cronbach's alpha of 0.88. The instrument is made up of three subscales: Family, Friends, and Significant Other; the subscales have also demonstrated adequate reliability, with alpha values of 0.91, 0.87, and 0.85, respectively. Sample items on the MSPSS include "My family is willing to help me make decisions", "I can count on my friends when things go wrong", and "There is a special person with whom I can share my joys and sorrows". The MSPSS was originally developed using a college sample of 275 students, half men and half women, with a mean age of 18.6 years (SD = 0.88 years), and was validated against the Hopkins Symptom Checklist (Derogatis, Lipman, Rickels, Uhlenhuth, & Covi, 1974). Individuals high in social support as measured by the MSPSS evidenced lower depression and anxiety on the Symptom Checklist than did those low in social support. Although the MSPSS was developed for general use in a healthy population, it has been used extensively among patients on hemodialysis (Gencoz & Astan, 2006; Kara, et al., 2007; Kimmel, et al., 1998; Kimmel, Peterson, Weihs, Simmens, Boyle, Cruz, et al., 1995; Kimmel, et al., 1996; Kimmel, Peterson, Weihs, Simmens, Boyle, Verme, et al., 1995; Soykan, et al., 2003). In one sample of 295 hemodialysis patients, researchers found that higher levels of social support, as measured by the MSPSS, were associated with lower negative affect, lower perceived disease burden, greater satisfaction with life, and better survival (Patel, Peterson, & Kimmel, 2005). In the present study, the MSPSS was primarily used as a measure of participants' general perceived available social support.

A modified version of the Diabetes Social Support Questionnaire-Family Version (DSSQ; La Greca & Bearman, 2002) was administered to assess participants' disease-specific support for their activities of ESRD self-management. The original DSSQ contains 58 items, on which respondents rate the frequency with which family members engage in each of the listed actions on a 6-point scale from 0 (Never) to 5 (At least once a day), and the supportiveness of that action on a 5-point scale ranging from -1 (Not supportive) to +3 (very supportive). Both the frequency and supportiveness scales have demonstrated excellent validity and reliability, with Cronbach's alpha scores of 0.95 and 0.98, respectively. The DSSQ asks respondents to rate the frequency and supportiveness of disease-specific support behaviors in five domains: insulin administration, blood glucose testing, meals, exercise, and emotional support. Sample items from the original DSSQ include "How often does a family member praise you for giving yourself shots correctly or on time?", "How often does a family member remind you to test your blood sugar?", "How often does a family member join you in eating the same foods as you?", "How often does a family member invite you to join in exercising with them?", and "How often does a family member understand when you sometimes make mistakes in taking care of your diabetes?" The original DSSQ has been validated against the Perceived Social Support Scale (Procidano & Heller, 1983), the Family Environment Scale (Moos & Moos, 1986), and the Adherence to Diabetes Care scale (Hanson, De Guire, Schinkel, Henggeler, & Burghen, 1992; Hanson, Henggeler, & Burghen, 1987).

For the present investigation, the DSSQ (La Greca & Bearman, 2002) was modified to capture the frequency and supportiveness of support from family members for activities of adherence to ESRD treatment. The items referring to support for insulin administration were revised to assess the frequency and supportiveness of support for respondents' medication use. For example, the item which previously read "How often does a family member keep track of when you have taken your insulin and when you need to take more?" read in the modified version "How often does a family member keep track of when you have taken your medication and when you need to take more?" Medication-taking items in the modified DSSQ referred to all the medications a participant takes for their kidney disease as well as other illnesses, such as hypertension. Items in the blood glucose testing domain were retained, as diabetes is commonly comorbid with ESRD (Christensen, 1997; Christensen & Ehlers, 2002; Gregory, et al., 1998; Hailey & Moss, 2000; McClellan, et al., 1993; Sumiyoshi, et al., 2010; Tijerina, 2009; Welch, et al., 2006) and many study participants had diabetes as well as kidney failure. Other items in the modified DSSQ included "How often does a family member let you know they understand how important it is for you to limit your fluids?", "How often does a family member praise you for following your diet?", and "How often is a family member available to listen to concerns or worries about your kidney disease and dialysis?". Although exercise is important for patients on dialysis (Wang & Jardine, 2011), exercise is often not an explicit component of disease self-management for patients with ESRD; as such, the exercise items from the DSSQ were removed in the modified version.

Measures of cognitive functioning. A battery of instruments was administered to evaluate cognitive functioning. Though the primary cognitive assessment of interest in the proposed study was the momentary reports of cognitive functioning in the electronic diary, standard baseline assessments of cognitive functioning were made as well. The Mini-Mental Status Examination (Folstein, et al., 1975), the Digit Span task (Wechsler, 1981), the short- and long-term recall subscales of the California Verbal Learning Test (Delis, Kramer, Kaplan, & Ober, 1987, 2000), the Benton Visual Retention Test (Sivan, 1991), and the Trail-Making Test (Reitan, 1958) were administered to participants during the orientation and assessment session. The MMSE is a series of twelve items designed to assess respondents' level of orientation to time and place, registration and recall, attention and calculation, language, writing, and drawing. Individuals are asked to engage in a number of tasks, such as reporting the current date and location, repeating a simple phrase, following verbal and written instructions, and copying a drawn figure. The MMSE was originally designed to assess cognitive function among patients for clinicians in a hospital setting, but has since been used extensively in both ill and healthy populations to determine basic cognitive ability. Administrators score the MMSE based on how many correct answers out of a total of 30 a respondent provides. Scores below 24 indicate impairment; scores between 18 and 23 indicate mild impairment, and scores 17 and below indicate significant cognitive dysfunction (Crum, Anthony, Bassett, & Folstein, 1993). MMSE scores are relatively stable (Marioni, Chatfield, Brayne, & Matthews, 2011) and have been shown to be accurate, reliable indicators of cognitive dysfunction in the general medical setting (Pezzotti, Scalmana, Mastromattei, & Di Lallo, 2008). Additionally, the MMSE has been used broadly in studies of patients with ESRD (Altmann, et al., 2007; Hain, 2008; Harciarek, et al., 2009; Harciarek, et al., 2010; Kurella, et al., 2004; Lux, et al., 2010; Madero, et al., 2008; Murray, 2008; Murray, et al., 2006; Nulsen, et al., 2008; O'Connor, et al., 2008; Pereira, et al., 2007). However, though the MMSE has been widely used and validated against gold-standard diagnostic interviews for dementia and other cognitive disorders, it has been criticized for focusing on verbal abilities and may be affected by education (Tombaugh & McIntyre, 1992), and may be more sensitive among individuals with lower cognitive functioning than among those with higher levels of cognition (Proust-Lima, Amieva, Dartigues, & Jacqmin-Gadda, 2007).

The Digit Span task (Wechsler, 1945, 1981) is a test of auditory, verbal working memory. Participants are read a string of digits, for example, 6-4-3-9, and asked to repeat the sequence. The digit strings increase in length until participants are no longer able to correctly repeat the sequence back to the administrator. These strings can range from 3 to 9 digits, and the maximum number of digits a given participant can accurately retain and repeat is considered their “digit span”. Participants are scored on the number of correct trials. The digit span task has both a forward and a backward version; in the forward task, participants are simply asked to repeat the string of numbers read to them. In the backward task, participants are asked to reverse the order of the digits they were read. The digit span task comprises one of the subscales of the Wechsler Adult Intelligence Scale, and has been used extensively in both healthy and ill populations. A number of studies have used the digit span task in samples with chronic kidney disease or ESRD. In one study, researchers found that, while patients on either peritoneal dialysis or hemodialysis performed similarly to one another, dialysis patients performed significantly worse on the digit span task than did patients with pre-dialysis chronic kidney disease (Conde, et al., 2010). Hemodialysis patients evidenced a mean of 7.6 correct responses on the forward digit span, compared to 9.1 correct responses among pre-dialysis patients. Though differences between the groups on the backward digit span, hemodialysis patients still had fewer correct responses (*M* = 4.1) than did pre-dialysis kidney disease patients (*M* = 5.0). Other researchers found that, in a sample of 56 middle-aged dialysis patients, those with better hematocrit levels performed significantly better on the forward digit span than those with lower hematocrit levels, though there was no difference between the groups on the backward task (Lee, et al., 2004). However, some investigators have found that patients with more severe kidney disease had worse performance on the backward task ($M = 3.0$) than did those with more mild kidney disease ($M = 4.9$), but not on the forward task (Tsai, Wang, & Fuh, 2010). Additionally, not all researchers have found evidence of cognitive dysfunction on the digit span among hemodialysis patients; in one small study of 10 well-dialyzed ESRD patients and 10 matched controls, patients did not differ from healthy individuals in their performance on a battery of cognitive measures, including the digit span task (Umans & Pliskin, 1998). However, it is difficult to generalize these findings to the broader dialysis patient population, and it may be the case that, given the demands of disease management for these patients, many hemodialysis patients are not stable enough to maintain cognitive function at the same level as a healthy individual.

The California Verbal Learning Test (CVLT; Delis, et al., 1987, 2000), is a measure of immediate and delayed recall. Participants are read a list of nine to sixteen words and are asked to recall as many of the words as they can. This task is performed twice – in the immediate recall task, participants are asked to repeat the list of words back to the administrator immediately after heating the list. In the delayed task, participants are asked to recall the words after a ten-minute delay. Scores reflect the number of words correctly remembered during each task; better performance is indicated by higher numbers of recalled words. The CVLT does not appear to have been used as extensively with hemodialysis patients as some other tests of cognitive functioning. However, some researchers have used the CVLT in the context of treatment for kidney failure. In one study, patients with chronic kidney disease performed significantly worse on the both the immediate and delayed CVLT than did healthy matched controls, with patients recalling an average of 40 (out of 5 trials, maximum score 45) words on the immediate recall task and 8 words on the delayed task, and controls recalling an average of 48 words on the immediate and 11 words on the delayed task (Thornton, Shapiro, Deria, Gelb, & Hill, 2007). In another study, investigators found a dose-response effect of degree of kidney failure on performance on both the immediate and the delayed CVLT tasks (Kurella, et al., 2004a). Kurella and colleagues (2004a) found that patients with ESRD had the worst verbal recall of all, followed by those with severe chronic kidney disease, those with mild kidney disease, and healthy controls. Healthy individuals performed significantly better on immediate and delayed tests of their verbal recall than did any of the kidney disease groups.

The Benton Visual Retention Test (BVRT; Benton, 1974; Sivan, 1991) is a measure of visual perception, memory, and the ability to recreate viewed images. During the task, participants are shown a series of 10 designs (chiefly line drawings and basic shapes arranged in patterns) for five to ten seconds each and are asked to reproduce the images via recall. Scores are computed by totaling the number of correctly reproduced designs. The BVRT has been used occasionally in samples of patients with kidney disease or ESRD; in one study, researchers found that performance on the task was significantly better after kidney transplant, with an average of 7.14 (*SD* = 2.01) correct reproductions, than while on dialysis, with an average of 5.82 correct reproductions (*SD* = 2.33; Griva, et al., 2006). In another study by the same research group, patients undergoing hemodialysis demonstrated significant improvement on a battery of neuropsychological tests, including the BVRT, from around 2 hours before dialysis to 24 hours after dialysis (Griva, et al., 2003).

Finally, to help avoid some of the issues presented by the MMSE in terms of its biases toward more educated or higher-functioning individuals, the Trail Making Tests A and B (TMT; Reitan, 1958) will also be used to make a baseline assessment of cognitive functioning in the proposed study. Whereas the MMSE is ostensibly verbal, asking respondents to spell words and recall verbal cues (Folstein, et al., 1975; Tombaugh & McIntyre, 1992), the TMT instructs respondents to trace a line connecting a series of numbers in numerical order. In Part A, respondents “connect the dots” between randomly ordered numbers; in Part B, letters are incorporated into the task, requiring respondents to alternate between numbers and letters to complete the chain (1-A-2-B-3-C and so on; Moses, 2004). Faster times to completion indicate better cognitive function; on average, respondents complete the Trails A in about 30 seconds, and Trails B in about 75 seconds. Cognitive impairment is thought to be present at completion times of greater than 78 seconds for Trails A and about 4 minutes for Trails B. The TMT has been used extensively to assess the cognitive abilities of those with neuropsychological dysfunction and neurological damage (Devos, et al., 2011; Miller, 1976) and has demonstrated excellent validity and reliability (Corrigan & Hinkeldey, 1987; Gaudino, Geisler, & Squires, 1995). The TMT has also been used frequently among patients with kidney disease (Bremer, et al., 1997; Brickman, Yount, Blaney, Rothberg, & De-Nour, 1996; Griva, et al., 2003; Griva, et al., 2010; Harciarek, et al., 2009; Jassal, et al., 2006; Lux, et al., 2010; Madero, et al., 2008; O'Connor, et al., 2008; Pereira, et al., 2007; Pliskin, Yurk, Ho, & Umans, 1996).

Measures of individual psychological factors. The Cognitive Depression Inventory (CDI; Kimmel, et al., 1993), a modification of the Beck Depression Inventory (Beck, Steer, & Garbin, 1988) has commonly been used in studies of hemodialysis patients (Kimmel, et al., 1998) and was administered as an assessment of participants’ depressive symptoms. As noted above, many somatic symptoms of depression, such as difficulty sleeping and loss of appetite, overlap with symptoms of kidney failure (Kimmel, 2000; Kimmel, et al., 1993; Smith, et al., 1985). The CDI includes 15 items from the BDI, and excludes those items asking respondents to report their fatigue, sleep, sexual interest, appetite, changes in weight, and general functioning. For the present investigation, the item asking respondents to indicate their level of suicidal ideation was also removed. The CDI asks respondents to report their level of sadness, pessimism, guilt, worthlessness, and other symptoms of depression on a 4-point scale from 0 (not experiencing that symptom at all) to 3 (extremely distressed by that symptom). The CDI has demonstrated adequate reliability in samples of ESRD patients, with a Cronbach's alpha level of 0.74. Research indicates that the CDI may be a better measure of depressive symptoms among kidney failure patients than depression scales that include confounded somatic items. In a study by Kimmel and colleagues (Sacks, Peterson, & Kimmel, 1990), investigators found that scores on the CDI were significantly associated with mortality risk, such that individuals who scored higher on the CDI were more likely to expire over a two-year follow-up period than those with lower CDI scores, though the scores on somatic symptoms of depression did not differ between the groups.

Because a number of psychological traits, particularly locus of control and personality factors such as conscientiousness, have been shown to influence the relationship between social support and adherence to treatment recommendations among patients on dialysis (Gencoz & Astan, 2006; Hoth, et al., 2007; Moran, et al., 1997), participants were administered the condition-specific form of the Multidimensional Health Locus of Control Scale (MHLC-C; Wallston, Stein, & Smith, 1994) as well as the NEO Five-Factor Inventory of Personality (NEO-FFI; Costa & McCrae, 1992). Both the MHLC-C and the NEO-FFI are reliable, valid measures that have been used extensively in both ill and healthy populations. The MHLC-C has been cited over 200 times, and has been frequently used in studies of patients with kidney disease (Billington, Simpson, Unwin, Bray, & Giles, 2008; Bremer, et al., 1997; Pang, et al., 2001). The MHLC-C (Wallston, et al., 1994) contains 18 items in four subscales – Internality, Chance, Doctors, and Other People – rated on a six-point Likert-type scale ranging from 1 (Strongly Disagree) to 6 (Strongly Agree). The MHLC-C asks respondents to indicate the degree to which they believe that they are responsible for their health condition and the degree to which other forces – fate, chance, healthcare providers, or other important persons in their lives – are responsible for their continued health or for aggravations of their medical problems. Sample items include "If my condition worsens, it is my own behavior which determines how soon I will feel better again", "Luck plays a big part in determining how my condition improves", and "The type of help I receive from other people determines how soon my condition improves". The MHLC-C is designed to allow investigators to tailor the specific condition of interest in the measure to their own study population; in the proposed study, "condition" was changed to "kidney disease"; for example, a sample item read "I am directly responsible for my kidney disease getting better or worse".

The NEO-FFI (Costa & McCrae, 1992; McCrae & Costa, 2004) is a 60-item inventory of personality traits on five factors – Conscientiousness, Agreeableness, Neuroticism, Openness, and Extraversion. The NEO-FFI and its predecessors have been used extensively in the literature in community samples as well as in patients with chronic diseases, such as kidney failure (Hoth, et al., 2007; Moran, et al., 1997). "Big Five" personality factors, in particular, Agreeableness, Conscientiousness, and Neuroticism, are among the best-known and most well-established traits associated with health outcomes among both ill and healthy persons (Kern & Friedman, 2008;

Smith & MacKenzie, 2006), and have been shown to be strongly associated engagement in health behaviors (Bogg & Roberts, 2004), including treatment adherence among individuals with chronic diseases (cf. Axelsson, Brink, Lundgren, & Lotvall, 2011; Hill & Roberts, 2011). Specifically, those individuals higher in conscientiousness and agreeableness and lower in neuroticism tend to be more likely to adhere to treatment recommendations than their less conscientious, more neurotic counterparts. The items of the NEO-FFI are rated on a five-point Likert-type scale ranging from 1 (Strongly Disagree) to 5 (Strongly Agree). Sample items include “I often try new and foreign foods” (Openness), “I work hard to accomplish my goals” (Conscientiousness), “I like to have a lot of people around me” (Extraversion), “I try to be courteous to everyone I meet” (Agreeableness), and “When I’m under a great deal of stress, sometimes I feel like I’m going to pieces” (Neuroticism).

Markers of stress and adherence. Individuals undergoing dialysis for ESRD often experience a great deal of psychological and physiological stress (Gurklis & Menke, 1995; Kimmel, 2000). The source of this stress can vary considerably, including aspects of the disease management process itself, particularly fluid and diet adherence (Pang, et al., 2001); the social consequences of treatment for kidney failure can also represent a significant source of stress for these patients (Lok, 1996; Wolcott, et al., 1988). Even mild, daily stresses can have a direct, negative influence on adherence among ESRD patients (Everett, et al., 1995; Hitchcock, et al., 1992). Stress can also have a deleterious impact on cognitive functioning, and declining cognitive abilities can represent a unique stressor in turn (Porter & Landfield, 1998; Sandstrom, et al., 2011; Touyarot, Venero, & Sandi, 2004). Subjective reports of stress were assessed using the electronic diary, detailed below.

Ecological Momentary Assessment. In addition to completing the interview measures described above, participants in the proposed study were also outfitted with a smartphone-based electronic diary system that prompted them at random intervals throughout the day to report on their moods, activities, treatment adherence, cognitive function, and perceived receipt of social support over the course of their week of at-home assessment. Diary programs designed and implemented by our lab have been used with a wide range of ages and a broad population base. More than 100 healthy and depressed individuals have used the present diary program successfully and with an adherence rate around 73%, even when prompts are issued up to 12 times per day over a two to three week period. The program is extremely flexible, capable of elegantly combining single-choice, multiple-choice, sliding-scale, and free-response items into a single assessment, which takes only one to two minutes to complete. The diary program is also capable of collecting information about participants' location using the smartphone's GPS system. When installed on a data- or wi-fi-enabled device, data are uploaded to a secure server within seconds of the completion of an entry; when data service is not available or enabled, data are encrypted and securely stored on the smartphone for later retrieval.

The recurring diary, which signaled participants 5-8 times each day, prompted respondents to report on their current activities, where they were, and what they were doing at the prompt. The diary also prompted participants to report how interesting or pleasurable they found this activity to be, rated on a sliding scale from 0 (not at all pleasurable, boring, unenjoyable) to 100 (exciting, engaging) in 5-unit increments, as well as how effortful they found the activity to be, rated from 0 to 100. The diary next prompted respondents to indicate who they were with at the time of the signal.

The next set of questions prompted participants to indicate their level of cognitive functioning at the time of the prompt. Respondents were asked to indicate how much have they reacted slowly to things that were said or done around them, how much they had difficulty concentrating or thinking, whether or not they became confused at all, and whether or not they found it difficult to make decisions since the last prompt. Each of these items was rated on a 6-point Likert-type scale, and respondents could indicate that they experienced these symptoms "None of the time", "A little of the time", "Some of the time", "A good bit of the time", "Most of the time", or "All of the time". These items were based on the cognitive function subscale of the KDQOL-SF (Hays, et al., 1997; Hays, et al., 1994) and the BDI (Beck, et al., 1988) and map well onto items from clinician-rated scales of transient cognitive dysfunction, such as the Delirium Rating Scale-Revised (Trzepacz, et al., 2001). A series of items then prompted participants to report on their current levels of sadness, tiredness and fatigue, annoyance, anger, restlessness or agitation, loneliness, stress, anxiety, hopelessness, happiness or contentment, optimism, and self-confidence. Each of these items was rated on a sliding scale from 0 to 100 in 5-point increments.

The next set of questions asked participants to report on their current levels of adherence to their ESRD treatment regimen. Respondents may have endorsed that they engaged in any number of activities related to their disease self-management since the last prompt, including checking their blood sugar, checking their blood pressure, taking medication, eating a snack or a meal that fit their diet plan, and eating a snack or a meal that was not on their diet plan. Following this checklist, respondents were prompted to indicate whether or not they had any fluids since the last prompt. If they marked "No", the diary program moved on to the next item. If they marked "Yes", the diary prompted participants to indicate about how much and what kinds of fluid they had consumed since the last signal. After the adherence questions, respondents were prompted to indicate whether they were currently experiencing any physical symptoms, whether related or unrelated to their ESRD. These symptoms were inclusive of those directly related to ESRD (lightheadedness, difficulty breathing) as well as those related to dialysis treatment (thirst, dry mouth, cramps) and unrelated to ESRD treatment (allergies, neck pain).

The next set of questions asked respondents to indicate what kinds of social interactions they had had since the last prompt, and if they had received any disease-related social support in that interval. Respondents were then asked to report the degree to which they felt supported in the moment, rated on a sliding scale from 0 to 100 in 5-point increments. This support could be emotional support, or it could be tangible or advice support, and refers to support in any domain – support for their activities of disease management, or support for things outside their ESRD. Following the general support item, respondents were prompted to indicate the various types of disease-specific support they had received since the last prompt. These items included actions which would traditionally be categorized as health-related social support, as well as those which might be termed health-related social control (Lewis & Rook, 1999; Rook & Pietromonaco, 1987). Items in this question set were "Someone helped you with your medication", "Someone bugged you about taking your medication", "Someone helped you with your diet", "Someone bugged you about what you were eating", "Someone helped you with your fluids", "Someone bugged you about how much fluid you had", "Someone helped you get to or from dialysis", and "Someone listened to your concerns about dialysis or your kidney disease treatment".

In addition to the recurring diary, two special diary entries were prompted each day, one in the morning and one in the evening. The morning diary, which signaled participants for an entry within one hour of their planned wake time, asked respondents to indicate their location, activities, moods, and adherence behaviors as in the recurring diary. In addition, the morning diary also prompted respondents to report on the quantity and quality of their sleep from the night before. Respondents were then asked to indicate if and what kind of support or control they had received for their activities of disease self-management since they got up that morning. Finally, respondents were asked to report how stressful they expected that day to be overall, rated on a sliding scale from 0 to 100 in 5-point increments.

The final diary entry of the day, which signaled participants within 30 minutes of their anticipated bedtime, also prompted participants to report on some special questions in addition to the recurring location, activity, mood, and adherence items. The evening diary first queried respondents about the degree to which they felt their day turned out as expected, and whether, overall, the quality of their social interactions that day was as they expected. The diary then prompted participants to report whether their appetite and thirst that day was more, the same, or less than usual. The next set of questions asked respondents to report on their cognitive functioning, as in the recurring diary, and to report on how their moods have been overall for the day, as well as how their overall social functioning was and the degree to which, overall, they engaged in disease self-management and received help or support for their adherence behaviors. Finally, respondents were prompted to indicate what time they intended to go to sleep that night.

Illustrations of selected diary items can be found in the Appendix.

Design considerations. Modern advances in the technology of microcomputers and cellular communications now allow the development of sophisticated mobile tools for use on cellular phones capable of capturing highly detailed information about individuals' location and activities in their unique social contexts. The ability of mobile devices, particularly smartphones, to describe the ways in which individuals interact with their environment and to deliver content that is sensitive to their locations, habits, and companions represents a unique opportunity to better understand how individuals' feelings, social relationships, and other environmental cues interact to affect their health, well being, and activities of daily living. The use of EMA via smartphone devices may be particularly useful in the context of adherence to treatment for individuals with ESRD because it enables researchers not only to record instances of health behaviors, such as medication use and fluid intake, but also to observe subtle changes in mood, memory, and cognitive function over several days in real time. Additionally, modern smartphones offer consumers the ability to download applications to their devices to keep track of their appointments, monitor their dietary intake, and keep track of blood pressure and glucose levels. However, while there are numerous such applications for patients with diabetes (for example, OnTrack Diabetes, GExperts, Inc., http://www.gexperts.com/; Diabetes Log, LuppTech, http://tech.luppen.com/; Diabetic Management System, Health Vision Solutions, LLC, http://www.diabeticsystem.com/), only one application for ESRD patients appears to be available (KidneyDiet, Pain Free Living, Inc., http://www.kidneydiet.com/).

While some have described the potential advantages to such an approach (Smith, 2011), it appears that the present study was the first to use smartphones in a sophisticated way to collect information from hemodialysis patients about their health behaviors and their activities of disease self-management. Only a few investigators have explored the use of smartphones as a data collection tool in this population; in one study, information about body weight and blood pressure were transmitted via a wearable sensor to a portable digital device (Giacomelli, Munaro, & Rosso, 2011), and in another, patients could access their laboratory records via their mobile phone (Sota, Yamamoto, Hirakawa, Doi, & Yamamoto, 2011). In addition to representing a context-sensitive, ecologically valid way to collect data about behaviors or patterns that may be too subtle or infrequent to capture using retrospective self-report, the use of a smartphone-based EMA system enables investigators to remotely and in real time monitor and improve adherence to the research protocol. Such capabilities have wide-ranging implications for the future design of technology-enabled interventions to improve patient monitoring and engender better disease self-management among individuals with chronic diseases such as ESRD.

Data analyses

The purpose of this study was to examine the relationship between adherence to fluid and diet restrictions, cognitive dysfunction, length of the interdialytic interval, and social support among patients with ESRD undergoing regular renal dialysis. It was expected that 1) patients higher in perceived social support would evidence improved IWG, serum phosphorus, and serum potassium levels and better self-reported adherence to fluid and diet restriction and medication taking compared to those patients lower in perceived support, 2) cognitive dysfunction would be increased as a function of time since dialysis, such that longer interdialytic intervals would be associated with greater cognitive dysfunction, 3) cognitive dysfunction would be associated with markers of poor fluid, diet, and medication adherence, such that greater IWG, greater serum potassium, and greater serum phosphorus would be associated with increased cognitive dysfunction, and 4) social support would moderate the relationship between cognitive function and adherence, such that individuals reporting greater family support would evidence better adherence at high levels of cognitive problems compared to those with less support.

The present study used a within-subjects design in which the relationships between cognitive function, adherence, and social support will be examined across short and long interdialytic intervals with each participant serving as his or her own control. However, data were collected using both interview measures and using ecological momentary assessment via an electronic diary over a period of seven to eight days. Analysis of this type of experience sampling data, in which respondents complete measures several times a day over multiple days, is necessarily complex. Random- and fixed-effect regression models, including mixed models and general estimating equations, with data clustered by person, were used to test the hypotheses that social support would be associated with increased adherence, that cognitive dysfunction would be associated with decreased adherence, that cognitive function would decrease as a function of increased time since dialysis, and that social support would moderate the relationship between cognitive function, adherence, and time since dialysis.

Fixed-effects regression models enable an assessment of the interactions between cognitive function, social support, and adherence over time within each participant to determine whether, for those high in social support, declines in adherence relative to cognitive function and time since dialysis will be minimal, and for those low in social support, these declines are substantial. Fixed-effects models are also able to capitalize on the density and fluid nature of experience sampling data, enabling a determination of whether these patterns of behavior exist above and beyond individual differences in self-reported support, adherence, and cognitive ability, by using each person as his or her own control (Allison, 2005; Whalen, Odgers, Reed, & Henker, 2011), making it possible to control for trait characteristics of the individual (Allison, 2005; Allison & Christakis, 2006; Halaby, 2004).

Fixed-effects regression models have two major assumptions; one, that the dependent variable be measured at least twice, and two, that the independent variables will potentially change across those two time points in the majority of the sample (Allison & Christakis, 2006). In the present study, the dependent variable (adherence to treatment) was measured multiple times in the electronic diary, thus meeting the requirements for fixed-effects regression.

Data were managed and coded using the SYSTAT 13 (Systat Software, Inc., San Jose, CA) and SPSS 21 (IBM, Armonk, NY) statistical packages. Analyses were completed using the SYSTAT 13 and SAS 9.4 (SAS Institute Inc., Cary, NC) statistical packages.

CHAPTER THREE

RESULTS

Characteristics of the sample

Enrollment and retention. Overall, 42 patients were approached about the opportunity to participate in the study or expressed interest in participating to a research team member or clinic staff member. Three interested patients ultimately refused participation. Reasons for refusal included concerns about confidentiality, concerns about using electronic devices, and unwillingness to invest the time required in participating. Three additional patients withdrew from the study before completing all study tasks. Reasons for withdrawal included inability to complete study tasks, concerns about using electronic devices, and unwillingness to invest the time required in completing study tasks. One patient expired before completing study tasks. To date, 35 participants have completed the study protocol or are still enrolled. Thirty-two completed the study protocol. Eight participants provided insufficient data on the electronic diary and were not included in the analysis. Electronic data for two participants were corrupted. Overall, 22 provided adequate data on the electronic diary. Participant enrollment and retention is illustrated in Figure 3.

Description of the selected subsample. Data are reported here for the 22 (Female *n* = 11, Male *n* = 11) subjects who provided adequate data on the electronic diary, unless otherwise indicated. The subsample did not differ significantly from the complete sample in terms of age, gender, education level, employment status, marital status, or language spoken. However, none of the dropped subjects had private insurance. The mean age of participants in the subsample was 44.4 years (*SD* = 16.6 years, Range 18-77). Sixty-three percent of subjects were Hispanic or Latino (*n* = 14, 63.6%); other subjects were Asian or Pacific Islander (*n* = 3, 13.6%), White (*n* = 2, 9.1%), Native American (*n* = 2, 9.1%), or African American (*n* = 1, 4.6%). Five participants were Spanish speakers; the remaining 17 respondents were English speakers. Nine respondents (40.9%) were currently married. Five participants (22.7%) had not completed high school, eight had completed high school (36.4%), four had attended some college (18.2%), and five had a college degree (22.7%). In terms of employment status, five subjects (15.2%) in the subsample were working at least part-time, with one working full time; seven participants (31.8%) were disabled, two (6.1%) were retired, and eight (36.4%) were unemployed or looking for work. All but two subjects (90.9%) had only public insurance; three had only Medicare (13.6%), five had only Medicaid (22.7%), and eleven had Medicare along with other insurance (usually Medicaid; 50.0%).

Data preparation. To determine whether outliers substantially influenced the results of the present investigation, outcomes on variables relevant to the core hypotheses were plotted by subject to assess for extreme values. In general, there were no concerns about anomalous values in the sample. Additionally, not all subjects dialyzed on the same days of the week. To confirm that any differences in outcomes relative to length of the interdialytic interval were not driven by shifts in cognitive functioning, social support, or treatment adherence over different days of the week, or by the different two-day intervals – Saturday/Sunday or Sunday/Monday – experienced by patients on different dialysis schedules, pertinent variables were plotted again by subject and by day of the week. No day-related patterns were detected. Additionally, there did not appear to be any differences in hypothesis-relevant outcomes for patients on the Monday-Wednesday-Friday dialysis schedule as opposed to the Tuesday-Thursday-Saturday schedule.

Descriptive findings: Health status and beliefs about kidney disease. Participants reported that they had been on dialysis for an average of 4.1 years (*SD* = 3.0, Range <1 – 10 years). Four had previously used peritoneal dialysis. Two had previously had a kidney transplant.

Fourteen participants used their own personal transportation to come to dialysis; the remaining subjects used a medical transport van or public transportation. The majority of subjects (*n* = 17) came to treatment alone; two came with a spouse or partner, one with a parent, one with a sibling, and one with a child. All but one subject came for dialysis three times a week; the remaining subject dialyzed four times a week. On average, participants dialyzed for 3.28 hours (*SD* = .33 hours; Median = 3 hours and 15 minutes). In general, participants felt that their dialysis schedule was convenient for them; three subjects reported that dialysis was either too early or too late to suit their schedules. No patients reported skipping dialysis sessions, but seven participants reported difficulties staying for their entire treatment session; six patients had shortened treatment at least once in the past month.

Patients reported very little difficulty taking medications and few reported any side effects. The most common side effects experienced were nausea or other stomach discomfort, and these effects did not affect participants' ability to stick to their medication regimen. However, although they believed fluid restriction is important, on average, patients reported adhering to their fluid restrictions only about half the time, and nearly half of subjects in the sample (*n* = 10) reported some difficulty sticking with their fluid limits. Reasons for failure to limit fluids included inability to control fluid intake, too many temptations, and knowing it was wrong to drink fluids but doing so anyway. Similarly, eleven subjects reported having difficulty controlling their diet, and reported watching their diet only about half the time. Reasons for dietary nonadherence were an inability to avoid unrecommended foods, unwillingness to control food intake, and feeling suppressed by diet restrictions.

Overall, patients in this sample were ambivalent about the restrictions their kidney disease places on them. Scores on the RAAQ (Rushe & McGee, 1998), a measure of general attitudes about diet and fluid restrictions, indicated that participants felt neutral about statements such as "My diet fits into my lifestyle", "My kidney disease diet is too much trouble", and "I feel better on my kidney disease diet". The average score on the RAAQ was 78.7 (out of a possible 130; *SD* = 12.6). Despite this, scores on the RABQ (Rushe & McGee, 1998), an assessment of perceived engagement in adherence behaviors, were generally moderate-to-high (*M* = 81.5 [out of a possible 125], *SD* = 9.1). On average, participants rated their health as "Fair" to "Good" (*M* = 3.0 [out of 5], *SD* = 1.1), and indicated only moderate levels of burden from dealing with the demands of their kidney disease. Patients felt similarly about each of the measures of burden, though the highest burden involved frustrations dealing with kidney disease, followed by feeling like a burden to one's family, time spent dealing with kidney failure and treatment, and interference of kidney disease on patients' lives. Mean levels of burden are shown in Table 2. Patients also reported on the causes of their kidney failure. Four participants reported that their ESRD was caused by diabetes, six by hypertension, and three by both diabetes and hypertension. Other self-reported causes included chronic glomerulonephritis, lupus, hepatitis, pregnancy, cystinosis, and focal segmental glomerulosclerosis. Two patients did not know what caused their kidney failure.

On the whole, patients' kidney failure was caused by a variety of upstream illnesses. Though patients had mixed feelings about their kidney disease treatment, they reported moderately high levels of global treatment adherence.

Descriptive findings: Social support. Respondents reported on their overall level of social support using the MSPSS (Zimet, Dahlem, Zimet, & Farley, 1988). Ratings of perceived availability of general support in this sample were high; the mean global support score was 49.1 (out of 60; *SD* = 7.8), with a mean item value of 4 out of 5 (Agree). Participants appeared to perceive the highest level of available support from significant persons in their lives. The mean rating on items regarding available support from family members was 3.8 (out of 5; *SD* = 1.0); the mean rating of support from friends was 3.8 (*SD* = 1.0), and the mean rating of support from significant others or special persons was 4.4 (*SD* = .7).

Participants also completed a modified version of the DSSQ (La Greca & Bearman, 2002). Overall, participants reported that family members helped them with various disease management behaviors somewhat infrequently, an average of once or twice a month. However, the frequency with which subjects reported receiving disease-specific support was highly variable (*M* = 1.7, *SD* = 1.4, Range 0-5). Participants also ranked how supported they felt when these behaviors were enacted by their family members; overall, perceptions of supportiveness were low, with an average score of "Not Supported" (*M* = -0.2, *SD* = .7, Range -1 to 1). Additionally, items on the DSSQ are grouped into subscales that reflect the receipt and perceived supportiveness of disease-specific support in different treatment domains, including dialysis, diet, fluid, medication, and glucose control for respondents who had comorbid diabetes. Patients received the highest level of support for dialysis, followed by diet, blood glucose monitoring, fluid, and medication. However, the level of supportedness was equally low for activities related to the dialysis procedure, for diet, for fluid, and for medication. These ratings of support of these domain-specific behaviors can be found in Table 3.

Overall, participants indicated high levels of global support but low to modest levels of disease-specific support on interview measures.

Descriptive findings: Individual psychosocial factors. Participants additionally completed a battery of measures assessing mood, personality characteristics, coping styles, and health locus of control. Respondents completed the CDI (Kimmel, et al., 1993), a modification of the Beck Depression Inventory (Beck, Steer, & Garbin, 1988). The present sample was relatively non-depressed, with a mean CDI score of 6.9 (out of possible 45; *SD* = 6.0) and a high score of 20. Personality was assessed in the present sample using the NEO-FFI personality inventory (Costa & McCrae, 1992). Levels of neuroticism, extraversion, openness, agreeableness, and conscientiousness were variable in this sample. On average, levels of neuroticism and extraversion tended to be high; levels of openness to experience, agreeableness, and conscientiousness tended to be low. Mean values on each of these personality spectra, and the criterion scores for each, are illustrated in Table 4.

Finally, health locus of control, or the degree to which patients believe that either they themselves or outside forces are responsible for their kidney disease and its treatment, was assessed using the MHLC-C (Wallston, Stein, & Smith, 1994). The condition-specific form of the MHLC consists of three subscales: Chance locus of control (LOC), Doctor LOC, and Powerful Others LOC. Scores on the MHLC-C were variable in this population; mean levels of orientation toward Chance, Doctor, or Powerful Others in responsibility for changes in kidney-related health are shown in Table 5. In general, patients estimated the bulk of the control for their kidney disease and treatment to be in the hands of chance, followed by doctors and powerful others. Additionally, since LOC is typically characterized in terms of Internal (self-focused) or External (other- or outside force-focused) orientations, items which referred to internal responsibility for the improvement or decrement of ESRD symptoms were grouped together to form an Internal LOC scale, and items which referred to external responsibility for changes in health were grouped together to form an External LOC scale. Average levels of Internal and External orientation were proportionately similar, but patients were somewhat more externally-oriented than internally. Mean values on the Internal and External LOC scales are presented in Table 5.

As a whole, the present sample was relatively non-depressed, high in neuroticism and extraversion, and had a somewhat externally-focused locus of control.

Descriptive findings: Neurocognitive function. A battery of instruments was administered to evaluate cognitive functioning. Participants completed the Mini-Mental Status Examination (Folstein, et al., 1975), the Digit Span task (Wechsler, 1981), the short- and long-term recall subscales of the California Verbal Learning Test (Delis, Kramer, Kaplan, & Ober, 1987, 2000), the Benton Visual Retention Test (Sivan, 1991), and the Trail-Making Tests (Reitan, 1958). MMSE scores below 24 indicate impairment, and scores 17 and below indicate significant cognitive dysfunction (Crum, Anthony, Bassett, & Folstein, 1993). Twenty-three percent of the sample had an MMSE score reflective of cognitive impairment; no patients had a score of 17 or below, though one patient had a score of 18, indicating possibly significant dysfunction. Additionally, cognitive impairment is thought to be present at completion times of greater than 78 seconds for Trails A and about 4 minutes for Trails B. Based on the Trails A, 14% of the sample evidenced cognitive impairment; based on the Trails B, 9% of the sample evidenced impairment. Mean values on each of the neurocognitive assessments in the present sample are provided in Table 6. In all, cognitive functioning in this sample was low, though on average, did not reflect clinically-significant impairment, with the best performance on visual recall, and the worst on verbal recall.

Descriptive findings: Momentary assessment of mood, social support, and health behaviors. Analysis of the EMA data revealed that adherence to the electronic diary protocol was much lower than anticipated. Participants were signaled an average of 59.1[1] (*SD* = 20) times over the course of their assessment period, and made an average of 20.1 (*SD* = 19.3) of prompted entries. The average rate of adherence to prompted entries was 33.4% (*SD* = 25.1%).

While not part of the present design, it was additionally possible for patients to manually make entries to the electronic diary program. Although making such entries was recommended to seven participants for a variety of reasons, described in the Discussion, nearly all patients made a number of these non-prompted entries. On average, patients made 18.8 (*SD* = 13.4) manual (non-prompted) entries in the electronic diary, for an average number of 38.8 (*SD* = 13.3) total diary entries. When manual entries were included, the combined rate of diary completion increased to 81.6% (*SD* = 84.1%). Compared to those who completed more than 65% of their prompted entries, those participants who were less adherent to the diary protocol (*n* = 17) reported significantly greater sadness, restlessness, and hopelessness in the electronic diary, greater slowed reaction time, and more diet-related support. While there were no differences between these two groups in terms of their activities of disease self-management, overall support, or stress ratings, or on their interview measures of global social support or cognitive functioning, such disparities between these groups brings into question the internal validity of the data, discussed in greater detail in the Discussion. However, due to the small sample size, for the purposes of these analyses, all valid entries, both randomly prompted and self-initiated, have been included.

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[1] One participant changed dialysis shifts during his study period and study staff were unable to pick his equipment up as scheduled. Although he was instructed to turn off the study equipment at the end of the assessment period, he did not and continued making entries in the electronic diary for several weeks. His entries have been removed from the count of entries. However, he demonstrated a high rate of adherence to the diary protocol (82.88% of signals) which did not differ significantly from the adherence rate, including manual entries, of the group overall. He did not make any manual entries during this time.

The mean momentary mood levels are shown in Table 7. In general, patients were low in negative mood, with a mean rating of sadness, for example, of 7/100, and loneliness of 14/100; ratings of positive moods – happiness, optimism, and self-confidence – were generally high. Only reports of happiness ($t = 2.8$, $p = .005$) and, to some extent, stress ($t = -1.7$, $p = .098$) differed on dialysis days and non-dialysis days. These mood differences are illustrated in Figure 4. Ratings of overall supportedness were high in this sample; participants rated their momentary general support an average of 72.9 (out of 100; *SD* = 33.6). On average, participants reported relatively few instances of disease-specific support and control, but rates of receipt were highly variable. Patients indicated the highest rate of disease-specific support for diet behaviors, followed by medication, concerns about health and treatment, fluid, and travel to dialysis treatment. Respondents indicated that in 36% of entries, no disease-specific support was received. Frequencies of these instances of disease-specific social support or control are shown in Table 8.

While diary-based ratings of medication support were positively correlated with interview-based assessments of receipt of disease specific support, there were no other significant associations between interview measures of disease-specific support and diary-based measures of disease-specific support, indicating a possible disconnect between global perceived support and actual receipt of support for activities of disease self-management. Correlations between the interview-based and diary measures of disease-specific support are shown in Table 9. In addition to reports of mood and support, participants also reported on their engagement in behaviors of disease self management. The rates of engagement in kidney disease-related behaviors are provided in Table 10. Respondents most frequently endorsed that they had consumed fluids, followed by taking medication, eating recommended foods, checking blood pressure, and eating unrecommended foods. Patients indicated that they had not engaged in any disease-related behaviors in only 16% of entries. On average, when patients consumed fluids, they had between half and most of one glass (*M* = 2.7 [out of 5], *SD* = 1.4). The most commonly consumed fluid was water or ice. Rates of consumption of different fluid types are illustrated in Figure 5.

Overall, momentary reports of cognitive dysfunction were minimal in this sample. Mean levels of cognitive dysfunction across days are shown in Table 11. Higher numbers indicate more cognitive dysfunction; overall, levels of cognitive dysfunction were below 1, or between "None of the time" and "A little of the time". The highest level of cognitive dysfunction was trouble thinking, with an average rating of 0.4 out of 5, followed by slowed reaction time, confusion, and difficulty making decisions.

Descriptive findings: Clinical measures of treatment adherence. Potassium, phosphorus, and IWG values were collected from patient medical records over the six month period surrounding the study assessment period. Weight values were reported each time a patient came to clinic for dialysis. On average, patients gained 3.11kg (*SD* = .90kg) between dialysis sessions. Weight gain following the two-day interdialytic interval (*M* = 3.76kg, *SD* = 1.07kg) was significantly greater than over the one-day interval (*M* = 2.79kg, *SD* = .85kg; *t* = -77.04, *p* < .0001).

Potassium, phosphorus, and other mineral and solute levels were collected from patients monthly. The mean level of potassium over the period of interest was 6.62mg/dL (*SD* = 8.73mg/dL); the mean level of serum phosphorus was 5.26mg/dL (*SD* = 1.51mg/dL). Target potassium values should be between 2.5 and 5mg/dL. Ten participants (45.45%) of the sample had mean potassium levels within the target range; 12 (54.55%) had mean levels outside the target range. Target values for phosphorus are between 3.5 and 5mg/dL; 9 participants (40.91%) had phosphorus values within the target range, and 13 (59.09%) had values outside the target range.

In general, objective markers of treatment adherence – high interdialytic weight gain, a large proportion of patients with serum mineral levels outside the acceptable range – indicate that disease self-management was relatively poor in this sample. Rates of engagement in adherence behaviors, shown in Table 10, similarly indicate that the level of treatment adherence in this sample was moderate.

Hypothesis 1: Relationships between social support and adherence

It was hypothesized that patients higher in perceived social support would demonstrate better self-reported adherence to both objective and subjective measures of fluid and diet restriction and medication taking compared to those patients lower in perceived support. Results indicate that disease-specific social support, but not overall support, was associated with self-reported adherence to activities of disease self-management.

Relationships between interview-based measures of support and adherence. Participants completed two primary interview-based measures of social support, the MSPSS (Zimet, Dahlem, Zimet, & Farley, 1988) and the modified DSSQ (La Greca & Bearman, 2002), and one interview measure of overall perceived level of engagement in behaviors of disease self-management, the RABQ (Rushe & McGee, 1998). Some measures of support were associated with reports of adherence, but in the opposite of the expected direction; global support scores significantly predicted lower scores on the interview measure of treament adherence ($\beta = -0.2$, *SE(B)* = .03; $p < .0001$), as did perceived supportiveness of interview-based disease-specific support ($\beta = -0.1$, *SE(B)* = .3; $p < .0001$).

Relationships between interview-based measures of support and momentary reports of adherence. Interview assessments of global social support were not significantly predictive of good diet behavior, bad diet behavior, fluid consumption, quantity of fluids consumed, or medication taking as reported in the electronic diary (all *p*s > .12). However, whereas general perceived availability of support was not predictive of engagement in disease-related health behaviors, interview measures of disease-specific support were associated with diary reports of adherence to behaviors of disease self-management in some domains. For instance, frequency of family members' engagement in support was associated with a decreased likelihood of drinking fluids (*OR* = 0.7, 95% CI = 0.5-1.0; *p* = .034), and with lower quantities of fluid consumed (β = -0.4, *SE(B)* = 0.2, *p* = .01). However, in some cases, family members' more frequent engagement in support behaviors was associated with poorer adherence; more frequent support for medication was predictive of less frequent medication taking (*OR* = 0.5, 95% CI = 0.3-0.8; *p* = .002).

The degree to which participants found their family members' disease-specific support behaviors supportive was also predictive of self-reported engagement in those behaviors in the electronic diary in some domains of adherence. However, in some cases, greater supportiveness was associated with lower adherence. Feeling more supported by family members' supportive behaviors overall was associated with a decreased likelihood of eating foods on the kidney disease diet (*OR* = 0.6, 95% CI = 0.5-0.8;, *p* = .0002) and medication taking (*OR* = 0.5, 95% CI = 0.2-1.1; *p* = .004). Encouragingly, increased feelings of supportedness for family members' engagement in fluid-specific supportive behaviors was associated with decreased likelihood of fluid consumption (*OR* = 0.4, 95% CI = 0.2-0.8; *p* = .002) and with lower fluid quantity (β = -.4, *SE(B)* = .1, *p* = .009). It is possible that this reflects a disconnect between patients' global perceptions of support and their actual engagement in behaviors or disease self-management; however, the low rate of adherence to prompted diary entries makes it possible that this discrepancy was driven by the inaccuracy of respondents' reports about their own behavior.

Relationships between momentary assessments of support and adherence. Mean ratings of momentary support were high overall for this sample, with an average rating of 72.93 (out of 100; *SD* = 33.59). Ratings of momentary support were significantly correlated with interview ratings of support ($r = .282$, $p < .0001$) but not with good diet behavior, poor diet behavior, quantity of fluid consumed, however (all *p*s > .18).

Participants reported receiving a moderate level of disease-specific support, shown in Table 8. However, although the effect sizes were moderate, diary assessments of disease management behaviors were not significantly correlated with interview assessments of perceived treatment adherence. The fact that all correlations were positive in direction indicates a possible disconnect between patients' perceived treatment adherence and their actual engagement in behaviors of disease self-management. For example, high scores on the RABQ indicate better perceived adherence, whereas higher scores on fluid quantity indicate greater fluid consumption. Correlations between the RABQ and diary reports of fluid, diet, and medication behaviors are shown in Table 12. The strongest correlation was between RABQ score and fluid quantity ($r = .57$), suggesting that higher perceived overall treatment adherence is counterintuitively associated with greater fluid consumption.

Contrary to overall momentary support, diary reports of disease-specific support were significantly associated with engagement in disease management behaviors in some domains. Although support for diet adherence was not associated with a lesser or greater likelihood of eating unrecommended foods, reports of receiving help with dietary adherence since the last diary entry were associated with a dramatically greater likelihood of consuming a meal or snack that did fit the kidney disease diet (*OR* = 13.1, 95% CI = 8.2-21.1; $p < .0001$). Medication support was associated with a slightly, though non-significantly, greater likelihood of medication taking (*OR* = 3.2, 95% CI = 0.8-12.7; $p = .09$). Unfortunately, fluid-specific support was not as strongly associated with positive fluid behaviors (all *p*s > .71).

To determine whether disease management-specific support was particular to a given domain of adherence, each set of relationships – diet support/fluid consumption, diet support/medication taking, fluid support/diet, fluid support/medication taking, medication support/diet, medication support/fluid consumption – were tested. However, it appears that any benefit of disease-specific support was also domain specific. Medication taking was the only domain of treatment adherence influenced by disease-specific support in other domains; receipt of diet-specific support was associated with a far greater likelihood of medication taking (*OR* = 11.0, 95% CI = 3.4-35.2; $p < .0001$). As above, such relationships may have been driven by a divergence in these constructs, or by qualitative differences in responses prompted by the electronic diary versus those initiated by respondents.

Relationships between social support and objective measures of adherence. Results indicate that higher levels of support of all types and in several domains was associated with poorer objective measures of fluid adherence – that is, greater weight gain between dialysis sessions. The strongest of these relationships was found between interview-based ratings of supportedness and IWG, followed by interview-based global ratings of support, interview ratings of received support, and momentary ratings of overall support. Surprisingly, the weakest of these relationships was between momentary reports of receipt of fluid support and interdialytic weight gain. These findings are illustrated in Table 13. However, support was less consistently associated with phosphorus or potassium levels. Receipt of any disease-specific support was associated with more than five times the odds of having phosphorus levels outside the acceptable range, whereas there was a trend toward better phosphorus adherence associated with receiving diet support. Although interview-based measures of support were more strongly associated with interdialytic weight gain, interview ratings of support appeared to have a negligible effect on objective markers of adherence to diet and medication. These findings are illustrated in Table 14.

In general, the relationship between support and adherence to treatment was highly variable, and depended on the type and parameter of support assessed, as well as the domain of disease self-management. Overall, though, disease-specific support appeared to be more tightly connected to engagement in behaviors of treatment adherence than was global ratings of perceived social support.

Hypothesis 2: Relationships between momentary reports of cognitive functioning and the interdialytic interval

It was hypothesized that diary reports of cognitive function (i.e., memory, concentration, decision-making) would decline as a function of time since last dialysis, such that longer, two-day interdialytic intervals would be associated with greater cognitive dysfunction compared to one-day intervals. In particular, it was expected that cognitive functioning would be worst on day two of the two-day interval as compared to the one-day intervals.

Although participants did indicate some degree of cognitive dysfunction in the electronic diary, these reports were not consistently correlated with scores on the clinical measures of neurocognitive functioning. Better performance on the digit span task, for instance, was associated with reports of better reaction time in the electronic diary. Worse performance on the trail-making test was associated with slower reaction time and greater confusion. However, there were no other significant relationships between clinical assessments of cognitive function and momentary reports of impairment. Correlations between the diary assessments of cognitive functioning and clinical assessments can be found in Table 15. Reports of cognitive dysfunction in the electronic diary were also compared with reports of cognitive dysfunction over the past four weeks with the same items on the KDQOL. Items were not significantly correlated with one another, indicating a disconnect between patients' global perceived cognitive dysfunction and their actual experiences of cognitive dysfunction. Of the three items which appear on both the source instrument and in the electronic diary, ratings of confusion were most strongly related to one another, but the correlations between ratings of slowed reaction time and trouble thinking or concentrating on the interview measure and the electronic diary were negligible. Correlations between the source items and the diary items can be found in Table 16. Additionally, a paired-samples t-test indicated that scores on the one-time assessment of cognitive dysfunction on the KDQOL were significantly higher than ratings of cognitive dysfunction in the electronic diary. The largest difference was between interview- and diary-based ratings of slowed reaction time, followed by confusion and trouble thinking. Differences in scores between the interview measure and the momentary measure of cognitive functioning can be found in Table 17.

Diary reports of cognitive functioning did differ somewhat between dialysis days and non-dialysis days for some parameters of functioning. There did not appear to be any differences in reaction time, trouble thinking, or decision making on dialysis days as compared to non-dialysis days (all *p*s > .28). However, contrary to expectations, confusion was greater on dialysis days (*M* = .18, *SD* = .70) than on non-dialysis days (*M* = .08, *SD* = .02; $t = 2.33$, $p = .02$). There did not appear to be any differences in cognitive functioning on any one-day interdialytic interval days compared to dialysis days.

There were minimal differences in cognitive functioning on day 2 of the two-day interdialytic interval compared to the one-day IDI. Momentary reports of trouble thinking, confusion, and difficulty making decisions did not differ significantly on Sundays or Mondays as compared to other IDI days during the week-long at-home assessment period (all *p*s > .22). However, counter to our hypothesis, reaction time was worse on the one-day IDIs (*M* = .29, *SD* = .05) than on day 2 of the two-day IDI (*M* = .09, *SD* = .06; *t* = -2.65, *p* = .009).

Because of the low variability in scores on the diary reports of cognitive functioning, the cognitive function items were dichotomized to reflect either the presence or absence of cognitive dysfunction in a given diary entry. Analyses were repeated to determine if the presence of any slowed reaction time, trouble thinking, confusion, or difficulty making decisions was greater on interdialytic days than dialysis days, or on two-day IDIs compared to one-day IDIs. Contrary to expectations, results indicate that the presence of any cognitive dysfunction was significantly greater on the one-day interdialytic days (*M* = .22, *SD* = .42) than on day 2 of the two-day IDI (*M* = .12, *SD* = .32; *t* = -2.51, *p* = .013). This effect was driven primarily by differences in slowed reaction time on the two-day IDI (*M* = .05, *SD* = .21) and on the one-day interdialytic interval (*M* = .17, *SD* = .02; *t* = -3.92, *p* < .0001), and to some extent by the higher levels of trouble thinking on the one-day (*M* = .19, *SD* = .39) versus the two-day IDI (*M* = .11, *SD* = .32; *t* = -1.90, *p* = .059). There were no differences in confusion or difficulty making decisions between the two-day and one-day IDIs.

Cognitive functioning may be influenced by age, education level, or employment status, and it was possible that any shifts in cognitive functioning over the interdialytic interval were due to these individual factors, rather than factors related to dialysis or interdialytic changes. In the present sample, however, these factors were not independently, significantly associated with cognitive functioning across days, though there was a trend toward improved cognitive functioning for those with more education (*p* = .057). Nevertheless, to account for any possible conflation, mixed models, controlling serially for age, education, and employment status were run to determine if these factors accounted for the difference in cognitive functioning reported on the one-day IDIs and the two-day IDIs. None of these variables demonstrably reduced the effect of IDI on cognitive dysfunction.

Hypothesis 3: Relationships between cognitive functioning and adherence

It was expected that cognitive dysfunction would be positively related to greater IWG, mean levels of serum potassium and phosphorus outside the target range, as well as poorer self-reported engagement in behaviors of disease self-management over the one-week at-home assessment period. In general, measures of cognitive functioning were inconsistently related to behaviors of treatment adherence.

Relationships between clinical measures of neurocognitive functioning and self-reported adherence. The Mini Mental Status Examination (MMSE; Folstein, Folstein, & McHugh, 1975) is considered the gold standard assessment of clinically-relevant cognitive functioning. In the present sample, MMSE scores were quite low; the mean MMSE score for this sample was slightly above the clinical cutoff of 23, and 23% of the sample had a score of 23 or below. MMSE scores were not predictive of diet behavior, fluid quantity, or medication taking (all *p*s > .21). However, individuals with higher MMSE scores had somewhat lower odds of consuming fluids during the one-week assessment period (*OR* = 1.13, 95% CI = 1.0-1.3; *p* = .065). None of the other clinical measures of neurocognitive impairment were significant predictors of any self-reported engagement in activities of disease self-management. However, it is possible that the adherence-relevant diary items were not the best assessment of engagement in these health behaviors, or that the present results are biased by the high number of self-initiated entries to the electronic diary.

Relationships between diary assessments of cognitive functioning and self-reported adherence. Diary-based assessments of cognitive functioning, including the degree to which participants experienced trouble thinking or concentrating, confusion, slow reaction time, and difficulty making decisions were variously predictive of adherence behaviors in several domains. Contrary to expectations, higher levels of trouble thinking were associated with a decreased likelihood of consuming fluids (*OR* = 0.6, 95% CI = 0.5-0.8; *p* = .0004), but not with any other adherence behaviors. Greater confusion was also unexpectedly associated with a lower likelihood of fluid consumption (*OR* = 0.6, 95% CI = 0.4-0.9; *p* = .0093). Slowed reaction time was associated with lower fluid quantity consumed as well (β = -.23, *SE(B)* = .11; *p* = .035), and was associated with a trend toward engagement in good diet behavior (*OR* = 1.3, 95% CI = 1.0-1.7; *p* = .08).

Relationships between clinical measures of neurocognitive functioning and objective measures of adherence. Standard measures of cognitive functioning significantly predicted average interdialytic weight gain, though the direction of the relationship differed for different parameters of cognitive functioning. For instance, higher scores on the MMSE, which indicate better overall cognitive functioning, were predictive of greater IWG, as were higher scores on the California Verbal Learning Test. Higher scores on the digit span tasks and the Benton Visual Retention Test were also associated with lower IWG. However, higher scores on the trail-making tests, which indicate poorer cognitive functioning, were associated with greater IWG. These values are presented in Table 18.

Contrary to expectations, clinical measures of cognitive functioning were not significantly associated with greater or lower odds of having average serum potassium or phosphorus levels outside the acceptable range. These findings are illustrated in Table 19.

Relationships between diary assessments of cognitive functioning and objective adherence. Diary measures of momentary cognitive functioning were somewhat consistently associated with mean levels of interdialytic weight gain such that greater cognitive dysfunction – higher ratings of slowed reaction time, confusion, and difficulty making decisions – were all significantly associated with higher IWG. The strongest association was found between slowed reaction time and interdialytic weight gain, followed very closely by the effects of difficulty making decisions and confusion on IWG. However, trouble thinking or concentrating did not significantly predict average IWG across six months. These findings can be found in Table 20. Conversely, cognitive dysfunction as measured in the electronic diary was not significantly associated with a greater likelihood of having potassium or phosphorus levels outside the acceptable range. Across all parameters, the influence of momentary reports of cognitive dysfunction on the likelihood of having mineral levels outside the acceptable range was negligible. The effects of dysfunction in various cognitive domains on objective measures of diet, fluid, and medication adherence are shown in Table 21.

While serum levels of potassium, phosphorus, and other minerals were collected from patients biweekly or monthly, each hemodialysis patient was weighed before and after each dialysis session to determine their interdialytic weight gain and assess the utility of dialysis to remove excess fluids and achieve a manageable “dry” weight. Measures of slowed reaction time, trouble thinking, confusion, and difficulty making decisions were not significantly predictive of same-day IWG. However, fixed-effect analyses indicate that confusion predicted next-session

IWG at a trend level of significance, but contrary to expectations, greater confusion tended to be associated with lower IWG (*t* = -1.81, *p* = .0763). No other parameters of cognitive functioning were associated with significantly greater or lower interdialytic weight gain over the subsequent IDI.

Overall, the influence of cognitive dysfunction on adherence to treatment varied considerably depending on the parameter of cognitive functioning and the domain of adherence assessed. On average, however, greater cognitive dysfunction was associated with improved markers of treatment adherence.

Hypothesis 4: Effects of cognitive functioning on discrepancies between objective and subjective adherence

It was hypothesized that cognitive dysfunction would be associated with greater discrepancies in self-reported adherence compared to objective measures of adherence. In order to determine whether or not a discrepancy was present between the clinical measure of adherence, including IWG and having mean serum phosphorus and potassium levels outside the acceptable range over six months, and self-reported measures of adherence, including the rate of fluid consumption, the quantity of fluid consumed, instances of diet adherence and non-adherence, and the rate of medication taking, a standardized score was computed for each of these factors. Self-reported adherence measures in each domain were then subtracted from objective measures in that domain (fluid quantity and consumption from IWG; diet and medication taking from potassium and phosphorus levels outside the acceptable target range). For fluid, positive scores indicate a score above the mean; negative scores indicate a score below the mean. For mineral levels, standardized rates of engagement in medication or diet behavior were subtracted from a binary score indicating whether the patient's potassium or phosphorus level was within the acceptable range. Rates of reported medication taking and diet behavior were the same; consequently, only one discrepancy score was computed between diet behavior and medication taking and potassium and phosphorus levels, respectively.

On average, discrepancies were not large. Sizes and ranges of such discrepancies are illustrated in Table 22. The largest discrepancy was between potassium level and rates of diet and medication adherence, followed by diet/medication and phosphorus discrepancies and IWG and fluid discrepancies. Values are in standard deviations from the mean. Results indicated that, for some parameters of momentary cognitive functioning, there were significant discrepancies between clinical measures of treatment adherence and self-reported engagement in activities of disease self-management. Slowed reaction time, trouble thinking or concentrating, confusion, and difficulty making decisions were all associated with large discrepancies in fluid consumption and IWG values. However, cognitive dysfunction did not appear to drive discrepancies between potassium or phosphorus levels and self-reported diet or medication adherence, nor did cognitive function appear to play a substantial role in driving any differences between IWG values and self-reported quantity of fluid consumed. Such associations are shown in Table 23.

Hypothesis 5: Mediating effect of cognitive function on the relationship between the interdialytic interval and treatment adherence

It was hypothesized that cognitive dysfunction would account for a portion of the relationship between the length of the interdialytic interval and adherence to treatment. Baron and Kenny’s (1986) steps for establishing mediation were used to determine if any effect of IDI length on treatment adherence could be explained by any parameters of cognitive dysfunction. First, the relationship between IDI length and any domains of treatment adherence was established. It did not appear that self-reported fluid consumption or quantity of fluid consumed differed on the two-day day 2 IDI as compared to the one-day IDIs. Contrary to hypotheses, both medication taking and good diet behavior were more frequent, rather than less frequent, on day two of the two-day IDI as compared to the one-day IDIs. The results of this step of the mediating analyses are shown in Table 24.

Second, the relationship between length of the IDI and any parameters of cognitive functioning, as measured by the electronic diary, was established. As noted above, reaction time was worse on the one-day IDIs (*M* = .29, *SD* = .05) than on day 2 of the two-day IDI (*M* = .09, *SD* = .06; *t* = -2.65, *p* = .009). Additionally, the presence of any cognitive dysfunction was significantly greater on the one-day interdialytic days (*M* = .22, *SD* = .42) than on day 2 of the two-day IDI (*M* = .12, *SD* = .32; *t* = -2.51, *p* = .013), due primarily to differences in slowed reaction time on the two-day (*M* = .05, *SD* = .21) and on the one-day interdialytic interval (*M* = .17, *SD* = .02; *t* = -3.92, *p* < .0001), and to some extent by the higher levels of trouble thinking on the one-day (*M* = .19, *SD* = .39) versus the two-day IDI (*M* = .11, *SD* = .32; *t* = -1.90, *p* = .059).

Third, the relationship between cognitive dysfunction and treatment adherence was established. As noted previously, higher levels of trouble thinking were associated with a decreased likelihood of self-reported fluid consumption (*OR* = 0.6, 95% CI = 0.5-0.8; *p* = .0004); greater confusion was also unexpectedly associated with a lower likelihood of fluid consumption (*OR* = 0.6, 95% CI = 0.4-0.9; *p* = .0093). Slowed reaction time was associated with lower fluid quantity consumed as well (*β* = -.23, *SE(B)* = .11; *p* = .035), and with a slightly greater likelihood of engaging in good diet behavior (*OR* = 1.3, 95% CI = 1.0-1.7; *p* = .08).

Of each of these binary relationships, the only potential mediating relationships – one in which all significantly associated factors appear at all three steps – is the association between

IDI, slowed reaction time, and engagement in good diet behavior. To complete the final step of the mediation analysis, the influence of IDI length on diet behavior was repeated, controlling for reaction time. Interestingly, rather than reducing or eliminating the influence of IDI on diet behavior, the inclusion of reaction time appeared to enhance the relationship between IDI and eating recommended foods, reducing the *p* value from .050 to .034. The results of the mediation analysis are shown in Table 25. The mediating model is illustrated in Figure 6.

Hypothesis 6: Interactions between cognitive functioning, treatment adherence, and social support

It was hypothesized that social support would moderate the relationship between cognitive function and adherence, such that individuals reporting greater support would evidence better treatment adherence, even at high levels of cognitive dysfunction, particularly over the longer interdialytic interval. However, it did not appear that the interaction between support and cognitive functioning significantly predicted engagement in behaviors of treatment adherence, including fluid consumption, diet behavior, or medication taking.

Exploratory findings: Associations between personality factors, individual psychological experiences, and health locus of control and cognitive functioning, social support, and adherence

Individual difference factors, such as neuroticism and conscientiousness (Christensen & Smith, 1995; Wiebe & Christensen, 1997) and health locus of control have been shown to account for some of the variance in treatment adherence (Schneider, et al., 1991). Consistent with other researchers' findings, neuroticism was significantly positively associated with objective measures of adherence, including average IWG ($r = .18$), both one-day ($r = .13$) and post-two-day IDI IWG ($r = .25$), and having serum potassium ($r = .49$), and serum phosphorus levels (*r* = .42; all *p*s < .0001) outside the acceptable range. As expected, conscientiousness was significantly negatively associated with each of these objective measures of adherence – with mean IWG (*r* = -.41), one-day IWG (*r* = -.39), post-two-day IDI IWG (*r* = -.41), potassium (*r* = -.30), and phosphorus levels (r = -.22; all ps < .0001). However, these personality characteristics were not as consistently associated with self-reported engagement in behaviors of disease management. Contrary to expectations, neuroticism was significantly, negatively associated with the self-reported quantity of fluid consumed (*r* = -.18, *p* = .016), while conscientiousness was associated with greater fluid quantity over the one-week assessment period (*r* = .24, *p* = .001). Neuroticism was, however, associated with fewer reports of medication taking (*r* = -.10, *p* = .012). There were no other significant associations between neuroticism or conscientiousness and self-reported treatment adherence.

To determine whether these personality characteristics influenced the effect of support or cognitive functioning on objective measures of adherence, analyses were repeated, controlling serially for neuroticism and conscientiousness. The inclusion of neuroticism or conscientiousness did not demonstrably influence any of the relationships between MSPSS scores, DSSQ scores, self-reported receipt of overall disease-specific support, receipt of fluid-specific support, receipt of diet-specific support, or medication-specific support and any of the objective adherence outcomes, including average IWG and having average serum potassium and phosphorus levels outside the target range. Likewise, conscientiousness and neuroticism did not appear to account substantially for the relationship between either clinical measures of cognitive functioning or diary measures of cognitive impairment and objective measures of treatment adherence.

Additionally, experiences of depressive symptoms (Kimmel, 2002; Kimmel, et al., 2003; Kimmel, Peterson, et al., 1998) have been associated with poorer treatment adherence, though somewhat inconsistently (Khalil & Frazier, 2010), among hemodialysis patients. Cognitive problems are also common among individuals high in depressive symptoms (Cohen, Weingartner, Smallberg, Pickar, & Murphy, 1982). For this reason, the level of depressive symptoms was explored as a potential contributor to the relationship between cognitive functioning, social support, and subjective and objective measures of adherence to treatment. Symptoms of depression as measured by the CDI (Kimmel, et al., 1993) were significantly correlated with average IWG ($r = .10$) as well as having mean serum phosphorus ($r = .57$) and potassium ($r = .46$; all ps $< .0001$) outside the acceptable range. Higher scores on the CDI were also significantly correlated with more self-reported fluid consumption ($r = .11$, $p = .023$), fewer good diet behaviors ($r = -.08$, $p = .015$), and less medication taking behavior ($r = -.10$, $p = .005$), but was conversely related to lower quantity of fluid consumption ($r = -.31$, $p < .0001$). CDI scores were not associated with frequency of eating unrecommended foods.

Level of depressive symptoms was also associated with most interview-based markers of social support and with some measures of momentary receipt of support. However, contrary to expectations, depression scores were positively correlated with interview-based global support scores ($r = .18$), received disease-specific support ($r = .52$), and with perceived supportiveness of disease-specific support behaviors ($r = .14$; all ps $< .0001$). Depressive symptoms were also positively correlated with reports of receipt of any disease-specific support in the electronic diary ($r = .09$, $p = .001$), and negatively correlated with reports that no disease specific support had been given in the previous interval ($r = -.07$, $p = .006$). As above, analyses of the effect of support or cognitive functioning on objective and self-reported measures of adherence were repeated, controlling serially for depression scores. Depressive symptoms did not appear to demonstrably influence these relationships in the present sample.

Health-related locus of control has also been shown to play a role in treatment adherence among patients on hemodialysis (Friend, Hatchett, Schneider, & Wadhwa, 1997; Schneider, et al., 1991). Contrary to expectations, in the present sample, both external ($r = .07$, $p = .024$) and internal health locus of control were positively associated with average IWG ($r = .15$, $p < .001$). Consistent with others' findings, however, higher internal LOC was associated with having mean serum potassium levels within the acceptable range (r = -.22, p < .0001). However, external LOC was not significantly correlated with potassium levels; locus of control was not associated with phosphorus levels. Consistent with the expected direction, internal locus of control was significantly, negatively associated with self-reported fluid quantity ($r = -.22$, $p = .001$), but not with any other self-reported engagement in behaviors of disease self-management. External health locus of control was correlated positively with rate of fluid consumption ($r = .15$, $p = .005$) and fluid quantity ($r = .18$, $p = .008$), but was unexpectedly positively correlated with good diet behavior ($r = .12$, $p = .003$) and with medication taking ($r = .15$, $p < .0001$). Despite these associations, health locus of control did not appear to account substantially for the relationships between cognitive functioning, social support, and treatment adherence.

Finally, as noted above, stress has been shown to be associated with poorer adherence (Everett, Brantley, Sletten, Jones, & McKnight, 1995; Hitchcock, Brantley, Jones, & McKnight, 1992; Wolcott, Nissenson, & Landsverk, 1988). Results from the present sample indicate that self-reported levels of stress were low over the week-long at-home assessment period (*M* = 9.54 [out of 100], *SD* = 16.69). However, stress was somewhat higher on dialysis days (*M* = 10.71, *SD* = 17.10) as compared to non-dialysis days (*M* = 8.63, *SD* = 16.33; $t = -1.66$, $p = .096$). Additionally, stress was slightly higher on day two of the two-day IDI (*M* = 12.12, *SD* = 21.01) than on the one-day IDIs (*M* = 7.80, *SD* = 14.48; $t = -1.91$, $p = .058$). Overall, higher levels of stress were associated with greater mean IWG values ($r = .28$), as well as with having potassium ($r = .35$) and phosphorus levels ($r = .31$; all ps < .0001) outside the acceptable range. Diary ratings of stress were not significantly predictive of diary ratings of fluid consumption, fluid quantity, diet behavior, or medication taking. As might be expected, however, stress was significantly predictive of some parameters of cognitive functioning as reported in the electronic diary. Mixed models indicated that stress was associated with higher ratings of slowed reaction time, confusion, and difficulty making decisions. Stress was not associated with increased reports of trouble thinking or concentrating. These results are shown in Table 26.

Despite these associations, including stress in models testing the effects of various parameters of cognitive dysfunction on engagement in behaviors of disease self-management did not appear to reduce any associations between slowed reaction time, confusion, or decision difficulty and reports of fluid consumption, fluid quantity, diet behavior, or medication taking.

In general, any effects of personality, locus of control, depressive symptoms, and reports of stress on cognitive dysfunction and adherence were in the expected directions and were consistent with other researchers' findings. However, none of these individual difference factors appeared to influence the relationships between social support, cognitive dysfunction, and adherence to treatment in the present sample.

Summary of the results

It was hypothesized that higher levels of social support would be associated with better fluid and diet restriction and with lower objective levels of treatment adherence. Results of the present study indicate that disease-specific support, particularly diet support, but not global measures of social support, are associated with better diet behavior. Social support was not strongly or exclusively associated with fluid behavior. It was additionally hypothesized that cognitive function would decrease as time since dialysis increased, and would be poorest over the two-day interdialytic interval. While cognitive dysfunction did differ over the interdialytic interval, these shifts were in the opposite of the anticipated direction, with cognitive functioning improving as time since dialysis increased. It was also expected that cognitive dysfunction would be related to poorer objective and subjective measures of adherence, including higher interdialytic weight gain and serum phosphorus and potassium levels outside the acceptable range. Contrary to expectations, cognitive dysfunction was associated with better, rather than worse, self-reported treatment adherence. Though it was anticipated that cognitive function would mediate the association between length of time since dialysis and engagement in behaviors of disease self-management, cognitive functioning did not account for the relationship between length of the interdialytic interval and treatment adherence. Finally, it was hypothesized that social support would moderate the relationship between cognitive functioning and treatment adherence. However, the effect of cognitive functioning on adherence to treatment was not influenced by receipt of social support.

CHAPTER FOUR

DISCUSSION

End-stage renal disease is a progressive, terminal illness that affects hundreds of thousands of individuals in the U.S. (USRDS, 2010). Although the contribution of psychosocial factors to the onset or advancement of kidney failure is not entirely clear, engagement in behaviors of disease self-management are critical for ESRD patients, for whom failing to adhere to treatment is associate with significant morbidity and a dramatically increased risk of morbidity. ESRD is enormously burdensome (Christensen, 1997; Christensen & Ehlers, 2002); in addition to regular attendance at dialysis treatment, patients must restrict fluid intake and eat a limited diet, as well as take numerous medications to control mineral and fluid levels (Cummings, et al., 1982; Denhaerynck, et al., 2007). Many demographic, psychological, social, and environmental factors play a role in determining ESRD patients' degree of adherence to the demands of their treatment. In the present investigation, it was hypothesized that social support, neurocognitive function, and the length of the interdialytic interval would interact to predict adherence to treatment, such that social support would buffer declines in adherence due to increased cognitive dysfunction over longer times since last dialysis.

Results indicate that, in this relatively young, non-depressed, primarily Hispanic sample, disease-specific support, particularly diet support, was associated with better self-reported diet and medication adherence, but overall poorer objective levels of adherence to diet and fluid restrictions. However, while better baseline cognitive function was generally associated with better objective indicators of adherence, better momentary cognitive functioning was associated with poorer adherence. Additionally, contrary to hypotheses, cognitive functioning was worse on the one-day interdialytic intervals than on the longer, two-day interval, even when controlling for influential factors such as age, education level, and employment status. Overall, cognitive functioning did not appear to mediate the relationship between length of the interdialytic interval, as hypothesized, nor was there a significant effect of the interaction between social support and cognitive functioning on this relationship.

Still, these findings should be interpreted with caution. Adherence to the electronic diary protocol, on which the core hypotheses hinge, was unexpectedly poor in this sample. Though there is little agreement as to a standard, acceptable level of adherence to EMA protocols, in previous studies in our lab, rates of diary compliance are around 75%. In the present sample, adherence to prompted entries was only 33%. *Post hoc* analyses were undertaken to determine whether those respondents with better adherence to prompted entries differed in any important ways from those who had poorer adherence to the electronic diary. It appears that non-compliers, defined as those who completed fewer than 65% of prompted entries (n = 17) reported significantly greater sadness, restlessness, and hopelessness in the electronic diary and, critically for the present hypotheses, slower reaction time and greater diet support. There were no differences between these two subgroups in terms of their health behaviors, overall supportedness, or stress ratings, nor were there any differences between the subgroups on their interview measures of global social support or their MMSE scores.

As mentioned above, most participants made a number of self-initiated entries to the electronic diary. There are many critical methodological and analytical differences between randomly-prompted entries and event-prompted or self-initiated entries to experience sampling assessments, discussed below. Under ideal circumstances, subjects whose adherence to the diary protocol fell below a reasonable threshold of 70-75% would be withdrawn from analysis to uphold the integrity of the data, and self-initiated entries – especially from those respondents to whom making such entries was not advised – would be removed. However, given the small size of the present sample, and the challenges encountered achieving even this modest degree of EMA compliance, the decision was made to retain self-initiated diary entries from participants who otherwise would not have provided sufficient data for analysis. Implications for the study findings, including these manual entries, are discussed below; in order to be confident in these results, though, the size of the diary-compliant sample would need to be increased.

Social support and ESRD: The unique influence of disease-specific support

Consistent with others' findings (Clarkson & Robinson, 2010; Thomas, et al., 2001), overall ratings of available social support were high in this sample, with the majority of patients reporting that they had adequate support from others in their life, particularly from a partner or significant other. Despite the fact that most subjects attended dialysis on their own, interview ratings of the perceived availability of disease-specific social support were high as well, as were ratings of the supportiveness of those disease-specific actions. Patients in the present sample also indicated that they were receiving roughly their desired amount of disease-specific support for their management of ESRD.

Social support has broadly been associated with improved outcomes and survival among individuals with kidney failure (Kimmel, et al., 1998; Szeto, et al., 2008), but somewhat less reliably with behaviors of disease self-management (Cukor, Cohen, Peterson, & Kimmel, 2007; Cohen, et al., 2007; Furr, 1998; Hailey & Moss, 2000; Kara, Caglar, & Kilic, 2007; Kutner, et al., 2002; Sensky, Leger, & Gilmour, 1996). The majority of the studies in this area have so far assessed the availability and receipt of support using standard interview measures of perceived social support. In the present sample, evidence for a relationship between general measures of social support and adherence was very limited, and in the opposite of the expected direction. Overall perceived availability of support was associated with poorer scores on interview-based measures of ESRD-related health behaviors. Additionally, general social support scores were not significantly related to of momentary reports of diet, fluid, or medication behaviors. A number of possible explanations may exist for this finding. It is not at all unheard of for social support to have unexpectedly negative effects on behaviors of disease self-management in hemodialysis patients; in one study, patients higher in social support were significantly less adherent to diet restrictions than those lower in social support (Sensky, Leger, & Gilmour, 1996). Researchers concluded that individuals who are more social may be more likely to eat out, or be more likely to be influenced by their companions' food decisions, which may not fit their kidney disease diet. There is additional evidence that, in a sample of older diabetic adults, behaviors that are positive or supportive in nature might still lead to dietary nonadherence when patients are tempted by partners' food choices (Henry, Rook, Stephens, & Franks, 2013). The presence of social partners, while most likely psychologically beneficial (Clarkson & Robinson, 2010; Isenberg & Trisolini, 2008; Symister & Friend, 2003) may have negative, though potentially unintentional, effect on ESRD patients' diet and fluid adherence.

It may also be the case that global support is simply too far removed from behaviors of treatment adherence to have a beneficial effect. Although perceived social support has been shown, generally, to be associated with better treatment adherence across a spectrum of illnesses (DiMatteo, 2004), in the unique case of ESRD, in may be that disease-specific support, rather than global perceptions of support, are more crucial in predicting adherence to behaviors of disease self-management. Comparatively fewer researchers have assessed the role of perceived availability of disease-specific support in better understanding treatment adherence. In one study, however, Thomas and colleagues (2001) found that available disease specific support ("Someone helps me follow my diet") was not consistently associated with diet adherence, but that lack of available diet-specific support (“My family doesn’t help me follow my diet”) was associated with poorer adherence to diet restrictions. In the present sample, overall perceptions of the availability of and the supportiveness of disease specific support was measured using a modified version of the Diabetes Social Support Questionnaire (La Greca & Bearman, 2002), on which respondents indicate their level of received support for disease behaviors, as well as how supportive they find these behaviors to be. Contrary to Thomas and colleagues’ findings, the present results indicate that interview measures of receipt of disease-specific support were not associated with general perceived engagement in disease management behaviors, and while perceived supportiveness was associated with adherence, it was predictive of worse, rather than better, global reports of adherence to treatment. However, interview-based disease-specific support was associated with better momentary reports of adherence to behaviors of disease self-management, particularly fluid adherence, as were feelings of supportedness. Many researchers have found that support is more robustly associated with some parameters of adherence than others (Brown & Fitzpatrick, 1988; Christensen, et al., 1992; Pang, et al., 2001; Untas, et al., 2011), with some of the strongest relationships between social support and fluid adherence (Brown & Fitzpatrick, 1988; Christensen, et al., 1992; Pang, et al., 2001; Untas, et al., 2011). It may be that such variations in the contribution of support to predicting adherence to treatment in patients on hemodialysis can be accounted for by the degree of specificity of the provision of support to the peculiar challenges of ESRD.

As with interview-based measures of global support, momentary measures of overall supportedness were not significantly associated with concomitant engagement in diet, fluid, or medication behavior. However, some forms of momentary disease-specific support – whether someone helped the patient with behaviors related to their diet, fluid restrictions, or medication taking – were significantly associated with adherence. In particular, support for diet adherence was associated with more than double the likelihood of engaging in good eating behavior. Contrary to the effect of interview measures of disease-specific support, diary measures of fluid-specific support were not associated with fluid restriction.

There may be several possible explanations for these effects, and for the discrepancies between the effects of the interview measure of disease-specific support and the momentary measures of support specific to ESRD-related behaviors. First, it may be the case that patients are poor estimators of the actual receipt of support for their behaviors of disease self-management in their everyday lives (Piasecki, Hufford, Solhan, & Trull, 2007; Shiffman, Stone, & Hufford, 2008; Stone, Broderick, Shiffman, & Schwartz, 2004; Takarangi, Garry, & Loftus, 2006). In the present interview-based assessment of disease-specific support, respondents are asked to report how often a family member engages in a variety of supportive behaviors, on a scale ranging from "At least once a day" to "Never". A given individual's ability to make this assessment may be clouded by any number of factors, such as their desire for support; they may also be overly optimistic about the support they do receive. Patients who actually do receive this kind of help multiple times a day may be accurate in their assessment, as might patients who truly never receive this kind of support from a family member or significant other. But research has shown that individuals have difficulty accurately reporting on the details of health-related behaviors over more than about three days (Dunbar-Jacob, Houze, Kramer, Luyster, & McCall, 2010); considering that supportive behaviors may be subtle or invisible (Bolger, Zuckerman, & Kessler, 2000), especially in the context of a close, complex, and otherwise rewarding relationship such as that between family members or partners, it may be the case that patients, perhaps unintentionally, minimize or enhance the support they do receive.

Second, in the present sample, patients' ratings of the supportiveness of family members' helpful behaviors was underwhelming. Although they are instructed to respond separately for the receipt of support and the degree to which they find those behaviors supportive, it is likely that the supportiveness of the behaviors themselves – or lack thereof – influence participants' ability to accurately recall the frequency of occurrence of those behaviors. Third, the DSSQ, while somewhat established in the diabetes literature, has not to the best of our knowledge been used in an ESRD population. Though there is evidence in the present sample that scores on the modified DSSQ are associated with improved outcomes, it would be worthwhile to validate this instrument in a hemodialysis population before drawing firm conclusions about its utility to determine the influence of perceived disease-specific support on adherence to treatment among patients with kidney failure.

Finally, it appears that most diary measures of the receipt of disease-specific social support are associated significantly with scores on the DSSQ. However, the low frequency of reported receipt of support in the electronic diary was unexpected. Rates of reporting that someone helped with medication, diet, or fluid restriction were all under 5% of the total number of entries made; in more than 36% of entries, respondents indicated that they had received no disease-specific support. For a population in which attention to health and health behaviors is a nearly constant task, it was surprising that so few participants indicated receiving high levels of support. However, it is possible that family members, friends, and significant others are engaged in the provision of support "under the radar", and participants simply do not recognize that they are receiving support for their behaviors of disease self-management. Though it has not yet been widely explored in the context of chronic disease, invisible support, or support that is provided by social network members but goes unrecognized by the recipient, has been repeatedly shown to be significantly related to reduced levels of stress (Bolger & Amarel, 2007; Bolger, et al., 2000; Girme, Overall, & Simpson, 2013; Howland & Simpson, 2010). Future studies might consider dyadic assessment of ESRD patients and spouses or other significant others to determine if the support that is being offered by others in the household in the service of maintaining or improving health is recognized by the patient, and if not, whether that invisible support is associated with better or poorer disease self-management and treatment outcomes.

Cognitive dysfunction and the interdialytic interval: Does cognitive impairment increase or decrease as a function of time since dialysis?

A growing body of evidence suggests that the incredible treatment demands faced by ESRD patients may be associated with shifts in cognitive functioning (Williams, et al., 2009). Cognitive problems, including memory and attention impairment, slowed reaction time, and decreased decision making abilities (Harciarek, et al., 2009) are common among dialysis patients (cf. Griva, et al., 2010; Lux, et al., 2010; Song, et al., 2011). However, the mechanisms underlying a relationship between cognitive function and adherence, and in turn, ESRD outcomes, are poorly understood. One hypothesis, a toxicity theory of cognitive functioning, has been that the steady increase in fluid volume as time since dialysis wears on leads to subtle shifts in cognitive abilities (Dogukan, et al., 2009; Kurella, Luan, Yaffe, & Chertow, 2004, Lux, et al., 2010), or that the buildup of waste products and minerals in the bloodstream over the interdialytic interval leads to confusion and cognitive impairment (Williams, Sklar, Burright, & Donovick, 2004). However, some researchers have failed to show that time since dialysis was associated with cognitive function (Post, et al., 2010). In the present study, consistent with findings that increased fluid volume and mineral buildup is associated with poorer cognitive performance, it was hypothesized that cognitive dysfunction would increase as time since dialysis increased, and that the poorest cognitive functioning would be evidenced on the two-day relative to the one-day interdialytic interval. Contrary to expectations, the present study did not find that reports of cognitive dysfunction increased over the longer, two-day interdialytic interval. Rather, it appeared that cognitive functioning was improved on the two-day compared to the one-day IDI, even when controlling for factors which may have influenced cognitive functioning, such as age, education level, and employment status.

There are a variety of possible explanations for this counterintuitive finding. While it may be that cognitive dysfunction results from fluid or mineral accumulation, it may instead be the case that it is the dramatic shifts in fluid levels from the pre- to post-dialytic state that influence cognitive functioning, or an osmotic theory of cognitive dysfunction. In this instance, cognitive functioning might be expected to improve as time since dialysis wears on, and be lowest during and shortly after dialysis. Indeed, two known dialysis-related syndromes – post-dialysis rebound (cf. Tattersall, Chamney, Aldridge, & Greenwood, 1996; Tattersall, DeTakats, Chamney, Greenwood, & Farrington, 1996) and dialysis disequilibrium (cf. Murray, 2008; Peterson & Swanson, 1964; Silver, Sterns, & Halperin, 1996) are associated with cognitive impairment during and shortly after hemodialysis treatment. Though it is not entirely clear how exactly the dialysis procedure contributes to these neurocognitive symptoms, it is commonly accepted that as urea concentrations are lowered during dialysis, the osmotic flow to cells throughout the body, including the brain, is disrupted, leading to cerebral edema that may take several hours or days to clear (Zepeda-Orozco & Quigley, 2012). This fluid imbalance then leads to cloudiness and inability to concentrate. In one study, researchers investigated the extent to which cognition varied over the interdialytic interval, assessing cognitive functioning before, during, after, and the day after dialysis, and found that impairment was lowest the day after dialysis or immediately before the dialysis session, and was highest during dialysis (Murray, 2008; Murray, et al., 2007). While this is counter to some findings that roughly one hour after dialysis initiation (Cormier-Daigle & Stewart, 1997) is a useful, acceptable time for patient interviews and/or health education, Murray and colleagues' (2007; 2008) findings are consistent with the results of the present study that some parameters of cognitive functioning was actually better at longer times since last dialysis.

More detailed analyses of any subtle shifts in cognitive impairments over the entire dialytic cycle are needed to better understand how cognitive functioning shifts during dialysis and the interdialytic interval. Unfortunately, the low rates of reported cognitive dysfunction and the high rate of missing data in the present study make it difficult to draw a firm conclusion about the nature of the effect of time since dialysis on cognitive functioning. Additionally, though the cognitive functioning items in the electronic diary were based on standard items from the Kidney Disease Quality of Life Scale (Hays, et al., 1997; Hays, et al., 1994), it is not known whether this constellation of questions, their rating scales, or the frequency with which they are presented represent the most sensitive, efficacious means of collecting accurate information about ESRD patients' neurocognitive state. To date, there do not appear to be any validated approaches to assessing subtle, momentary changes in cognitive functioning using ecological momentary assessment approaches, nor do any gold-standard measures of attention, orientation, recall, or concentration appear to have been translated into tools suitable for experience sampling. However, many of these tasks – for example, the Trail-Making Test (Reitan, 1958) – lend themselves well to adaptation for use on mobile, electronic devices such as those used in the present study. It may also be the case that patients are not the best source of information about their own cognitive status, especially given the high level of burden and demand placed on them by their kidney disease diagnosis and treatment requirements. It might be helpful to have corroboration from a partner or family member about the perceived level of confusion, disorientation, and forgetfulness of the patient on and between dialysis days. Future studies might investigate the development and employment of more sensitive, sophisticated means of assessing cognitive functioning over the dialytic cycle among patients on hemodialysis, as well as collecting reports from significant others about patients' status.

Cloudiness, forgetfulness, and inattention: Cognitive dysfunction and adherence to treatment

Though the literature in this area is relatively new, a number of researchers have provided evidence that cognitive dysfunction is not only common among patients in kidney failure (Altmann, Barnett, & Finn, 2007; Griva, et al., 2010; Hain, 2008; Harciarek, Biedunkiewicz, Lichodziejewska-Niemierko, Debska-Slizien, & Rutkowski, 2009; Jassal, Devins, Chan, Bozanovic, & Rourke, 2006; Lux, et al., 2010; Madero, Gul, & Sarnak, 2008; Murray, 2008; Nulsen, et al., 2008; Pereira, et al., 2007; Radic, et al., 2010; Song, et al., 2011), but further complicates their ability to remain adherent to the behaviors associated with their disease self-management (Post, et al., 2010; Williams, et al., 2009; Williams, Manias, & Walker, 2008). In previous studies, difficulties with information processing and memory were associated with poorer medication adherence, for example, and reduced cognitive abilities may make it more challenging to avoid errors in diet and fluid restriction (Hain, 2008; Radic, et al., 2010). Additionally, among those patients who are chronically non-adherent, cognitive dysfunction is considerably more common. By and large, evidence from the present study is consistent with others' findings that patients who are more cognitively impaired suffer in terms of their treatment adherence and intermediate treatment outcomes, though this varied from measure to measure. In terms of standard, clinical measures of cognitive functioning, higher levels of impairment significantly predicted greater average interdialytic weight gain, higher serum potassium levels, and higher serum phosphorus levels across 6 months. However, scores on standard measures of neurocognitive functioning were not consistently associated with self-reported diet behavior, fluid quantity, or medication taking.

Relationships between momentary assessments of cognitive functioning and adherence, however, were considerably more variable. Higher diary ratings of momentary cognitive dysfunction were associated with higher interdialytic weight gain, but lower levels of serum phosphorus. However, contrary to hypotheses and to other researchers' findings, higher levels of trouble thinking, confusion, and slowed reaction time were associated with a lower self-reported likelihood of consuming fluids, and were largely not predictive of other self-reported adherence behaviors, though consistent with the dominant literature, slowed reaction time was associated with poorer diet adherence. Additionally, and unexpectedly, momentary ratings of cognitive dysfunction were not reliably associated with fluid weight gain over the next interdialytic interval. The reason for these differences is not entirely clear. One explanation is simply that, as described above, assessments of cognitive impairment in the electronic diary were insufficiently sensitive to likely very subtle shifts in cognitive functioning over the dialytic cycle, and as such, were less likely than standard measures to significantly predict treatment adherence. Another is that treatment adherence is better reflected by clinical laboratory measures of fluid and mineral levels over longer periods of time than by momentary engagement in behaviors of disease self-management.

An additional possibility is that individuals are poor judges of how well or how frequently they engage in activities of disease self-management, even if those reports are made several times each day. Although the electronic diary prompts participants to report on whether they have engaged in any diet, fluid, or medication taking behavior since the last time they completed an entry, the time between entries is highly variable, even for a given subject, and many of the randomly prompted entries were missed. It is possible that, even over just a few hours, reports of engagement in adherence behaviors are inaccurate (Bolger & Laurenceau, 2013). There were, indeed, some discrepancies between the degree of interdialytic weight gain and the reported frequency of fluid consumption as well as between IWG and the self-reported amount of fluid consumed; there were additional small discrepancies between the frequency of diet and medication behaviors and phosphorus and potassium levels. If participants had been faithful, objective reporters of their behavior, we would expect these discrepancies to be negligible. Although on average the difference between the standardized scores of laboratory measures of adherence and the standardized frequency of adherence behaviors was small, these difference scores were highly variable, and, for some parameters of adherence, were associated with poorer cognitive functioning. These results indicate that although cognitive dysfunction, as measured in the present study, may not be consistently associated with absolute levels of adherence, patients who experience greater cognitive dysfunction are more likely to underreport (and perhaps fail to recognize) their own nonadherence and, in turn, have greater difficulty meeting the demands of fluid restriction, diet management, and medication taking. If this is the case, then it makes sense that measures of cognitive functioning are more strongly associated with objective levels of adherence than to self-reported engagement in adherence behaviors.

Time since dialysis, and adherence to treatment: Does cognitive dysfunction account for the relationship between adherence and the length of the interdialytic interval?

In the present study, it was hypothesized that cognitive dysfunction would account for a portion of the relationship between the length of the interdialytic interval and adherence to treatment. However, across the various parameters of cognitive functioning and domains of adherence, only one relationship met criteria for tests of mediation – the relationship between interdialytic interval length, slowed reaction time, and engagement in good diet behavior. Participants made significantly fewer reports of good diet behavior – eating foods on their kidney disease diet – on the two-day compared to the one-day interdialytic interval. Surprisingly, poorer cognitive dysfunction, as measured by slowed reaction time, enhanced rather than reduced the relationship between IDI and eating recommended foods. It is not immediately clear why this may be the case. Certainly any number of factors may influence the degree to which patients are able to adhere to the strict limits on their diet. For instance, patients often report the belief that dialysis will compensate for overindulgences in food or fluid (Smith, et al., 2010), especially if they imbibe right before dialysis. On an internet forum for kidney disease patients (http://www.kidneyspace.com/), many report that if they are going to eat some unrecommended foods, especially those high in sodium, they do so an hour or so before dialysis. Anecdotal observations by project team members during the present investigation often revealed that patients who otherwise reported good treatment adherence brought unrecommended food or drinks, such as coffee and donuts, with them to clinic to consume right before or during dialysis, despite the fact that a normal dialysis session is not designed to “compensate” for this additional fluid and mineral content. It may be the case that, regardless of their level of cognitive function, patients take advantage of opportunities to eat foods that do not fit their kidney disease diet as their next dialysis session grows nearer. It is also possible that, over the two-day IDI session, more time is spent with family and friends, and remaining adherent to the kidney disease diet when those around you are eating out, perhaps, is too challenging. However, at least in the present sample, the frequency of reporting engagement in social activities was not demonstrably higher on two-day IDI days than on one-days. It is also important to note that although the rate of good diet behavior was lower over the two-day as compared to the one-day interdialytic intervals, IDI length was not significantly associated with bad diet behavior, or eating unrecommended foods, nor did the frequency of engagement in good versus bad diet behavior differ significantly by day of the week. Consequently, it is difficult to pinpoint the precise mechanisms behind the complex relationship between length of the interdialytic interval and adherence to dietary limitations.

Social support, cognitive functioning, and adherence: Does support buffer the influence of cognitive dysfunction on behaviors of disease self-management?

The final specific aim of the present study was to determine whether social support would moderate the relationship between cognitive function and adherence. It was hypothesized that individuals reporting greater support would report better adherence, even at high levels of cognitive dysfunction, compared to those fewer reports of support. Contrary to expectations, this hypothesis was not supported; none of the interactions between support and any parameters of cognitive functioning significantly predicted self-reported fluid consumption, diet behavior, or medication taking. Overall, reports of support varied very little across the dialytic cycle. Although patients did report receiving more medication support and more travel support (travel to and from dialysis) on dialysis days compared to non-dialysis days, there were no significant differences in the frequency of received disease-specific support on the two-day versus the one-day interdialytic intervals. A number of possible explanations may exist for this finding. First, as described above, these results only reflect the patients' report that someone helped them with their fluid, diet, or medication since the last time they completed a diary entry. It is possible that partners, children, or other family members or friends are providing help to the patient that is going unrecognized by the recipient, and future studies should consider the survey of partners and other significant others in better understanding how support is offered and utilized by patients on hemodialysis. Second, while patients were asked routinely if they received any help for their activities of disease self-management, it is not known whether receipt of support is in line with demand for support. While on average patients reported high levels of overall supportedness in the electronic diary, we know from the interview measures of disease-specific support that participants did not find it overwhelmingly supportive when their family members helped them with their ESRD-related behaviors. It is possible that receipt of support does not vary depending on the length of the interdialytic interval, but demand for support does. Future studies should explore in more depth patients' need for support for these activities of disease self-management. It is also possible that support is being offered or given, and recognized, but is not wanted. On the DSSQ, participants indicated that the support they receive is not necessarily well-matched to the support they feel from receiving it. In future investigations, the relationship between perceived need for support, desire for support, receipt of support, and adherence to treatment should be examined.

Explorations of personality factors, individual psychological experiences, and health locus of control and study factors

A number of individual factors, such as such as neuroticism, conscientiousness (Christensen & Smith, 1995; Wiebe & Christensen, 1997), health locus of control (Schneider, et al., 1991), depressive symptoms (Kimmel, 2002; Kimmel, et al., 2003; Kimmel, Peterson, et al., 1998), and perceived stress (Everett, Brantley, Sletten, Jones, & McKnight, 1995; Hitchcock, Brantley, Jones, & McKnight, 1992; Wolcott, Nissenson, & Landsverk, 1988) have been shown to account for some of the variance in treatment adherence among hemodialysis patients. In the present study, these factors were explored as covariates and potential mediators of the relationships between social support, cognitive dysfunction, and engagement in behaviors of disease self-management. Consistent with other researchers' findings, neuroticism and conscientiousness were significantly associated with average interdialytic weight gain and with mean potassium and phosphorus levels, but not as strongly or consistently with self-reported adherence behaviors. Neither of these personality factors substantially influenced any of the relationships between support and adherence, nor did they influence the association between cognitive functioning and adherence. The reason for this absence of an effect is unclear. It may be that only very highly neurotic or conscientious individuals show a dramatic effect of their personality on the relationship between social support and health (Park, et al., 2013), while levels of neuroticism and conscientiousness in this sample were quite moderate. It may be that, as described above, participants did not faithfully report their behaviors of adherence, or that individual personality factors are more predictive of global measures of adherence than subtle, momentary behaviors. It is also possible that personality is associated more with the quality of a given behavior rather than its frequency, or that neuroticism and conscientiousness only influence adherence via their interaction with other variables, such as perceived disease severity (Wiebe & Christensen, 1997), which was not assessed in the present study. There may also be an effect of ethnicity and culture at play in the present sample; neuroticism has been shown to be associated with in general to be associated with lower social support, but in one study, neuroticism among Hispanic women was did not influence ratings of support or distress (Campos, et al., 2014). In this primarily Hispanic sample, neuroticism may not have had the same effect on support and adherence as has been observed in other samples.

Depressive symptoms (Kimmel, 2002; Kimmel, et al., 2003; Kimmel, Peterson, et al., 1998) have been also been associated with poorer treatment adherence and more cognitive problems (Cohen, Weingartner, Smallberg, Pickar, & Murphy, 1982). The present results indicate that symptoms of depression were significantly associated with greater average interdialytic weight gain and phosphorus, as well as more self-reported fluid consumption, fewer good diet behaviors, and less medication taking. Depressive symptoms were also positively correlated with nearly all measures of general and disease-specific support. As a result, it was surprising that depressive symptoms did not appear to significantly influence the relationship between social support and adherence, or between cognitive functioning and adherence. However, depression in this sample was low overall; in a larger, more symptomatic sample, depressive symptoms may have played a larger role in the associations between social support, cognitive functioning, and adherence to ESRD treatment. Likewise, although health locus of control was associated with some adherence outcomes, it did not appear to affect the broader relationships between support, cognitive functioning, and adherence.

Finally, stress has been linked with poorer adherence (Everett, Brantley, Sletten, Jones, & McKnight, 1995; Hitchcock, Brantley, Jones, & McKnight, 1992; Wolcott, Nissenson, & Landsverk, 1988), and although self-reported levels of stress were low in this sample, stress levels did vary over the course of the dialytic cycle. Additionally, higher levels of stress were associated with greater mean interdialytic weight gain values but not with reports of engagement in behaviors of disease self-management. Ratings of stress were associated, however, with greater slowed reaction time, confusion, and difficulty making decisions. Despite these associations, stress did not demonstrably influence any relationships between cognitive functioning and reports of fluid, diet, or medication behavior. Perhaps momentary reports of stress are not the best measure of the type of stress that influences disease-relevant behaviors in patients with chronic illness. When prompted by the electronic diary, patients responded to the question “How stressed are you now?” by rating their overall stress level on a scale from 0 to 100. However, patients were not asked about their kidney disease- or treatment-related stresses. It is possible that general perceptions of stress do not influence behaviors of disease self-management to the same extent as other types of stress.

Although some older studies have found a link between stress and factors related to treatment adherence among ESRD patients, such findings have been inconsistent. Similarly, in studies of individuals with diabetes, global perceived stress has not been consistently associated with adherence to treatment (Garay-Sevilla, et al., 2000; Walker, Gebregziabher, Martin-Harris, & Egede, 2014). Future studies might explore in more detail any impact of global and disease-specific stress on particular behaviors, as well as consider its interaction with other psychological factors such as depression, which have been shown to jointly impact treatment adherence in other chronic disease patient populations (Bottonari, Safren, McQuaid, Hsiao, & Roberts, 2010).

Additionally, although stress and concomitant reports of cognitive dysfunction are significantly associated with one another, the direction of this relationship has not been elucidated. It may be important to know whether higher levels of stress lead to greater cognitive dysfunction, or whether greater cognitive impairment leads to higher levels of stress. The relationship between these variables may be causative or pseudo-causative, rather than interactive. Future work might examine more closely the temporal nature of reports of stress, particularly disease-specific stress, cognitive functioning, and behaviors of disease self-management.

Assessing disease self-management in real time: The potential of mobile technologies

To the best of our knowledge, the present study is the first to explore the relationships between cognitive functioning, social support, length of the interdialytic interval, and treatment adherence in a hemodialysis population using ecological momentary assessment, carried out via a sophisticated mobile monitoring system. In fact, to date, very few published studies have used EMA in the context of hemodialysis treatment at all (Abdel-Kader, et al., 2014; Riis, et al., 2005), and even fewer have used EMA to monitor disease self-management (Blowey, et al., 1997; Curtin, Svarstad, Andress, Keller, & Sacksteder, 1997; Curtin, Svarstad, & Keller, 1999). More recently, Sevick and colleagues (Sevick, et al., 2005; Sevick, et al., 2008) employed a personal digital assistant (PDA)-based food tracking program in their study of adults with ESRD, but the program did not specifically address issues of diet or fluid restriction. The present study reflects potentially the first study of its kind to use a mobile electronic monitoring system to collect information about patients' behaviors in real time. A key advantage of using EMA approaches, particularly in populations such as hemodialysis patients, where behaviors of disease self-management are carried out multiple times each day, is that it reduces reliance on global estimates of engagement in behaviors and instead allows researchers to capture the frequency and context of health behaviors in a naturalistic manner, reducing retrospective bias (Dunbar-Jacob, et al., 2010; Shiffman, 2007) and increasing ecological validity.

The present results give us some clues that, as previous researchers have found, EMA uncovers slightly different patterns of behavior than are revealed using traditional interview- and self-report-based assessments of psychosocial experiences and behaviors. For example, while interview-based assessments of receipt of disease specific support were positively correlated with diary-based ratings of disease-specific support, these associations were small to moderate in size. It is possible that the global perception of the frequency with which disease specific support is received differs somewhat from the frequency with which it is actually received. If we had only the interview measure of support to go on, on average, we would assume that patients only received disease-specific support once or twice each month, and these ratings were not highly variable. Conversely, using the diary measure, it appears that all but one patient experienced at least one instance of disease-specific support during their week of assessment, and, in most cases, were regularly receiving such support. Because the demands of ESRD symptoms and treatment can shift over the course of hours or days, the ability to explore the provision of support in such a detailed way could be crucial to the development of more sophisticated assessments of support in the hemodialysis population as well as to the design of interventions to improve adherence to treatment. More study is needed to better understand how support operates in the day-to-day lives of patients with ESRD and how it influences micro- and macro-level outcomes.

In the present study, as in many EMA based studies, data were collected using an electronic diary presented on a smartphone or tablet computer. Diary entries were randomly scheduled throughout the participants’ waking hours; each time participants were due to complete an entry, an audible chime would sound to alert the respondent to log in and answer the diary items. The mobile monitoring system has been used extensively with a variety of populations, and adherence to the monitoring protocol in previous studies has been reasonably high. However, ecological momentary assessment of this variety is not without its faults. EMA approaches have the potential to be considerably more disruptive to participants than standard, one-time interview or survey methods (Bolger & Laurenceau, 2013). More frequent samples provide a more detailed picture of the individual's life as it is lived, but are a considerable intrusion to participants. In this already heavily burdened population, the decision was made to prompt participants somewhat infrequently – no more than about 8 times per day. The trade-off for less frequent sampling, though, is that missing data are more damaging overall to the integrity of the dataset than are missing entries from, for instance, a possible 20 or more signals per day.

Additionally, although randomly-scheduled prompts for information reduce the retrospective biases inherent in one-time measures, unless all the variables of interest are truly momentary, there will be demand for recall over at least an hour or so (Bolger & Laurenceau, 2013). In the present study, it was unlikely that participants would be signaled at the precise moment they were being provided with support, engaging in behaviors of disease self-management, or experiencing cognitive dysfunction. As such, they were asked if they had experienced any of these events since the last time they completed a diary entry. If respondents were adherent to the diary protocol, they would need to recall the events and experiences of the past two to three hours. However, if participants missed one or more entries, the period of recall could easily become several hours or most of one day.

Random prompting is only one way to use ecological momentary assessment. When entries are randomly scheduled throughout the day, it can give researchers the most descriptive picture of a respondent's typical day. There are alternative EMA designs, including event-prompted assessments, in which respondents are triggered to self-initiate an entry during or following a particular kind of event, such as a headache or argument (Bolger & Laurenceau, 2013). There are advantages and disadvantages to each of these approaches; event-triggered assessments can make clear the antecedents and consequences of particular salient issues in the respondent's life, but rely heavily on respondents to pay attention to their environment, experiences, and behaviors in a way that is perhaps not naturalistic, and can influence the ways in which assessments are made. For instance, if participants are instructed to record their pain level each time they get a headache, they may become hypervigilant to pain-related cues, which may change the way in which headaches are experienced. On the other hand, random prompts may become burdensome; ideally, respondents become more facile at answering the questions, and in turn, become more transparent. As the assessment period wears on, however, respondents may become distant in their responses, focused only on moving through the assessment quickly, and in some cases, may become accustomed to a schedule of prompts that is not perfectly random, and come to expect an alert. In the present investigation, a random prompting strategy was used to best capture the minute shifts in cognitions and behaviors over the dialytic cycle.

Due to the equipment limitations early in the study, several participants were instructed to initiate an entry if they knew they had missed a prompt (for example, they heard the signal, but did not get to the device in time to make an entry), or if the device stopped making noise entirely. Once data collection was moved to smartphones, with more reliable signaling and volume control, project staff stopped making this recommendation. Regardless, virtually all respondents made a number of self-initiated entries. There was not a distinct pattern to these entries, although more study is needed to better understand if there were particular location-based, time, or social contexts associated with making self-entries compared to only random entries. Additionally, as described above, overall adherence to randomly-prompted entries in this sample was exceptionally low. It is clear that there are qualitative differences between the entries made by those respondents who were more compliant with the electronic diary protocol and those made by less compliant respondents. An increase to the size of the sample of compliant respondents is needed to better understand the present findings and be more confident that the research questions have been adequately addressed.

An additional drawback to the use of mobile, momentary assessment is the utility of the data collection device. As smartphones and other mobile devices become more ubiquitous, and users become more facile with advancing technologies, the issues of training study participants to use the data collection instruments becomes less challenging. However, in populations where experience using such devices is limited, data collection may be more difficult. In the present sample, many participants had minimal experience using smartphones, and were not entirely comfortable with the data collection approaches. Additionally, some populations have physical limitations that may make using mobile devices for data collection impractical. Older adults have often been cited as an example of a group for whom the use of mobile phones or palmtop computers for EMA may be troublesome, because they may have more trouble seeing and using small screens or buttons (Tennen, Affleck, Coyne, Larsen, & Delongis, 2006). Other groups which may have difficulty with the type of mobile data collection devices, such as those used in the present study, are those with visual impairments. In the present sample, several patients suffered from diabetic retinopathy and had difficulty using the smartphone devices. Such limitations were unexpected, and are important considerations for the use of ecological momentary assessment in ESRD patient populations going forward.

Another way to use modern mobile technologies to better collect more sophisticated, context-sensitive data from participants, while reducing the burden on participants, would be to capitalize on the information passively collected by devices without requiring input from respondents. Most smartphones and tablet computers are equipped with location services, accelerometers, and other onboard capabilities that collect information in the background, enabling researchers to better observe participants' whereabouts, movements, and so on. Additionally, an almost endless number of peripheral devices are now commercially available that can connect to a respondent's smartphone or tablet via Bluetooth or radio-frequency identification (RFID) connections and unobtrusively collect a variety of physiological data points, such as heart rate and blood pressure. Importantly for hemodialysis patients, devices are also available to passively assess fluid levels. The mc10 hydration sensor (http://www.mc10inc.com/consumer-products/sports/hydration-sensor/) is a wearable patch that measures the user's hydration levels and transmits the information to a smartphone or computer via Bluetooth. Developed for high-performance athletes, it is possible that such passive devices could be enormously useful in monitoring ESRD patients' fluid volume over the course of a dialysis session, or over the interdialytic interval. Feedback from the patch could be sent to patients, their family members or other supporters, or to their healthcare providers, enabling patients to better connect their behaviors to objective outcomes related to their fluid volume and their overall health maintenance. Future studies should explore the utility of these passive devices and applications to collect data relevant to dialysis patients' behaviors of disease self-management, as well as the potential for these technologies to be translated into validated, tailored interventions to improve adherence to treatment.

Study limitations

The present study had a number of limitations. First, at twenty-two participants, the sample size was quite small. Although sample sizes in this literature are often on the small side (Clarkson & Robinson, 2010; Isenberg et al, 2008; Post et al, 2010; Sevick, et al., 2005; Sevick, et al., 2008; Tovazzi & Mazzoni, 2012), and small samples have successfully been run at the present recruitment site (Pahl, Gollapudi, et al., 2010; Pahl, Vaziri, et al., 2010), it is difficult to make generalizations from such a limited number of participants. Additionally, a high rate of non-adherence to the research protocol was experienced in the present sample. Possible reasons for this non-adherence, and strategies to improve adherence to such a complex protocol, are detailed below. Encouragingly, though the final sample was small in size, participants in the final sample did not differ significantly from the overall pool of participants in terms of their demographic or disease characteristics, and the final sample was generally well-balanced in terms of gender, employment status, and educational background.

Another limitation that somewhat limits generalizability to the broader hemodialysis population is the ethnic composition of the present sample. Consistent with the overall catchment of the recruitment site, the majority of participants in the present sample were Hispanic or Latino. These patients may be unique in many ways; firstly, a number of researchers have established that patterns of social support, particularly family support, may differ in Hispanic and Latino groups than in other ethnic groups (Campos, et al., 2014; Mulvaney-Day, Alegría, & Sribney, 2007; Tomaka, Thompson, & Palacios, 2006; Vaux, 1985). For instance, in the present sample, disease-specific support was associated with improved dietary outcomes, but further study would be required to determine whether this pattern is also true for individuals from other ethnic and cultural backgrounds. Additionally, Hispanic and Latino patients represent the largest and fastest-growing ESRD population in the U.S., and may have peculiar risk factors for kidney failure that make them less comparable to other groups. A final limitation related to the characteristics of the study sample is the income and insurance status of participants in the present investigation. The UC Irvine Medical Center is the largest provider of healthcare to indigent patients in Orange County, and in the present study, the majority of patients used only public insurance, and some subjects were uninsured; very few subjects were presently employed. Consequently, the results generated in the present study may not be generalizable to wealthier patient populations seen in private, corporate clinics or in other geographical regions.

Other study weaknesses had to do with the limitations of the electronic devices selected for data collection. Originally, the study protocol called for participants to use a small tablet computer to complete entries on the electronic diary and, at the conclusion of the study period, to keep the tablets for their personal use. The purpose of this approach was twofold: first, the tablets would serve as compensation for their time in the study. Second, other studies conducted by our research team have suggested that having participants use their own devices for data collection, as opposed to using devices loaned to them just to complete study tasks, improves protocol adherence and enhances participant interest in the project. However, there were a number of unforeseen complications to using these tablet computers for data collection. First, each time participants are scheduled to complete an entry in the electronic diary, the diary chimes to alert subjects to log in and complete the survey items. The volume level on the selected tablet computers was unusually low, and despite attempts to increase the sound level using volume-boosting applications as well as external speakers, many participants found it very difficult to hear the diary signals, and in turn, to complete the study tasks. Second, the present study was the first effort at using tablets, rather than smartphones, for data collection. Although ownership of the tablets was intended to increase buy-in to the study, participants found it cumbersome to keep the tablets with them at all times, even just for the one-week assessment period. For participants accustomed to having their smartphone with them during the majority of their activities, completing diary entries on their own device was a quick and fairly seamless task, but for individuals unused to carrying a device with them, participant burden was unintentionally increased, as was the potential for forgotten devices and missed entries. The tablet computers were used as data collection instruments only for the first eight participants; for the remaining subjects, respondents were issued a smartphone to use for their assessment period, and were given the tablet computer strictly as compensation for participation.

It was also anticipated that at least a subset of patient participants would use their own compatible Android smartphones to complete their electronic diary entries. Currently, 90% of American adults own a cell phone, with 58% owning and using a smartphone, including 61% of Hispanic adults, the highest rate of smartphone ownership of any surveyed ethnic group (Smith, 2013). Additionally, more than 30% of smartphone users, especially minority and low-income users, use their smartphone as their primary internet access, rather than a computer. While roughly equal numbers of smartphone users use Android and iPhone devices, worldwide, Android has the largest installed base of any mobile operating system, and more Android devices are sold than any other type of smartphone (http://www.statisticbrain.com/android-phone-statistics/). Android devices are also most popular among the lowest-income groups. Consequently, it was surprising that only one subject owned a smartphone compatible with the Android-based electronic diary program and used her own device for data collection. However, anecdotal observations by members of the research team suggest that patients who already owned a smartphone or tablet computer – especially those who were observed using them while on dialysis – were those who were least interested in participating in the study. It is not known whether the fact that participants would be compensated with a tablet computer influenced only certain participants to volunteer. Given what we have learned from previous studies about the benefits of having participants use their own devices for data collection, and the advantages of using smartphones over tablet computers, future studies might consider providing participants with smartphone devices for data collection as well as compensation, as resources allow.

An additional technical limitation to the present study was the low level of experience with technology in this sample. Although technological literacy was not formally assessed in the present study, anecdotal observation by interviewers suggests that many participants and would-be participants were uncomfortable with the electronic devices used for data collection. Indeed, a key reason for otherwise interested patients to ultimately refuse enrollment, and for enrolled participants to withdraw from participation, was discomfort with using smartphones and tablets, an issue which has never arisen in our other samples. Additionally, though project team members carefully trained participants to use the smartphone and tablet devices and to use the electronic diary program, the low level of adherence to the study protocol was often attributed to participants' inability to properly use the diary system on their own. Clinic staff later informed project team members that computer ownership and experience at the recruitment site is very low, and for many patients, the tablet computer provided to them as part of the study represented their first and/or only computer. In future studies, it might be worthwhile to assess technological literacy to better determine the skill level of participants being asked to use electronic devices, and adjust subject training approaches accordingly.

Conclusions

Changes in cognitive and psychosocial functioning over the course of the dialytic cycle may have important consequences for the maintenance of health and treatment outcomes for patients in kidney failure. The purpose of the present study was to explore the effects of several parameters of cognitive functioning, general and disease-specific social support, and their interactions on both clinical and self-reported adherence to treatment over the interdialytic interval in a sample of patients on hemodialysis. The study was the first of its kind to examine the complex interactions between these factors using an ecological momentary assessment approach, collecting highly detailed data from participants via a mobile electronic diary system.

Results of the present investigation provide support for an osmotic theory of cognitive dysfunction resulting from hemodialysis. Contrary to hypotheses, reports of cognitive functioning in this small, relatively young, non-depressed, and well-supported sample were better over the longer, two-day interdialytic interval as compared to the one-day intervals. However, although cognitive functioning was associated with engagement in behaviors of disease self-management, it did not significantly account for the relationship between length of the interdialytic interval and treatment adherence. Additionally, the present findings indicate that while social support, particularly diet-specific support, is associated with improved adherence to dietary restrictions, support did not influence the association between cognitive functioning and treatment adherence. However, these findings should be interpreted with caution pending recruitment of a larger sample. Future studies should assess the sensitivity of experience sampling methods to detect shifts in cognitive functioning over the dialytic cycle in more depth, and capitalize on advances in the ability of sophisticated modern mobile technologies to collect health-related information passively, as well as explore these relationships in larger, more diverse samples in order to translate these findings into effective interventions to improve adherence to treatment among patients with end-stage renal disease.

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Table 1

Study measures

	Construct Measured	Scale Name
Outcomes	*Treatment Adherence (Subjective)*	• End-Stage Renal Disease Adherence Questionnaire (ESRD-AQ) • Renal Adherence Attitudes Questionnaire (RAAQ) • Renal Adherence Behaviors Questionnaire (RABQ) • Kidney Disease Quality of Life Scale-Short Form (KDQOL-SF) • Electronic Diary: Momentary assessments of adherence
	Treatment Adherence (Objective)	• IWG, serum potassium, and serum phosphorus levels from health record for 3 months prior and 3 months following assessment
Predictors	*Social Support*	• Multidimensional Scale of Perceived Social Support (MSPSS) • Diabetes Social Support Questionnaire-Family Version (DSSQ) • Electronic Diary: Momentary assessments of support availability and utility
	Cognitive Functioning	• Mini-Mental Status Examination (MMSE) • Digit Span • California Verbal Learning Test (CVLT) • Benton Visual Retention Test (BVRT) • Trail-Making Test • Electronic Diary: Momentary assessments of cognitive functioning
Covariates	*Affect*	• Cognitive Depression Inventory (CDI) • Electronic Diary: Momentary assessments of stress and mood
	Personality	• NEO Five-Factor Inventory (NEO-FFI)
	Health Locus of Control	• Multidimensional Health Locus of Control Scale (MHLCS)
	Physiological markers of stress and adherence	• Blood pressure

Table 2

Self-reported disease burden.

	Mean	*SD*
My kidney disease interferes too much with my life.	3.1 *(out of 5)*	1.5
Too much of my time is spent dealing with my kidney disease.	3.1	1.5
I feel frustrated dealing with my kidney disease.	3.4	1.4
I feel like a burden on my family.	3.2	1.5

Table 3

DSSQ subscale ratings

	Mean	*SD*
Received Support for Dialysis	2.2 *(out of 5)*	1.2
Received Support for Diet	2.0	1.5
Received Support for Fluid	1.5	1.6
Received Support for Medication	1.4	1.7
Received Support for Blood Glucose Monitoring *(when applicable)*	1.6	1.7
Supportiveness of Dialysis Support	-.2 *(out of 1)*	.8
Supportiveness of Diet Support	-.2	.8
Supportiveness of Fluid Support	-.2	.8
Supportiveness of Medication Support	-.2	.8
Supportiveness of Blood Glucose Monitoring Support	.03	.6
Received/Supportiveness Ratio for Dialysis	.6 *(out of 1)*	1.5
Received/Supportiveness Ratio for Diet	.3	1.5
Received/Supportiveness Ratio for Fluid	.4	1.9
Received/Supportiveness Ratio for Medication	.3	1.6
Received/Supportiveness Ratio for Blood Glucose Monitoring	.4	1.7

Table 4

Personality characteristics of the present sample

	Neuroticism		Extraversion		Openness		Agreeableness		Conscientiousness	
	M	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*
Mean	20.2	7.7	28.5	6.2	24.8	6.8	28.4	5.5	31.2	5.3
Low	*14.5*		*24.5*		*23*		*30*		*31*	
High	*23*		*30.5*		*30*		*35.5*		*37.5*	

Table 5

Kidney disease-specific health locus of control

	Mean	*SD*	Range
Internal LOC	25.4	6.0	11-36
External LOC	41.6	8.1	27-61
Chance LOC	17.5	5.7	7-30
Doctor LOC	13.7	2.9	6-18
Others LOC	10.0	3.0	5-16

Table 6

Mean levels of neurocognitive function

	Mean	*SD*	Range
MMSE Score	25.6	3.1	18-30
California Verbal Learning Test	6.1	2.8	2-13 words
Digit Span Forward	6.7	1.3	4-8 digits
Digit Span Backward	4.8	1.4	3-7 digits
Benton Visual Retention Test	8.7	1.8	3-10 figures
Trail-Making Test A	46.4	28.4	20-131 seconds
Trail-Making Test B	166.2	212.6	47-863 seconds

Table 7

Average mood ratings in the electronic diary

	Mean	*SD*
Sad	6.9	15.3
Tired	22.5	26.9
Annoyed	9.7	18.5
Angry	6.8	14.9
Restless	12.3	21.1
Lonely	14.1	26.8
Stressed	9.5	16.7
Anxious	13.0	19.9
Hopeless	16.7	29.4
Happy	71.2	31.7
Optimistic	60.7	35.1
Confidence	66.9	34.5

Table 8

Rates of receipt of momentary disease-specific social support and control

	% of entries	*SD*
Medication Support	3.9%	19.5%
Medication Control	2.2%	14.7%
Diet Support	5.0%	21.8%
Diet Control	1.4%	11.8%
Fluid Support	2.7%	16.3%
Fluid Control	1.3%	11.2%
Travel Support	2.7%	16.3%
Concern Support	3.4%	18.2%
No Support	36.3%	48.1%

Table 9

Associations between interview and diary measures of disease-specific support

		DSSQ Received Support	DSSQ Supportiveness of Support	Received/ Supportiveness Ratio for Diet	Received/ Supportiveness Ratio for Fluid	Received/ Supportiveness Ratio for Medication
Medication Support	*r*	.54*	.50*	.55**	.49*	.74**
Diet Support		0.25	0.08	0.05	0.11	-0.03
Fluid Support		0.38	0.39	0.35	0.41	0.29
No Support Behaviors Received		-0.43	-0.33	-0.18	-0.22	-0.26

Note. * *p* < .05. ** *p* < .001.

Table 10

Rates of diary-reported ESRD-related health behaviors

	% of entries	*SD*
Consumed Fluids	60.7%	48.9%
Checked Blood Glucose	9.4%	29.2%
Checked Blood Pressure	18.0%	38.5%
Took Medication	22.2%	41.6%
Ate Foods on the Diet Plan	19.4%	39.6%
Ate Unrecommended Foods	9.4%	29.2%
No Health Behaviors	16.2%	36.8%

Table 11

Mean levels of momentary cognitive dysfunction across days

	Mean	*SD*
Slowed Reaction Time	.3 *(out of 5)*	.8
Trouble Thinking	.40	1.1
Confusion	.1	.5
Difficulty Making Decisions	.1	.5

Table 12

Correlations between RABQ scores and diary reports of adherence behaviors

		Fluid Consumption	Fluid Quantity	Medication Taking	Good Diet Behavior	Bad Diet Behavior
RABQ Score	*r*	.25	.57†	.34	.40	.45

Note. † *p* = .055.

Table 13

Relationship between social support and mean interdialytic weight gain

	β	*SE(B)*
MSPSS	.30***	.00
DSSQ Received Support	.23***	.02
DSSQ Supportiveness	.33***	.03
Overall Momentary Support	.13**	.00
Any Disease Specific Support	.07**	.08
Fluid Support	.05[†]	.14

Note. ** $p < .001$. *** $p < .0001$. [†] $p = .06$.

Table 14

Relationship between social support and phosphorus and potassium levels

		OR	*95% CI*		
MSPSS	Potassium Outside Target	1.1	1.0	-	1.2
	Phosphorus Outside Target	1.0	0.9	-	1.1
DSSQ Received Support	Potassium Outside Target	1.1	0.6	-	2.1
	Phosphorus Outside Target	1.6	0.8	-	3.2
DSSQ Supportiveness	Potassium Outside Target	1.4	0.3	-	6.3
	Phosphorus Outside Target	1.7	0.3	-	9.6
Overall Momentary Support	Potassium Outside Target	1.0	1.0	-	1.0
	Phosphorus Outside Target	1.0	1.0	-	1.0
Any Disease Specific Support	Potassium Outside Target	0.6	0.2	-	2.2
	Phosphorus Outside Target	0.8	0.2	-	2.8
Diet Support	Potassium Outside Target	0.3	0.1	-	1.2
	Phosphorus Outside Target	0.3†	0.1	-	1.1
Medication Support	Potassium Outside Target	2.6	0.4	-	15.4
	Phosphorus Outside Target	5.7*	1.4	-	22.7

Note. * $p < .05$. † $p = .0645$.

Table 15

Comparison of clinical and diary measures of cognitive functioning

		Momentary Assessments			
Interview Assessments		Slowed Reaction Time	Trouble Thinking	Confusion	Difficulty Making Decisions
MMSE Score	*r*	.19	.15	.11	.21
California Verbal Learning Test		.16	.15	.07	.10
Digit Span Forward		.05	.38	-.05	.23
Digit Span Backward		-.46*	-.20	-.40	-.35
Benton Visual Retention Test		-.30	-.04	-.48*	-.34
Trail-Making Test A		.51*	-.39	.62**	.18
Trail-Making Test B		-.07	.23	.14	-.16

Note. For momentary measures of cognitive functioning (columns) and Trail-Making Tests, higher values represent poorer cognitive functioning. For MMSE Score, California Verbal Learning Test, Digit Span Forward, Digit Span Backward, and Benton Visual Retention Test, higher values represent better cognitive functioning. * $p < .05$. ** $p < .01$.

Table 16

Correlations between diary- and interview-based assessments of reaction time, trouble thinking, and confusion

	Interview vs. Diary Assessment
Slowed Reaction Time	-.04
Trouble Thinking	-.07
Confusion	.25

Table 17

Relationship between diary- and interview-based assessments of reaction time, trouble thinking, and confusion

	Mean	*SD*	*t*
Interview Slowed Reaction Time	1.0	1.3	11.9**
Diary Slowed Reaction Time	0.3	0.8	
Interview Trouble Thinking	0.6	1.0	2.7**
Diary Trouble Thinking	0.4	1.1	
Interview Confusion	0.4	0.9	8.5***
Diary Confusion	0.1	0.5	

Note. ** $p < .01$. *** $p < .001$.

Table 18

Relationships between clinical measures of neurocognitive functioning and average interdialytic weight gain across 6 months

	B	*SE(B)*	*β*
MMSE Score	.03	.01	.11***
California Verbal Learning Test	.05	.01	.15***
Digit Span Forward	-.10	.02	-.15***
Digit Span Backward	-.26	.02	-.40***
Benton Visual Retention Test	-.19	.01	-.39***
Trail-Making Test A	.02	.00	.50***
Trail-Making Test B	.00	.00	.18***

Note. * $p < .05$. ** $p < .01$. *** $p < .0001$. † $p = .06$.

Table 19

Relationships between clinical measures of neurocognitive functioning and phosphorus and potassium levels across 6 months

		OR	*95% CI*		
MMSE Score	Potassium Outside Target	0.9	0.7	-	1.1
	Phosphorus Outside Target	0.9	0.7	-	1.2
California Verbal Learning Test	Potassium Outside Target	0.9	0.6	-	1.3
	Phosphorus Outside Target	0.8	0.5	-	1.2
Digit Span Forward	Potassium Outside Target	0.8	0.5	-	1.5
	Phosphorus Outside Target	1.1	0.6	-	2.1
Digit Span Backward	Potassium Outside Target	1.1	0.5	-	2.1
	Phosphorus Outside Target	1.4	0.7	-	2.8
Benton Visual Retention Test	Potassium Outside Target	1.1	0.7	-	1.8
	Phosphorus Outside Target	1.1	0.7	-	1.7
Trail-Making Test A	Potassium Outside Target	1.0	1.0	-	1.0
	Phosphorus Outside Target	1.0	0.9	-	1.0
Trail-Making Test B	Potassium Outside Target	1.0	1.0	-	1.0
	Phosphorus Outside Target	1.0	1.0	-	1.0

Note. * $p < .05$. *** $p < .0001$.

Table 20

Relationships between momentary measures of neurocognitive functioning and mean interdialytic weight gain across 6 months

	B	*SE*	*β*
Slowed Reaction Time	.26	.05	.22***
Trouble Thinking	.03	.03	.03
Confusion	.29	.07	.16***
Difficulty Making Decisions	.32	.07	.17***

Note. ** $p < .01$. *** $p < .0001$. † $p = .05$.

Table 21

Relationships between momentary measures of neurocognitive functioning and phosphorus and potassium levels across 6 months

		OR	*95% CI*		
Slowed Reaction Time	Potassium Outside Target	1.1	0.7	-	1.7
	Phosphorus Outside Target	1.0	0.6	-	1.6
Trouble Thinking	Potassium Outside Target	0.9	0.7	-	1.1
	Phosphorus Outside Target	0.9	0.7	-	1.1
Confusion	Potassium Outside Target	1.3	0.7	-	2.3
	Phosphorus Outside Target	1.1	0.6	-	2.1
Difficulty Making Decisions	Potassium Outside Target	1.3	0.7	-	2.4
	Phosphorus Outside Target	0.9	0.6	-	1.5

Table 22

Mean values and ranges for discrepancies between objective and subjective treatment adherence

	Mean	*SD*	Range
Mean IWG vs. Fluid Quantity	-0.2	1.7	-3.8 to 3.9
Mean IWG vs. Rate of Fluid Consumption	.02	1.9	-2.9 to 2.6
Mean Potassium vs. Rate of Diet/Medication	.85	.93	-.78 to 1.72
Mean Phosphorus vs. Rate of Diet/Medication	.74	.94	-.78 to 1.96

Table 23

Associations between cognitive dysfunction and discrepancies in objective and subjective adherence

		β	*SE(B)*
Mean IWG vs. Fluid Quantity	Slowed Reaction Time	1.96†	.08
	Trouble Thinking	1.87†	.10
	Confusion	.36	.14
	Difficulty Making Decisions	-.26	.16
Mean IWG vs. Rate of Fluid Consumption	Slowed Reaction Time	.31***	.11
	Trouble Thinking	.09†	.08
	Confusion	.21***	.15
	Difficulty Making Decisions	.19***	.17
Potassium Outside Target vs. Rate of Diet/Medication	Slowed Reaction Time	.29	.42
	Trouble Thinking	.23	.55
	Confusion	.31	.79
	Difficulty Making Decisions	.35	.97
Phosphorus Outside Target vs. Rate of Diet/Medication	Slowed Reaction Time	.26	.48
	Trouble Thinking	.35	.60
	Confusion	.35	.87
	Difficulty Making Decisions	.20	1.1

Note. *** $p < .0001$. † $p = .06$.

Table 24

Relationships between length of the interdialytic interval and markers of treatment adherence

		% of Entries	*SD*	*t*
Fluid Consumption	One-day IDI	65.5	0.5	-1.1
	Two-day IDI	72.6	0.5	
Fluid Quantity§	One-day IDI	2.8 (out of 5)	1.4	-0.4
	Two-day IDI	2.9	1.4	
Medication Taking	One-day IDI	21.6	0.4	-1.8†
	Two-day IDI	30.4	0.5	
Good Diet	One-day IDI	19.1	0.4	-2.0*
	Two-day IDI	28.7	0.5	
Bad Diet	One-day IDI	10.4	0.3	-0.02
	Two-day IDI	10.4	0.3	

Note. * $p < .05$. † $p = .07$. § Fluid quantity values are the mean values of the amount consumed, rather than the percent of entries.

Table 25

Enhancing effect of slowed reaction time on the relationship between IDI length and good diet behavior

	Model 1				Model 2			
Variable	*B*	*SE(B)*	*β*	*p*	*B*	*SE(B)*	*β*	*p*
IDI	-0.1	0.04	-2.0	.050	-0.2	0.1	-2.1	.034
Reaction Time					0.1	0.04	1.8	.079

Table 26

Effects of momentary reports of stress on concomitant reports of cognitive dysfunction

	B	*SE(B)*	*ß*
Reaction Time	0.004	0.002	2.3*
Trouble Thinking	0.000	0.003	0.1
Confusion	0.003	0.001	2.5*
Decisions	0.004	0.001	3.9***

Note. * *p* < .05. *** *p* < .0001.

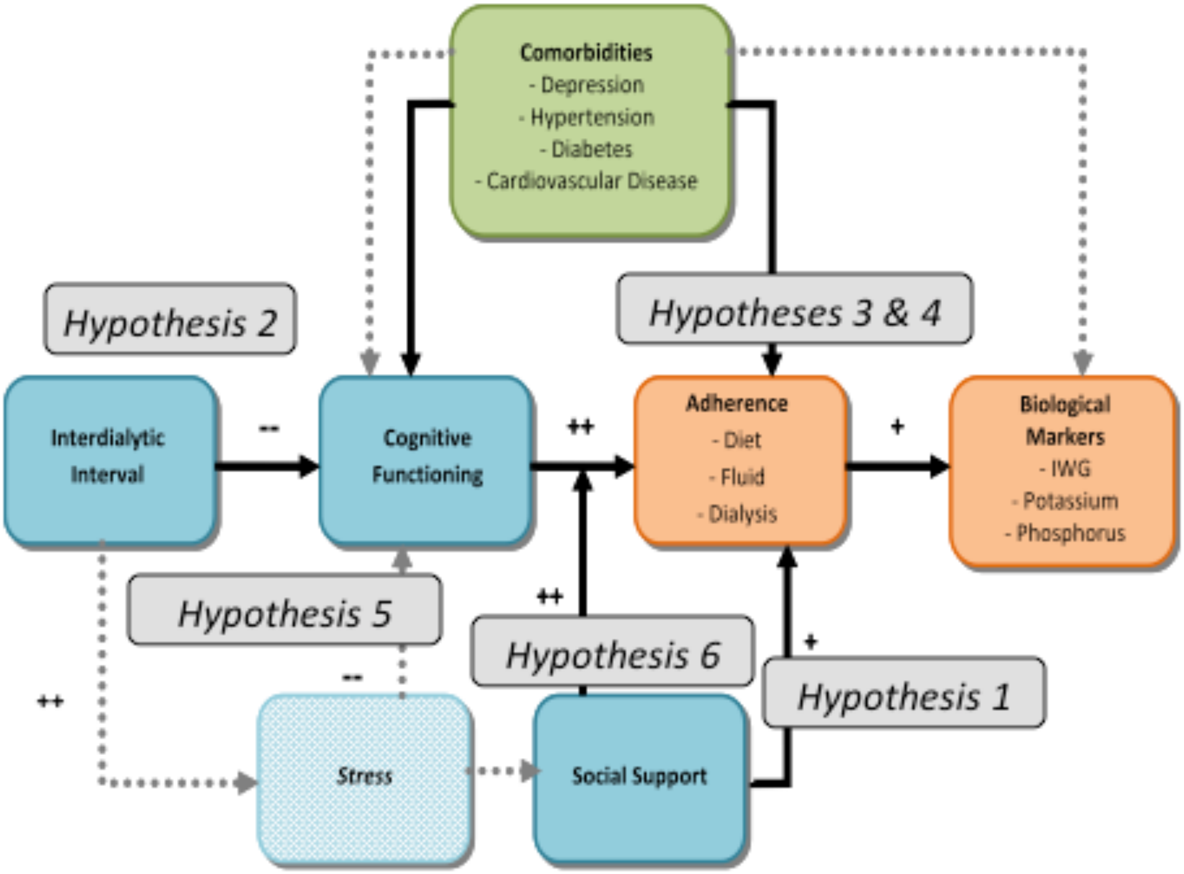
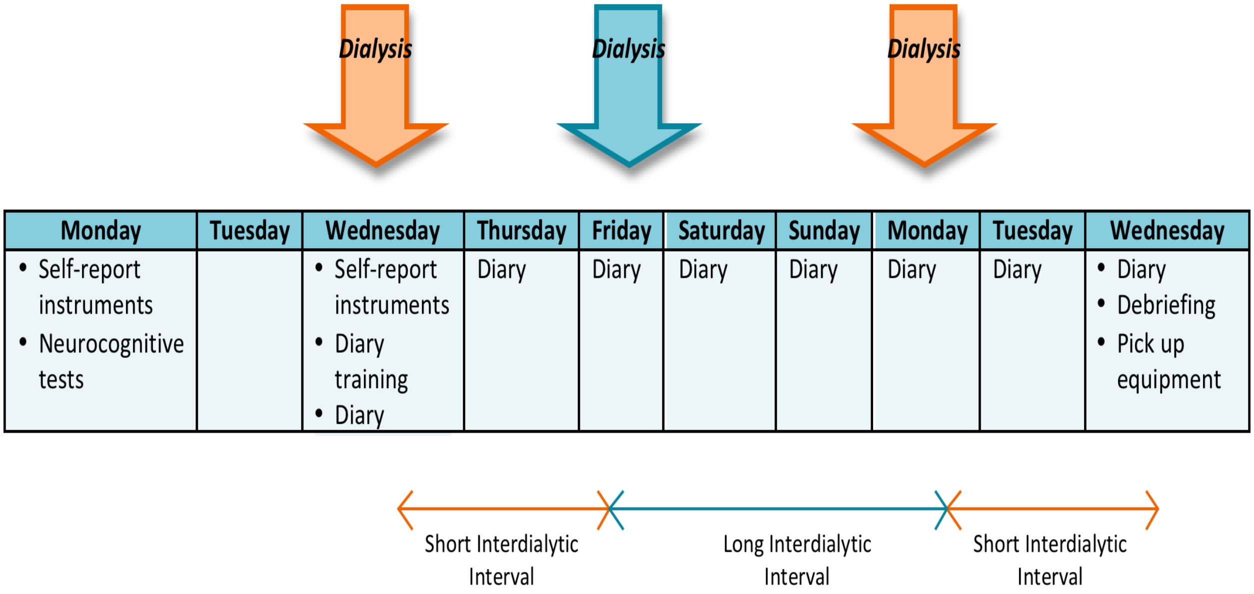


Figure 1. The present study.



Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday	Monday	Tuesday	Wednesday
• Self-report instruments • Neurocognitive tests		• Self-report instruments • Diary training • Diary	Diary	Diary	Diary	Diary	Diary	Diary	• Diary • Debriefing • Pick up equipment

Figure 2. Sample timeline for one participant.

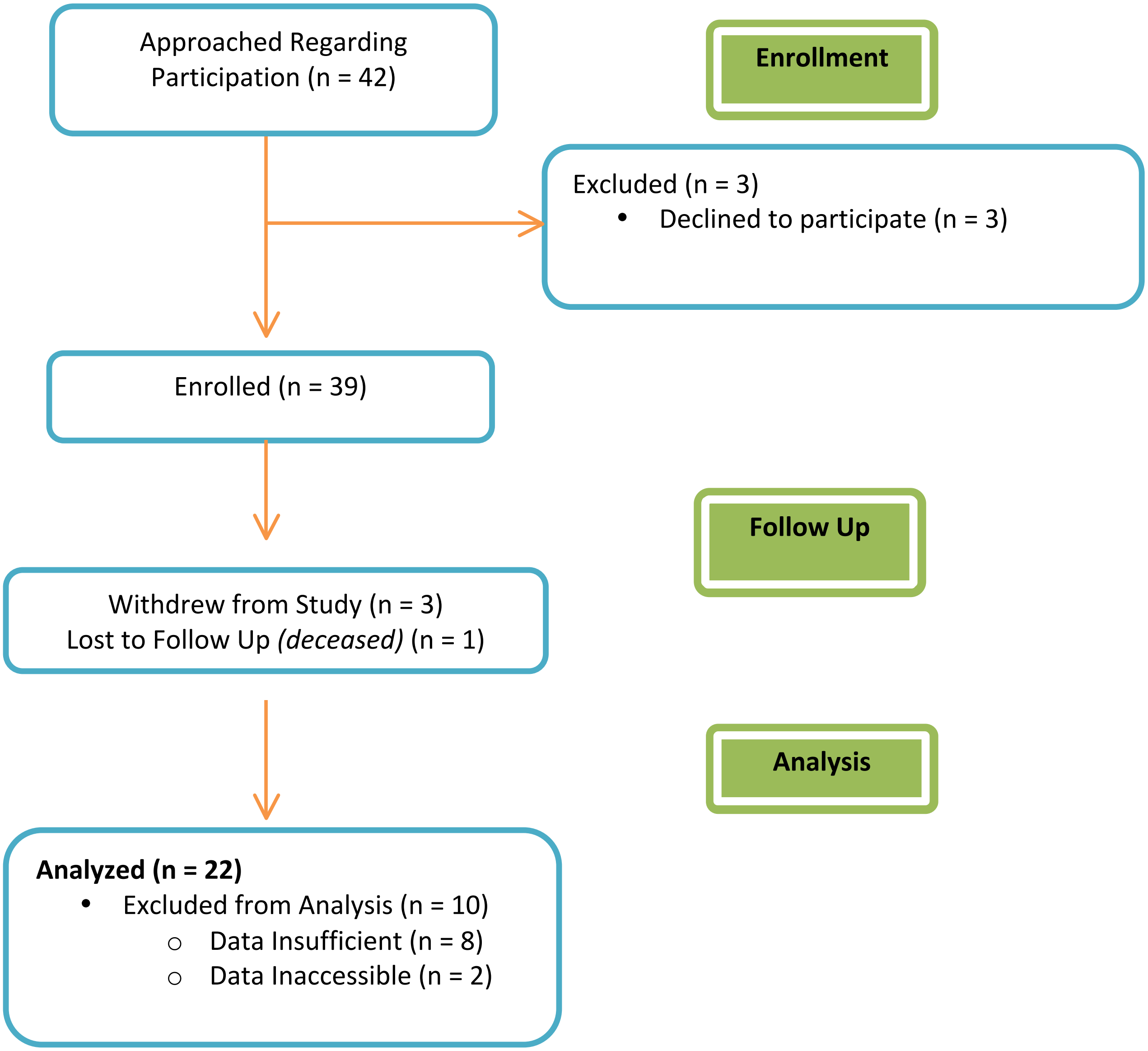


Figure 3. Participant enrollment and retention.

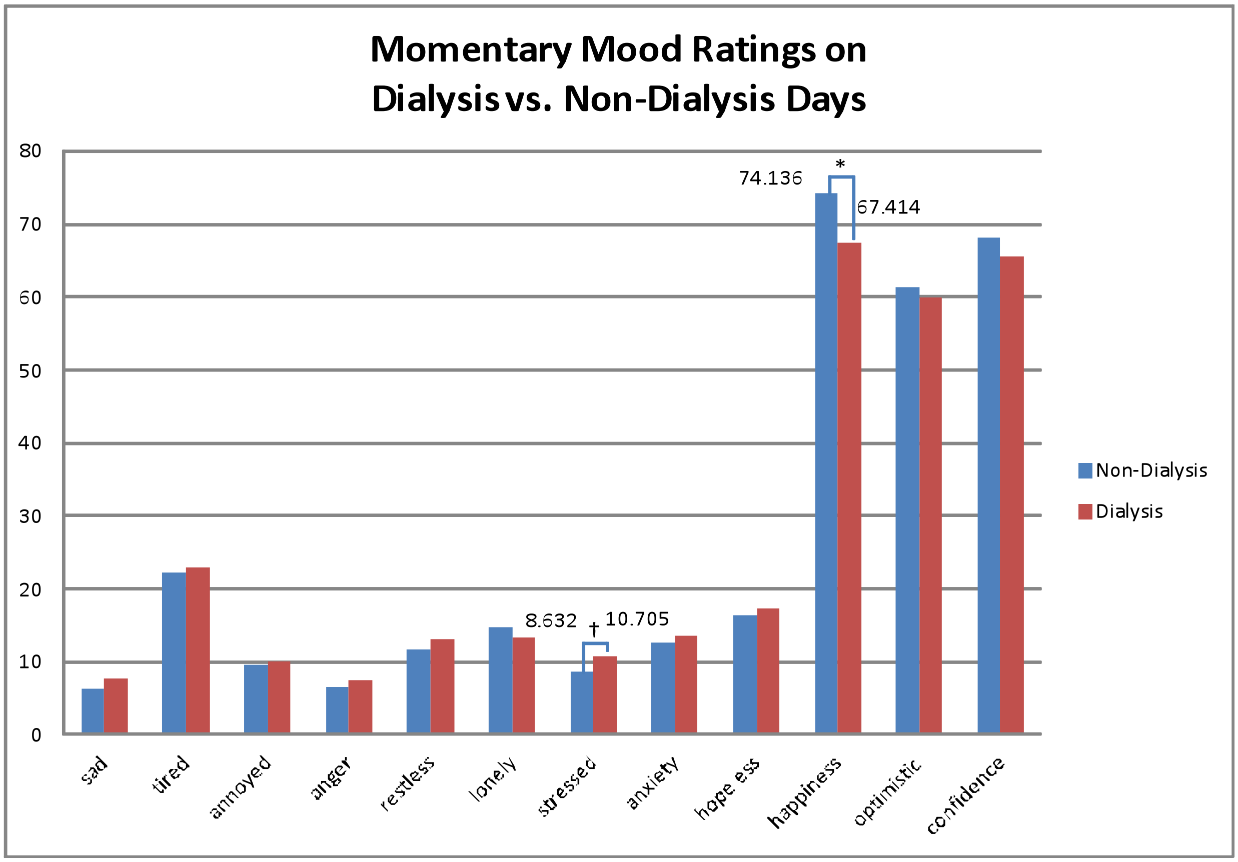


Figure 4. Momentary mood ratings on dialysis vs. non-dialysis days.

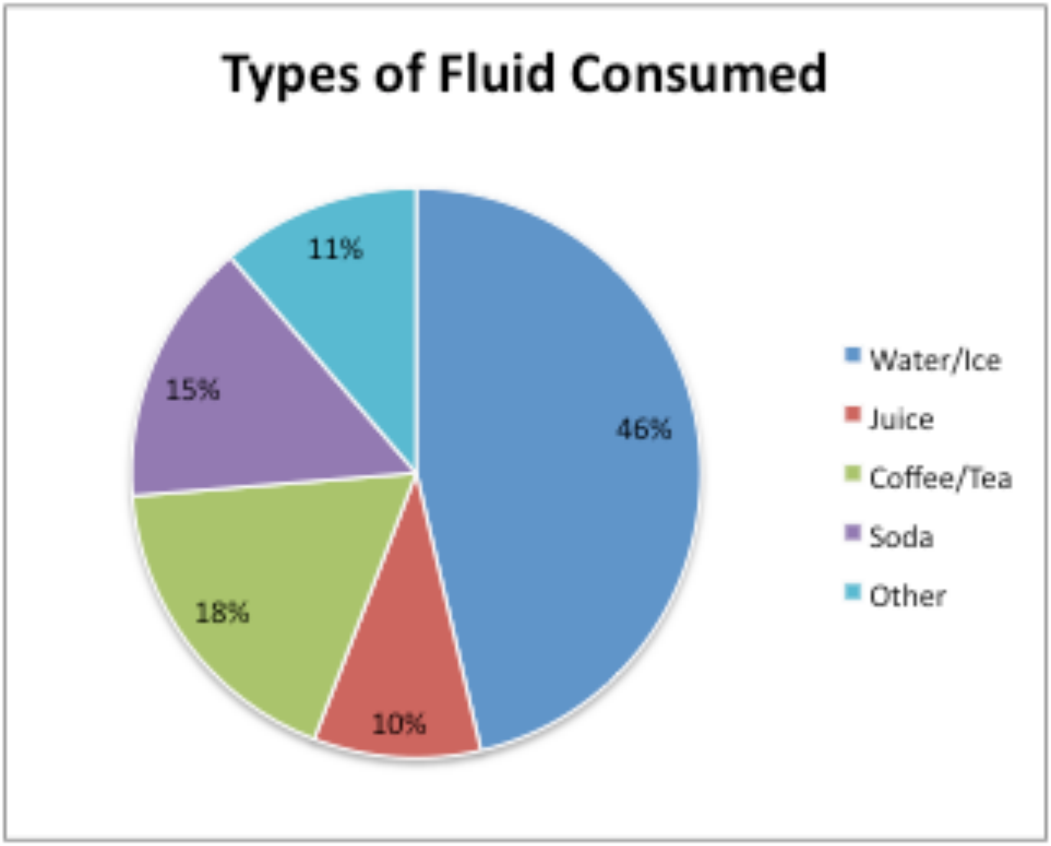


Figure 5. Types of fluids consumed.

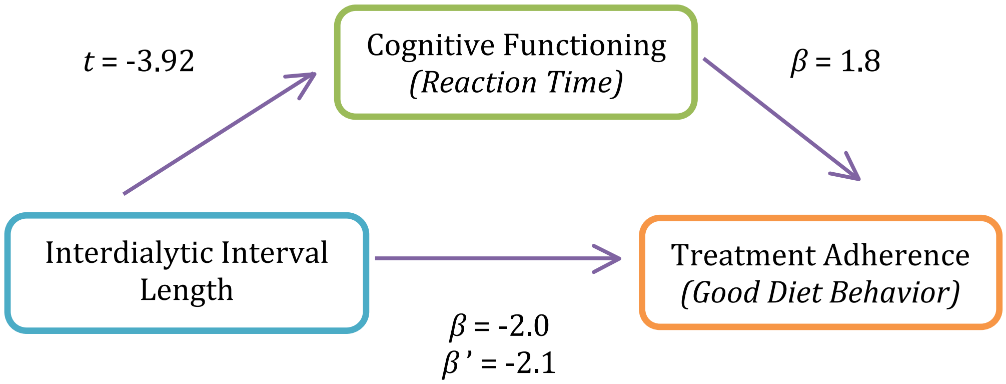


Figure 6. Mediating effects of cognitive dysfunction on IDI length and adherence.

APPENDIX
STUDY MEASURES

TABLE OF CONTENTS

ESRD-AQ

This survey asks for your opinion about how well you follow your dialysis treatment schedule and about medical recommendations related to medication, diet, and fluid intake. This information will help us to understand if you have difficulty following your dialysis treatment, medication regimen, fluid restriction, and recommended diet. Please answer every question by marking the appropriate box. If you are unsure about how to answer, please choose one best answer that applies to you.

I. General Information

1.	When did you begin your hemodialysis treatment?	Beginning Date:	__________ / __________ Month Year
	Did you ever stop and restart hemodialysis treatment?	Yes No	
	If Yes, when did you restart treatment?	Restart Date:	__________ / __________ Month Year
2.	Have you ever had chronic peritoneal dialysis treatment?	Yes No	
	If Yes, when did you have peritoneal dialysis?	I had peritoneal dialysis from:	__________ / __________ Month Year
3.	Have you had a kidney transplant?	Yes No	
	If Yes, when was your kidney transplant?	I had a kidney transplant once from:	__________ / __________ Month Year
		I had kidney transplants twice from:	__________ / __________ Month Year
		and	__________ / __________ Month Year
		If you have had transplants more than twice, please write the dates in the spaces above for the last two transplants.	

4. What type of transportation do you use to go to the dialysis center?	☐ Personal transportation ☐ Bus ☐ Taxi ☐ Medical transportation van ☐ Other (Specify): ______________________________
5. Who accompanies you to the dialysis center?	☐ Myself ☐ Parent ☐ Spouse or Partner ☐ Child ☐ Friend ☐ Other (Specify the person): ____________________

II. Hemodialysis Treatment

6. How many days a week do you receive hemodialysis treatment?	☐ 2 days or less ☐ 3 days ☐ 4 days ☐ More than 4 days ☐ More than 5 days
7. How many hours are you treated for each hemodialysis?	☐ Less than 3 hours ☐ 3 hours ☐ 3 hours and 15 minutes ☐ 3 hours and 30 minutes ☐ 3 hours and 45 minutes ☐ 4 hours ☐ More than 4 hours ☐ Other (Specify the hours):

____

8.	Is your dialysis schedule convenient for you? (Please choose one best answer that applies to you.)	☐ Yes ☐ No, because I have to come to the dialysis center too early ☐ No, because I have to come to the dialysis center too late ☐ No, because of my work schedule ☐ No, because it is my meal time and I get hungry during dialysis treatment ☐ No, because it is my medication time and I have to take medicines/insulin ☐ No, because of (Other): ____
9.	When was the last time a medical professional (your doctor, nurse, dietician, or other medical staff) talked to you about the importance of not missing your dialysis treatment?	☐ This week ☐ Last week ☐ One month ago ☐ More than a month ago ☐ When I first began dialysis treatment ☐ Never ☐ Other (Specify): __________________________________
10.	How often does a medical professional (your doctor, nurse, dietician, or other medical staff) talk to you about the importance of staying for the entire dialysis time during your dialysis treatment?	☐ Every dialysis treatment ☐ Every week ☐ Every month ☐ Every 2 to 3 months ☐ Every 4 to 6 months ☐ When I have abnormal blood or other test results ☐ Rarely ☐ Irregularly ☐ Never

11. How important do you think it is to follow your dialysis schedule?	☐ Highly important ☐ Very important ☐ Moderately important ☐ A little important ☐ Not important
12. Why do you think it is important to follow your dialysis schedule? (Please choose one best answer that applies to you.)	☐ Because I fully understand that my kidney condition requires dialysis as scheduled ☐ Because following the dialysis schedule is important to keep my body healthy ☐ Because medical professional (my doctor, nurse, or dietitian) told me to do so ☐ Because I had an experience that I was sick after I missed dialysis ☐ Because I had an experience that I was hospitalized after I missed dialysis ☐ I don't think following the dialysis schedule is very important to me ☐ Other (Specify): ___________________________________
13. How much difficulty have you had staying for your entire dialysis treatment as ordered by your doctor?	☐ No difficulty ☐ A little difficulty ☐ Moderate difficulty ☐ A lot of difficulty ☐ Extreme difficulty
14. During the *last month,* how many dialysis treatments did you miss completely?	☐ None (I did not miss any treatments) ☐ Missed one dialysis treatment ☐ Missed two dialysis treatments ☐ Missed three dialysis treatments ☐ Missed four or more dialysis treatments

15. What was the main reason you missed your dialysis treatment *last month*?	☐ Not applicable: I did not miss any treatment ☐ Transportation problems ☐ I had other things to do (Please explain): ☐ Hemodialysis access (graft, fistula, or catheter) clotted ☐ Physician (medical or surgical) appointment ☐ I had to go to the emergency room ☐ I was hospitalized ☐ Forgot ☐ “Didn't want to go” or “Couldn't go” *(Go to the next question: Question #16)* ☐ Other (Please specify): ____________
16. (Answer this question when you marked the above question as *“Didn't want to go Couldn't go.”*) Why didn't you want to go to the dialysis center? (Please choose one best answer that applies to you)	☐ Because dialysis treatment makes me anxious ☐ Because I had vomiting/diarrhea ☐ Because I had cramping ☐ Because I often get hungry during dialysis treatment ☐ Because I was physically uncomfortable (Specify the condition) ☐ Because I was sick due to other conditions (Specify the conditions) ☐ Because I was emotionally depressed ☐ Other: ____
17. During the *last month*, ***how many times*** have you ***shortened*** your dialysis time?	☐ Not applicable: I have not shortened my dialysis time ☐ Once ☐ Twice ☐ Three times ☐ Four to five times ☐ Other (Specify frequency): ____________

18. During the *last month*, when your dialysis treatment was shortened, what was the ***average number of minutes?***	☐ Not applicable: I have not shortened my dialysis time ☐ Less than 10 minutes or 10 minutes ☐ 11 to 20 minutes ☐ 21 to 30 minutes ☐ More than 31 minutes ☐ Other (Specify) (If you need to write two or more different time because you shortened dialysis more than once, please use this space): ______________________________
19. What was the main reason you have shortened your dialysis treatment?	☐ Not applicable: I have not shortened my dialysis time ☐ Cramping ☐ Bathroom use ☐ Restlessness ☐ Low blood pressure ☐ Access (graft, fistula, or catheter) clotted ☐ Physician (medical or surgical) appointment ☐ Personal business or emergency ☐ Work schedule ☐ Transportation problems ☐ Staff decision (**Why? Please explain:** For example, poor blood flow, clotting dialyzer, machine malfunction, etc.): ____________________________ ☐ Did not feel like staying ☐ Other (Please specify): _________________________

III. Medication

20. When was the last time a medical professional (your doctor, nurse, dietician or other medical staff) spoke to you about your medicines?

☐ This week
☐ Last week
☐ One month ago
☐ More than a month ago
☐ When I first began dialysis treatment
☐ Never
☐ Other (Specify): ______________________________

21. How often does a medical professional (your doctor, nurse, dietician or other medical staff) talk to you about the importance of taking medicines as ordered?

☐ Every dialysis treatment
☐ Every week
☐ Every month
☐ Every 2 to 3 months
☐ Every 4 to 6 months
☐ When I have abnormal blood or other (for example, blood pressure) test results
☐ Rarely
☐ Irregularly
☐ Never
☐ Other (Specify): ____________

22. How important do you think it is to take your medicines as scheduled?

☐ Highly important
☐ Very important
☐ Moderately important
☐ A little important
☐ Not important

23. Why do you think it is important to take your medicines as scheduled? (Please choose one best answer that applies to you.)	☐ Because I fully understand that my kidney condition requires to take medicines as scheduled ☐ Because taking medicines is important to keep my body healthy ☐ Because a medical professional (my doctor, nurse, dietician, or other medical staff) told me to do so ☐ Because I had an experience that I was sick after I missed medicines ☐ Because I had an experience that I was hospitalized after I missed medicines ☐ I don't think taking medicines is very important to me ☐ Other (Specify): ___________________________
24. Have you had any difficulty with taking your medicines?	☐ No ☐ Yes
25. How much difficulty have you had with taking your prescribed medicines?	☐ No difficulty ☐ A little difficulty ☐ Moderate difficulty ☐ A lot of difficulty ☐ Extreme difficulty
26. During the *past week*, ***how often*** have you missed your prescribed medicines?	☐ None of the time: I did not miss my medicines ☐ Very seldom ☐ About half of the time ☐ Most of the time ☐ All of the time

27. What was the main reason for not taking your prescribed medicines this *past week*?	☐ Not applicable: I did not miss medicines ☐ Forgot to take medicines ☐ Forgot to order medicines ☐ Medicine cost ☐ Inconvenience ☐ I was hospitalized ☐ Side effects *(Go to question #28)* ☐ Other: ___________________________________
28. *(Answer this question when you have marked the above question as "Side effects.")* What kind of side effect(s) to the medication(s) did you have? (Please choose one best answer that applies to you.)	☐ Loss of appetite ☐ Nausea/vomiting/diarrhea/constipation ☐ Stomach pain ☐ Dizziness ☐ Headache ☐ Itching/skin problems ☐ Other (Specify symptoms): _______________________________________

IV. Fluid

29. When was the last time a medical professional (your doctor, nurse or dietician or other medical staff) spoke to you about your fluid restrictions?	☐ This week ☐ Last week ☐ One month ago ☐ More than a month ago ☐ When I began dialysis treatment ☐ Never(☐ Other (Specify)(7): _____________

30. How often does a medical professional (your doctor, nurse, dietician or other medical staff) talk to you about the importance of fluid restriction?

- ☐ Every dialysis treatment
- ☐ Every week
- ☐ Every month
- ☐ Every 2 to 3 months
- ☐ Every 4 to 6 months
- ☐ When I have abnormal blood or other (for example, blood pressure) test results
- ☐ Rarely
- ☐ Irregularly
- ☐ Never
- ☐ Other (Specify): ___________________

31. During the *past week*, how often have you followed the ***fluid restriction*** recommendations?

- ☐ All of the time
- ☐ Most of the time
- ☐ About half of the time
- ☐ Very seldom
- ☐ None of the time

32. How important do you think it is to limit your fluid intake?

- ☐ Highly important
- ☐ Very important
- ☐ Moderately important
- ☐ A little important
- ☐ Not important

33. Why do you think it is important for you to limit your fluid intake? (Please choose one best answer that applies to you.)	☐ Because I fully understand that my kidney condition requires limiting fluid intake ☐ Because limiting fluid intake is important to keep my body healthy ☐ Because a medical professional (my doctor, nurse, dietician, or other medical staff) told me to do so ☐ Because I got sick after I drank lots of fluid ☐ Because I was hospitalized after I drank lots of fluid ☐ I don't think limiting fluid is very important to me ☐ Other (Specify): __________________
34. Have you had any difficulty with limiting your fluid intake?	☐ No ☐ Yes
35. How much difficulty have you had following your fluid restriction recommendations?	☐ No difficulty ☐ A little difficulty ☐ Moderate difficulty ☐ A lot of difficulty ☐ I was unable to follow any recommendations at all
36. If you had difficulty following your fluid restriction recommendations, ***what type of difficulty*** have you had?	☐ No difficulty ☐ Not interested ☐ I was unable to control fluid intake ☐ I don't understand how to follow the fluid restriction ☐ Other: ________________________

37. During the past week, how many times have you weighed yourself ***at home*** (outside dialysis center)?

☐ More than 3 times
☐ 3 times
☐ Twice
☐ Once
☐ None of the time
☐ Other: ____________

38. How important do you think it is to weigh yourself daily?

☐ Highly important
☐ Very important
☐ Moderately important
☐ A little important
☐ Not important

V. Diet

39. When was last time a medical professional (your doctor, nurse, dietician, or other medical staff) talked to you about your diet?

☐ This week
☐ Last week
☐ One month ago
☐ More than a month ago
☐ When I first began dialysis treatment
☐ Never
☐ Other (Specify): ________________________________

40. How often does a medical professional (your doctor, nurse, dietician or other medical staff) talk to you about the importance of following a proper diet?

☐ Every dialysis treatment
☐ Every week
☐ Every month
☐ Every 2 to 3 months
☐ Every 4 to 6 months
☐ When I have abnormal blood or other (for example, blood pressure) test results
☐ Rarely
☐ Irregularly
☐ Never
☐ Other (Specify): ________________________

---

41. How important do you think it is to watch the types of food you eat each day?

☐ Highly important
☐ Very important
☐ Moderately important
☐ A little important
☐ Not important

---

42. Why do you think it is important for you to watch your diet daily? (Please choose one best answer that applies to you.)

☐ Because I fully understand that my kidney condition requires to watch my diet
☐ Because watching my diet is important to keep my body healthy
☐ Because a medical professional (my doctor, nurse, or dietician) told me to do so
☐ Because I got sick after eating certain food that I was not supposed to eat
☐ Because I was hospitalized after eating certain food that I was not supposed to eat
☐ I don't think watching my diet is important to me

43. Have you had any difficulty following your dietary recommendations?	☐ No ☐ Yes
44. How much difficulty have you had following your dietary recommendations?	☐ No difficulty ☐ A little difficulty ☐ Moderate difficulty ☐ A lot of difficulty ☐ I was unable to follow any recommendations at all
45. What type of difficulty have you had keeping your dietary recommendations?	☐ Not applicable: No difficulty ☐ I was not willing to control what I want to eat ☐ I was unable to avoid certain unrecommended food ☐ I don't understand what type of diet to follow ☐ Other (Specify): ________________________
46. During the *past week*, how many times have you followed the diet recommendations?	☐ All of the time ☐ Most of the time ☐ About half of the time ☐ Very seldom ☐ None of the time

RAAQ

Please indicate the degree to which these statements are true of you.

	Strongly Disagree				**Strongly Agree**
1. My diet fits into my lifestyle.	1	2	3	4	5
2. Patients should make up their own minds about their kidney failure treatment.	1	2	3	4	5
3. Fluid is vital for my physical well-being.	1	2	3	4	5
4. My social functions are prevented by my treatment.	1	2	3	4	5
5. My dietician is overconcerned with fluid restriction.	1	2	3	4	5
6. I feel the benefits of restricting foods.	1	2	3	4	5
7. I am able to drink fluid today as ever.	1	2	3	4	5
8. I worry about gaining weight.	1	2	3	4	5
9. My dietician is overconcerned with food restriction.	1	2	3	4	5
10. It has been easier to keep to my diet over time.	1	2	3	4	5
11. I do not feel benefits of my diet restriction.	1	2	3	4	5
12. I don’t have any worry about gaining weight.	1	2	3	4	5
13. I feel the benefits of restricting salt.	1	2	3	4	5
14. I feel better on my kidney disease diet.	1	2	3	4	5
15. Restricting fluid prevents my enjoyment of life.	1	2	3	4	5
16. My kidney disease diet is too much trouble.	1	2	3	4	5
17. My kidney disease diet severely disrupts my life.	1	2	3	4	5
18. My kidney disease diet is costly.	1	2	3	4	5
19. My diet has no impact on my social life.	1	2	3	4	5
20. I put a lot of importance on my family and friends in my treatment.	1	2	3	4	5
21. Breaking my diet does not cause me any consequences.	1	2	3	4	5
22. I am unable to accept the restrictions of my diet.	1	2	3	4	5
23. Over time, my diet has become more difficult to manage.	1	2	3	4	5
24. I feel guilty when I break my diet.	1	2	3	4	5
25. My kidney disease diet fits easily into my life.	1	2	3	4	5
26. I experience a lot of frustration because of my diet.	1	2	3	4	5

RABQ

Please indicate the degree to which these statements are true of you.

	Never				**Always**
1. I listen to my dietician.	1	2	3	4	5
2. I have difficulty restricting beer or wine.	1	2	3	4	5
3. I cannot resist forbidden foods.	1	2	3	4	5
4. I bargain over food.	1	2	3	4	5
5. I feel that breaking my diet makes no difference.	1	2	3	4	5
6. I get careless about food when I am upset.	1	2	3	4	5
7. I drink fluid today as I always have.	1	2	3	4	5
8. My family helps with my diet and fluid.	1	2	3	4	5
9. I eat out.	1	2	3	4	5
10. I drink more than I should when I am upset.	1	2	3	4	5
11. I avoid foods containing salt.	1	2	3	4	5
12. I am careful with fluid.	1	2	3	4	5
13. I drank a lot of fluid in the past.	1	2	3	4	5
14. I am preoccupied with food.	1	2	3	4	5
15. I take my prescribed medication.	1	2	3	4	5
16. I am careful to weigh my food.	1	2	3	4	5
17. I find it difficult to restrict fluid in the summer.	1	2	3	4	5
18. I weigh myself regularly.	1	2	3	4	5
19. I get away with drinking extra fluid.	1	2	3	4	5
20. I decide on my own food choices.	1	2	3	4	5
21. I always use salt.	1	2	3	4	5
22. I restrict my potassium.	1	2	3	4	5
23. I restrict my salt.	1	2	3	4	5
24. I take my medication.	1	2	3	4	5
25. I restrict my fluids.	1	2	3	4	5

KDQOL-SF

This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. This survey includes a wide variety of questions about your health and your life. We are interested in how you feel about each of these issues. Please answer the questions by circling the appropriate number or by filling in the answer as requested. Several items in the survey ask about the effect of kidney disease on your life. Some items will ask about limitations related to your kidney disease and some items will ask about your well-being. Some questions may look like others, but each one is different. Please answer every question as honestly as possible. If you are unsure about how to answer a question, please give the best answer you can. This will allow us to have an accurate picture of the different experiences of individuals with kidney disease.

1. **In general, would you say your health is:**

Excellent	Very Good	Good	Fair	Poor

2. **Compared to one year ago**, how would you rate your health in general **now**?

Much better now than one year ago □
Somewhat better now than one year ago □
About the same as one year ago □
Somewhat worse than one year ago □
Much worse than one year ago □

3. The following items are about activities you might do during a typical day. **Does your health now** limit you in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	No, not limited at all
Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	1	2	3
Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, golf	1	2	3
Lifting or carrying groceries	1	2	3
Climbing several flights of stairs	1	2	3
Climbing one flight of stairs	1	2	3
Bending, kneeling, or stooping	1	2	3
Walking more than a mile	1	2	3
Walking one block	1	2	3
Bathing or dressing yourself	1	2	3

4. During the past 4 weeks, have you had any of the following problems with your work or other regular activities as a result of your **physical health**?

Cut down on the amount of time you spent on work or other activities?	Yes	No
Accomplished less than you would have liked?	Yes	No
Were limited in the kind of work our other activities you could do?	Yes	No
Had difficulty performing the work or other activities (for example, it took extra effort)?	Yes	No

5. During the past 4 weeks, have you had any of the following problems with your work or other regular activities as a result of any **emotional problem**s (such as feeling depressed or anxious)?

Cut down on the amount of time you spent on work or other activities?	Yes	No
Accomplished less than you would have liked?	Yes	No
Didn’t do work or other activities as carefully as usual?	Yes	No

6. During the past 4 weeks, to what extent have your **physical health or emotional problems** interfered with your normal social activities with family, friends, neighbors, or groups?

Not at all ☐
Slightly ☐
Moderately ☐
Quite a bit ☐
Extremely ☐

7. How much **bodily pain** have you had during the past 4 weeks?

None ☐
Very mild ☐
Mild ☐
Moderate ☐
Severe ☐
Very severe ☐

8. During the past 4 weeks, how much did pain **interfere** with your normal work (including both work outside the home and housework)?

Not at all ☐
Slightly ☐
Moderately ☐
Quite a bit ☐
Extremely ☐

9. During the past 4 weeks, how much of the time have your physical health or emotional problems interfered with your **social activities** (like visiting with friends, relatives, etc.)?

All of the time ☐
Most of the time ☐
Some of the time ☐
A little of the time ☐
None of the time ☐

10. Please choose the answer that best describes how **TRUE** or **FALSE** each of the following statements is for you.

	Definitely True	**Mostly True**	**Don't Know**	**Mostly False**	**Definitely False**
I seem to get sick a little easier than other people	1	2	3	4	5
I am as healthy as anybody I know	1	2	3	4	5
I expect my health to get worse	1	2	3	4	5
My health is excellent	1	2	3	4	5

11. How **TRUE** or **FALSE** is each of the following statements for you?

	Definitely True	**Mostly True**	**Don't Know**	**Mostly False**	**Definitely False**
My kidney disease interferes too much with my life	1	2	3	4	5
Too much of my time is spent dealing with my kidney disease	1	2	3	4	5
I feel frustrated dealing with my kidney disease	1	2	3	4	5
I feel like a burden on my family	1	2	3	4	5

12. These questions are about how you feel and how things have been going during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the past 4 weeks…

	None of the Time	A Little of the Time	Some of the Time	A Good Bit of the Time	Most of the Time	All of the Time
Did you isolate yourself from people around you?	1	2	3	4	5	6
Did you react slowly to things that were said or done?	1	2	3	4	5	6
Did you act irritable toward those around you?	1	2	3	4	5	6
Did you have difficulty concentrating or thinking?	1	2	3	4	5	6
Did you get along well with other people?	1	2	3	4	5	6
Did you become confused?	1	2	3	4	5	6

13. During the past 4 weeks, to what extent were you bothered by each of the following?

	Not at All Bothered	Somewhat Bothered	Moderately Bothered	Very Much Bothered	Extremely Bothered
Soreness in your muscles?	1	2	3	4	5
Chest pain?	1	2	3	4	5
Cramps?	1	2	3	4	5
Itchy skin?	1	2	3	4	5
Dry skin?	1	2	3	4	5
Shortness of breath?	1	2	3	4	5
Faintness or dizziness?	1	2	3	4	5
Lack of appetite?	1	2	3	4	5
Washed out or drained?	1	2	3	4	5
Numbness in hands or feet?	1	2	3	4	5
Nausea or upset stomach?	1	2	3	4	5
Problems with your access site?	1	2	3	4	5

14. Some people are bothered by the effects of kidney disease on their daily life, while others are not. How much does kidney disease bother you in each of the following areas?

	Not at All Bothered	Somewhat Bothered	Moderately Bothered	Very Much Bothered	Extremely Bothered
Fluid restriction?	1	2	3	4	5
Dietary restriction?	1	2	3	4	5
Your ability to work around the house?	1	2	3	4	5
Your ability to travel?	1	2	3	4	5
Being dependent on doctors and other medical staff?	1	2	3	4	5
Stress or worries caused by kidney disease?	1	2	3	4	5
Your sex life?	1	2	3	4	5
Your personal appearance?	1	2	3	4	5

15. For the following question, please rate your sleep using a scale ranging from 0 (Very Bad) to 10 (Very Good). If you think your sleep is halfway between Very Bad and Very Good, please circle 5. If you think your sleep is one level better, circle 6. If you think your sleep is one level worse, circle 4, and so on.

On a scale from 0 to 10, how would you rate your sleep overall?

0	1	2	3	4	5	6	7	8	9	10
Very Bad										Very Good

16. How often in the past 4 weeks did you…

	None of the Time	A Little of the Time	Some of the Time	A Good Bit of the Time	Most of the Time	All of the Time
Awaken during the night and have trouble falling asleep again?	1	2	3	4	5	6
Get the amount of sleep you needed?	1	2	3	4	5	6
Have trouble staying awake during the day?	1	2	3	4	5	6

17. Concerning your family and friends, how satisfied are you with…

	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied	Very Satisfied
The amount of time you are able to spend with your family and friends?	1	2	3	4
The support you receive from your family and friends?	1	2	3	4

18. During the past 4 weeks, did you work at a paying job?	Yes	No
19. Does your health keep you from working at a paying job?	Yes	No

20. Overall, how would you rate your health?

0	1	2	3	4	5	6	7	8	9	10
Worst possible (as bad or worse than being dead)					Halfway between worst and best					Best possible health

21. How TRUE or FALSE is each of the following statements?

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
Dialysis staff encourage me to be as independent as possible.	1	2	3	4	5
Dialysis staff help me in coping with my kidney disease.	1	2	3	4	5

22. Do you currently take prescription medications regularly (4 or more days a week) that are prescribed by your doctor for a medical condition? Please don't count over the counter medications like antacids or aspirin. Yes No

If yes, how many medications do you take? __________

23. How many days total in the last 6 months did you stay in a hospital overnight or longer? (If none, please write 0) __________

24. How many days total in the last 6 months did you receive care at a hospital, but came home the same day? (If none, please write 0) __________

25. What caused your kidney disease?

	Check ALL that apply
Don’t know	☐
Hypertension (High Blood Pressure)	☐
Diabetes	☐
Polycystic Kidney Disease	☐
Chronic Glomerulonephritis	☐
Chronic Pyelonephritis	☐
Other (Please specify):	____________________

26. When were you born?

______________ / ______________ / ______________
Month Day Year

27. What is the highest level of school you have completed?

8th grade or less	☐
Some high school	☐
High School diploma or GED	☐
Vocational school or some college	☐
College degree	☐
Professional or Graduate degree	☐

28. What is your gender? Male Female

29. How do you describe yourself?

African American or Black	☐
Hispanic or Latino	☐
Native American or American Indian	☐
Asian or Pacific Islander	☐
White	☐
Other	☐

30. Are you currently married? Yes No

31. During the last 30 days, were you:

Working full-time ☐
Working part-time ☐
Unemployed, laid off, or looking for work ☐
Retired ☐
Disabled ☐
In school ☐
Keeping house ☐
None of the above ☐

32. What kind of health insurance do you have?

None, I have no health insurance ☐
Medicare only ☐
Medicare and any other insurance ☐
Medi-Cal only ☐
Private, fee-for-service health insurance ☐
HMO, PPO, IPA, or other pre-paid plan ☐
Other ☐
Don’t know ☐

MSPSS

Please check the box to indicate how much you agree with each statement.

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
There is a special person who is around when I am in need.					
There is a special person with whom I can share my joys and sorrows.					
My family really tries to help me.					
I get the emotional help and support I need from my family.					
I have a special person who is a real source of comfort to me.					
My friends really try to help me.					
I can count on my friends when things go wrong.					
I can talk about my problems with my family.					
I have friends with whom I can share my joys and sorrows.					
There is a special person in my life who cares about my feelings.					
My family is willing to help me make decisions.					
I can talk about my problems with my friends.					

MDSSQ-FV

For this section, please indicate **HOW OFTEN A FAMILY MEMBER HELPS YOU** with the following activities.

How OFTEN does a family member…

	Never	**Less than twice a month**	**Twice a month**	**Once a week**	**Several times a week**	**At least once a day**
1. Give you your medication?	0	1	2	3	4	5
2. Remind you to take your medication?	0	1	2	3	4	5
3. Praise you for taking your medication correctly or on time?	0	1	2	3	4	5
4. Keep track of when you have taken your medication and when you need to take more?	0	1	2	3	4	5
5. Check after you've taken your medication to make sure you have done it?	0	1	2	3	4	5
6. Let you know they appreciate how difficult it is to take your medication?	0	1	2	3	4	5
7. Encourage you to eat the right foods?	0	1	2	3	4	5
8. Let you know they understand how important it is for you to eat right?	0	1	2	3	4	5
9. Let you know they understand how important it is for you to limit your fluids?	0	1	2	3	4	5
10. Ask if certain foods are okay for you to eat, before serving them?	0	1	2	3	4	5
11. Do the grocery shopping for your meals?	0	1	2	3	4	5
12. Schedule meals at the times you need to eat?	0	1	2	3	4	5
13. Remind you about sticking to your meal plan?	0	1	2	3	4	5
14. Suggest foods you can eat on your meal plan?	0	1	2	3	4	5
15. Join you in eating the same foods as you?	0	1	2	3	4	5
16. Get on your case after you ate something you shouldn't?	0	1	2	3	4	5

How OFTEN does a family member…

	Never	Less than twice a month	Twice a month	Once a week	Several times a week	At least once a day
17. Get on your case for drinking too many fluids?	0	1	2	3	4	5
18. Avoid tempting you with food or drinks that you shouldn't have?	0	1	2	3	4	5
19. Watch what you eat and drink to make sure that you eat the right foods?	0	1	2	3	4	5
20. Cook meals for you that fit your meal plan?	0	1	2	3	4	5
21. Choose restaurants that serve food you can eat?	0	1	2	3	4	5
22. Eat at the same time you do?	0	1	2	3	4	5
23. Praise you for following your diet?	0	1	2	3	4	5
24. Praise you for sticking to your fluid limits?	0	1	2	3	4	5
25. Tell you when you've eaten too much or too little?	0	1	2	3	4	5
26. Tell you when you drank too much fluid?	0	1	2	3	4	5
27. Show they're pleased when you've eaten right?	0	1	2	3	4	5
28. Show they're pleased when you've stuck to your fluid limit?	0	1	2	3	4	5
29. Keep track of your mean plan for you?	0	1	2	3	4	5
30. Keep track of your fluid intake for you?	0	1	2	3	4	5
31. Buy special foods that you can eat?	0	1	2	3	4	5
32. Tell you not to eat something you shouldn't?	0	1	2	3	4	5
33. Tell you not to drink too many fluids?	0	1	2	3	4	5
34. Are available to listen to concerns or worries about your kidney disease and dialysis?	0	1	2	3	4	5
35. Give you things to read on kidney disease and dialysis?	0	1	2	3	4	5

How OFTEN does a family member…

	Never	Less than twice a month	Twice a month	Once a week	Several times a week	At least once a day
36. Tell you how well you've been doing with your dialysis and kidney disease care?	0	1	2	3	4	5
37. Encourage you to do a good job of taking care of your kidney disease?	0	1	2	3	4	5
38. Understand when you sometimes make mistakes in taking care of your kidney disease?	0	1	2	3	4	5

Do you have diabetes and check your blood glucose at home? *If **yes**, continue. If **no**, skip to Question #51.*							
How OFTEN does a family member…	**Never**	**Less than twice a month**	**Twice a month**	**Once a week**	**Several times a week**	**At least once a day**	**NOT APPLICABLE**
39. Ask you about the results of your blood tests?	0	1	2	3	4	5	
40. Watch you test your blood sugars to see what the values are?	0	1	2	3	4	5	
41. Test your blood sugar for you?	0	1	2	3	4	5	
42. Remind you to test your blood sugar?	0	1	2	3	4	5	
43. Make sure you have materials needed for blood testing?	0	1	2	3	4	5	
44. Let you know that they appreciate how hard it is to test blood sugars every day?	0	1	2	3	4	5	
45. Set up materials you need for testing your blood sugar?	0	1	2	3	4	5	
46. Praise you for testing your blood sugar on your own?	0	1	2	3	4	5	
47. Help out when you test your blood sugar?	0	1	2	3	4	5	
48. Keep track of testing results for you?	0	1	2	3	4	5	
49. Watch for signs that your blood sugar is low?	0	1	2	3	4	5	
50. Help out when you might be having a reaction?	0	1	2	3	4	5	

For this section, please indicate **HOW SUPPORTED YOU FEEL** when your family members help you with each activity.

How SUPPORTED do you feel when a family member…

	Not Supported	Neutral	A little supported	Supported	Very Supported
51. Gives you your medication?	0	1	2	3	4
52. Reminds you to take your medication?	0	1	2	3	4
53. Praises you for taking your medication correctly or on time?	0	1	2	3	4
54. Keeps track of when you have taken your medication and when you need to take more?	0	1	2	3	4
55. Checks after you've taken your medication to make sure you have done it?	0	1	2	3	4
56. Lets you know they appreciate how difficult it is to take your medication?	0	1	2	3	4
57. Encourages you to eat the right foods?	0	1	2	3	4
58. Lets you know they understand how important it is for you to eat right?	0	1	2	3	4
59. Lets you know they understand how important it is for you to limit your fluids?	0	1	2	3	4
60. Asks if certain foods are okay for you to eat, before serving them?	0	1	2	3	4
61. Does the grocery shopping for your meals?	0	1	2	3	4
62. Schedules meals at the times you need to eat?	0	1	2	3	4
63. Reminds you about sticking to your meal plan?	0	1	2	3	4
64. Suggests foods you can eat on your meal plan?	0	1	2	3	4
65. Joins you in eating the same foods as you?	0	1	2	3	4
66. Gets on your case after you ate something you shouldn't?	0	1	2	3	4

How SUPPORTED do you feel when a family member…

	Not Supported	Neutral	A little supported	Supported	Very Supported
67. Gets on your case for drinking too many fluids?	0	1	2	3	4
68. Avoids tempting you with food or drinks that you shouldn't have?	0	1	2	3	4
69. Watches what you eat and drink to make sure that you eat the right foods?	0	1	2	3	4
70. Cooks meals for you that fit your meal plan?	0	1	2	3	4
71. Chooses restaurants that serve food you can eat?	0	1	2	3	4
72. Eats at the same time you do?	0	1	2	3	4
73. Praises you for following your diet?	0	1	2	3	4
74. Praises you for sticking to your fluid limits?	0	1	2	3	4
75. Tells you when you've eaten too much or too little?	0	1	2	3	4
76. Tells you when you drank too much fluid?	0	1	2	3	4
77. Shows they're pleased when you've eaten right?	0	1	2	3	4
78. Shows they're pleased when you've stuck to your fluid limit?	0	1	2	3	4
79. Keeps track of your mean plan for you?	0	1	2	3	4
80. Keeps track of your fluid intake for you?	0	1	2	3	4
81. Buys special foods that you can eat?	0	1	2	3	4
82. Tells you not to eat something you shouldn't?	0	1	2	3	4
83. Tells you not to drink too many fluids?	0	1	2	3	4
84. Are available to listen to concerns or worries about your kidney disease and dialysis?	0	1	2	3	4
85. Gives you things to read on kidney disease and dialysis?	0	1	2	3	4
86. Tells you how well you've been doing with your dialysis and kidney disease care?	0	1	2	3	4

How SUPPORTED do you feel when a family member…

	Not Supported	Neutral	A little supported	Supported	Very Supported
87. Encourages you to do a good job of taking care of your kidney disease?	0	1	2	3	4
88. Understands when you sometimes make mistakes in taking care of your kidney disease?	0	1	2	3	4

Do you have diabetes and check your blood glucose at home?
*If **yes**, continue. If **no**, skip the remaining questions.*

How SUPPORTED do you feel when a family member…	Not Supported	Neutral	A little supported	Supported	Very Supported	NOT APPLICABLE
89. Asks you about the results of your blood tests?	0	1	2	3	4	
90. Watches you test your blood sugars to see what the values are?	0	1	2	3	4	
91. Tests your blood sugar for you?	0	1	2	3	4	
92. Reminds you to test your blood sugar?	0	1	2	3	4	
93. Makes sure you have materials needed for blood testing?	0	1	2	3	4	
94. Lets you know that they appreciate how hard it is to test blood sugars every day?	0	1	2	3	4	
95. Sets up materials you need for testing your blood sugar?	0	1	2	3	4	
96. Praises you for testing your blood sugar on your own?	0	1	2	3	4	
97. Helps out when you test your blood sugar?	0	1	2	3	4	
98. Keeps track of testing results for you?	0	1	2	3	4	
99. Watches for signs that your blood sugar is low?	0	1	2	3	4	
100. Helps out when you might be having a reaction?	0	1	2	3	4	

CDI

Please read each group of statements carefully, then pick out the **one statement** in each group which best describes the way you have been feeling during the **PAST WEEK, INCLUDING TODAY**! Check the line next to the statement you have picked.

If several statements in the group seem to apply equally well, simply check the line next to the statement which has the largest number. Be sure that you do **not** check more than one line for Item 15 (change in sleeping pattern) and Item 17 (change in appetite).

1. Sadness

_____ I do not feel sad. (0)
_____ I feel sad much of the time. (1)
_____ I am sad all the time. (2)
_____ I am so sad or unhappy that I can't stand it. (3)

2. Pessimism

_____ I am not discouraged about my future. (0)
_____ I feel more discouraged about my future than I used to be. (1)
_____ I do not expect things to work out for me. (2)
_____ I feel my future is hopeless and will only get worse. (3)

3. Past Failure

_____ I do not feel like a failure. (0)
_____ I have failed more than I should have. (1)
_____ As I look back, I see a lot of failures. (2)
_____ I feel I am a total failure as a person. (3)

4. Loss of Pleasure

_____ I get as much pleasure as I ever did from the things I enjoy. (0)
_____ I don't enjoy things as much as I used to. (1)
_____ I get very little pleasure from the things I used to enjoy. (2)
_____ I can't get any pleasure from the things I used to enjoy. (3)

5. Guilty Feelings

_____ I don't feel particularly guilty. (0)
_____ I feel guilty over many things I have done or should have done. (1)
_____ I feel quite guilty most of the time. (2)
_____ I feel guilty all of the time. (3)

6. Punishment Feelings

_____ I don't feel I am being punished. (0)
_____ I feel I may be punished. (1)
_____ I expect to be punished. (2)
_____ I feel I am being punished. (3)

7. Self Dislike
_____ I feel the same about myself as ever. (0)
_____ I have lost confidence in myself. (1)
_____ I am disappointed in myself. (2)
_____ I dislike myself. (3)

8. Self Criticalness
_____ I don't criticize or blame myself more than usual. (0)
_____ I am more critical of myself than I used to be. (1)
_____ I criticize myself for all of my faults. (2)
_____ I blame myself for everything bad that happens. (3)

9. Crying
_____ I don't cry any more than I used to. (0)
_____ I cry more than I used to. (1)
_____ I cry over every little thing. (2)
_____ I feel like crying but I can't. (3)

10. Agitation
_____ I am no more restless or wound up than usual. (0)
_____ I feel more restless or wound up than usual. (1)
_____ I am so restless or agitated that it's hard to stay still. (2)
_____ I am so restless or agitated I have to keep moving or do something. (3)

11. Loss of Interest
_____ I have not lost interest in other people or activities. (0)
_____ I am less interested in other people or things than before. (1)
_____ I have lost most of my interest in other people or things. (2)
_____ It's hard to get interested in anything. (3)

12. Indecisiveness
_____ I make decisions about as well as ever. (0)
_____ I find it more difficult to make decisions than usual. (1)
_____ I have much greater difficulty in making decisions than I used to. (2)
_____ I have trouble making any decisions. (3)

13. Worthlessness
_____ I do not feel I am worthless. (0)
_____ I don't consider myself as worthwhile or useful as I used to. (1)
_____ I feel more worthless as compared to other people. (2)
I feel utterly worthless. (3)

14. Irritability

_____ I am no more irritable than usual. (0)
_____ I am more irritable than usual. (1)
_____ I am much more irritable than usual. (2)
_____ I am irritable all the time. (3)

15. Concentration Difficulty

_____ I can concentrate as well as ever. (0)
_____ I can't concentrate as well as usual. (1)
_____ It's hard to keep my mind on anything for long. (2)
_____ I find I can't concentrate on anything. (3)

NEO-FFI

Please read each statement carefully and then circle the number that best represents your opinion of yourself according to the answer choices below.

		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1.	I am not a worrier	1	2	3	4	5
2.	I like to have a lot of people around me	1	2	3	4	5
3.	I don't like to waste my time daydreaming	1	2	3	4	5
4.	I try to be courteous to everyone I meet	1	2	3	4	5
5.	I keep my belongings clean and neat	1	2	3	4	5
6.	I often feel inferior to others	1	2	3	4	5
7.	I laugh easily	1	2	3	4	5
8.	Once I find the right way to do something, I stick to it	1	2	3	4	5
9.	I often get into arguments with my family and co-workers	1	2	3	4	5
10.	I'm pretty good about pacing myself so as to get things done on time	1	2	3	4	5
11.	When I'm under a great deal of stress, sometimes I feel like I'm going to pieces	1	2	3	4	5
12.	I don't consider myself especially "light-hearted"	1	2	3	4	5
13.	I am intrigued by the patterns I find in art and nature	1	2	3	4	5
14.	Some people think I'm selfish and egotistical	1	2	3	4	5
15.	I am not a very methodical person	1	2	3	4	5
16.	I rarely feel lonely or blue	1	2	3	4	5
17.	I really enjoy talking to people	1	2	3	4	5
18.	I believe letting students hear controversial speakers can only confuse and mislead them	1	2	3	4	5

		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
19.	I would rather cooperate with others than compete with them	1	2	3	4	5
20.	I try to perform all the tasks assigned to me conscientiously	1	2	3	4	5
21.	I often feel tense and jittery	1	2	3	4	5
22.	I like to be where the action is	1	2	3	4	5
23.	Poetry has little or no effect on me	1	2	3	4	5
24.	I tend to be cynical and skeptical of others' intentions	1	2	3	4	5
25.	I have a clear set of goals and work toward them in an orderly fashion	1	2	3	4	5
26.	Sometimes I feel completely worthless	1	2	3	4	5
27.	I usually prefer to do things alone	1	2	3	4	5
28.	I often try new and foreign foods	1	2	3	4	5
29.	I believe that most people will take advantage of you if you let them	1	2	3	4	5
30.	I waste a lot of time before settling down to work	1	2	3	4	5
31.	I rarely feel fearful or anxious	1	2	3	4	5
32.	I often feel as if I'm bursting with energy	1	2	3	4	5
33.	I seldom notice the moods or feelings that different environments produce	1	2	3	4	5
34.	Most people I know like me	1	2	3	4	5
35.	I work hard to accomplish my goals	1	2	3	4	5
36.	I often get angry at the way people treat me	1	2	3	4	5
37.	I am a cheerful, high-spirited person	1	2	3	4	5
38.	I believe we should look to our religious authorities for decisions on moral issues	1	2	3	4	5
39.	Some people think of me as cold and calculating	1	2	3	4	5
40.	When I make a commitment, I can always be counted on to follow through	1	2	3	4	5

		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
41.	Too often, when things go wrong, I get discouraged and feel like giving up	1	2	3	4	5
42.	I am not a cheerful optimist	1	2	3	4	5
43.	Sometimes when I am reading poetry or looking at a work of art, I feel a chill or wave of excitement	1	2	3	4	5
44.	I am hard-headed and tough-minded in my abilities	1	2	3	4	5
45.	Sometimes I'm not as dependable or reliable as I should be	1	2	3	4	5
46.	I am seldom sad or depressed	1	2	3	4	5
47.	My life is fast-paced	1	2	3	4	5
48.	I have little interest in speculating on the nature of the universe or the human condition	1	2	3	4	5
49.	I generally try to be thoughtful and considerate	1	2	3	4	5
50.	I am a productive person who always gets the job done	1	2	3	4	5
51.	I often feel helpless and want someone else to solve my problems	1	2	3	4	5
52.	I am a very active person	1	2	3	4	5
53.	I have a lot of intellectual curiosity	1	2	3	4	5
54.	If I don't like people, I let them know it	1	2	3	4	5
55.	I never seem to be able to get organized	1	2	3	4	5
56.	At times I have been so ashamed I just want to hide	1	2	3	4	5
57.	I would rather go my own way than be a leader of others	1	2	3	4	5
58.	I often enjoy playing with theories or abstract ideas	1	2	3	4	5
59.	If necessary, I am willing to manipulate people to get what I want	1	2	3	4	5
60.	I strive for excellence in everything I do	1	2	3	4	5

MHLCS

Each item below is a belief statement about your kidney disease with which you may agree or disagree. Beside each statement is a scale which ranges from strongly disagree (1) to strongly agree (6). For each item we would like you to circle the number that represents the extent to which you agree or disagree with that statement. The more you agree with a statement, the higher will be the number you circle. The more you disagree with a statement, the lower will be the number you circle. Please make sure that you answer **EVERY ITEM** and that you circle **ONLY ONE** number per item. This is a measure of your personal beliefs; there are no right or wrong answers.

	Strongly Disagree	**Moderately Disagree**	**Slightly Disagree**	**Slightly Agree**	**Moderately Agree**	**Strongly Agree**
If my kidney disease worsens, it is my own behavior which determines how soon I will feel better again.	1	2	3	4	5	6
As to my kidney disease, what will be will be.	1	2	3	4	5	6
If I see my doctor regularly, I am less likely to have problems with my kidney disease.	1	2	3	4	5	6
Most things that affect my kidney disease happen to me by chance.	1	2	3	4	5	6
Whenever my kidney disease worsens, I should consult a medically trained professional.	1	2	3	4	5	6
I am directly responsible for my kidney disease getting better or worse.	1	2	3	4	5	6
Other people play a big role in whether my kidney disease improves, stays the same, or gets worse.	1	2	3	4	5	6
Whatever goes wrong with my kidney disease is my own fault.	1	2	3	4	5	6
Luck plays a big part in determining how my kidney disease improves.	1	2	3	4	5	6
In order for my kidney disease to improve, it is up to other people to see that the right things happen.	1	2	3	4	5	6
Whatever improvement occurs with my kidney disease is largely a matter of good fortune.	1	2	3	4	5	6
The main thing which affects my kidney disease is what I myself do.	1	2	3	4	5	6
I deserve the credit when my kidney disease improves and the blame when it gets worse.	1	2	3	4	5	6

	Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree
Following doctor's orders to the letter is the best way to keep my kidney disease from getting any worse.	1	2	3	4	5	6
If my kidney disease worsens, it's a matter of fate.	1	2	3	4	5	6
If I am lucky, my kidney disease will get better.	1	2	3	4	5	6
If my kidney disease takes a turn for the worse, it is because I have not been taking proper care of myself.	1	2	3	4	5	6
The type of help I receive from other people determines how soon my kidney disease improves.	1	2	3	4	5	6

Mini-Mental State Examination (MMSE)

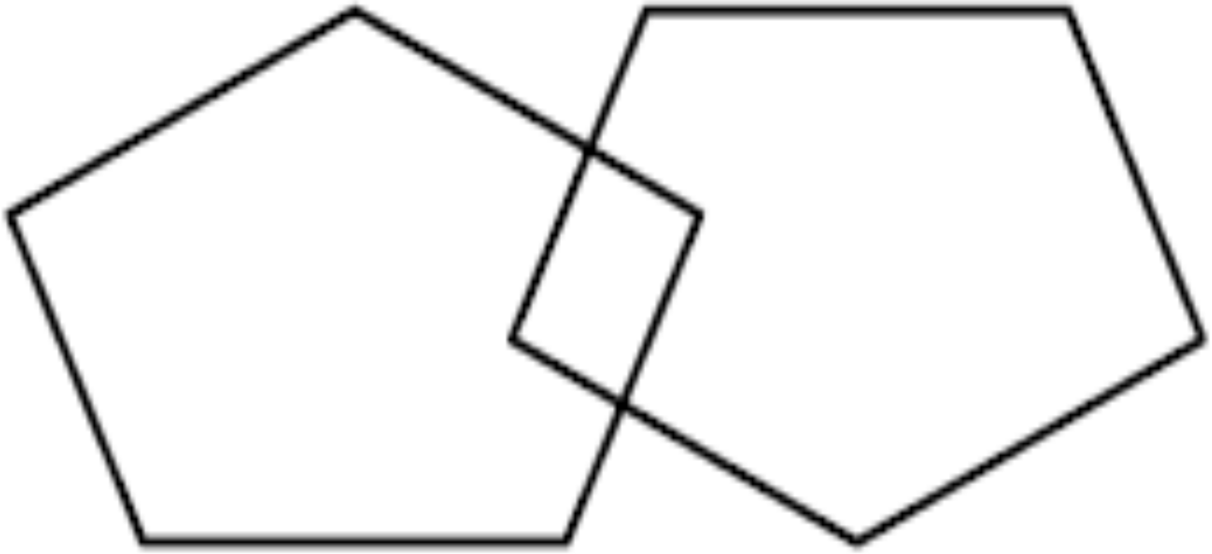
Ask the participant each question in the order it appears. Score one point for each correct response within each question or activity.

I'm going to start by asking you a few questions. Are you ready?

Question	Participant's Score	Maximum Score
What is the year? **What season is it?** **What day of the week is it?** **What month is it?** **What is the date today?**		**5**
What state are we in now? **What county?** **What city?** **What hospital?** **What clinic?**		**5**
Repeat these words back to me: **Clock** **Bottle** **Paperclip** **Number of trials to complete: __________**		**3**
I would like you to count backwards from 100 by sevens. **93** **86** **79** **72** **65** **Stop participant after 5 correct answers.**		**5**
Earlier I told you the names of three objects. Can you tell me what those were? **Clock** **Bottle** **Paperclip**		**3**
Can you tell me what this is called? (SHOW PEN/PENCIL) **Can you tell me what this is called? (SHOW WATCH OR PHONE)**		**2**
Repeat the phrase "No ifs, ands, or buts."		**1**
Take the paper in your right hand, fold it in half, and hand it back to me. **(HAND PARTICIPANT A PIECE OF PAPER)**		**3**

Question	Participant's Score	Maximum Score
Please read this and do what it says. **(HAND PARTICIPANT CARD READING "CLOSE YOUR EYES")**		**1**
Make up and write a sentence about anything you want. **(SENTENCE MUST CONTAIN AT LEAST ONE NOUN AND ONE VERB.)**		**1**
Please copy this picture. **(SHOW PARTICIPANT CARD WITH INTERSECTING PENTAGONS)**		**1**
TOTAL		**30**

CLOSE YOUR EYES



Digit Span – Forward

Now I want to see how well you can pay attention. I am going to say some numbers and when I am through, I want you to say them back to me. Are you ready?

If the participant gets the first series of a set correct, continue with the next higher series until they fail both trials of a given set. Check the box of the HIGHEST trial they got correct.

	6 4 3 9
	7 2 8 6
	4 2 7 3 1
	7 5 8 3 6
	6 1 9 4 7 3
	3 9 2 4 8 7
	5 9 1 7 4 2 3
	4 1 7 9 3 8 6
	5 8 1 9 2 6 4 7
	3 8 2 9 5 1 7 4

Digit Span – Backward

Now I want to see how well you can hold numbers in your mind. I am going to read to you a set of numbers, and when I am through, I want you to say them after me BACKWARD. So, for example, if I say 1 – 9 – 5, you should say… **[PAUSE FOR PARTICIPANT TO RESPOND – CORRECT ANSWER IS 5 – 9 – 1]**

If they get the practice trial wrong: That was not quite right, you should have said 5 – 9 – 1. Listen again and remember, say them back to me BACKWARD. Are you ready?

If they get the practice trial right: Great! Remember, say each of these sets of numbers back to me BACKWARD. Are you ready?

If the participant gets the first series of a set correct, continue with the next higher series until they fail both trials of a given set. Check the box of the HIGHEST trial they got correct.

	2 6 3
	4 1 5
	3 2 7 9
	4 9 6 8
	1 5 2 8 6
	6 1 8 4 3
	5 3 9 4 1 8
	7 2 4 8 5 6
	3 1 2 9 3 6 5
	4 7 3 9 1 2 8

California Verbal Learning Test

Participants are read a list of nine to sixteen words and are asked to recall as many of the words as they can. This task is performed twice – in the immediate recall task, participants are asked to repeat the list of words back to the administrator immediately after hearing the list. In the delayed task, participants are asked to recall the words after a ten-minute delay. Scores reflect the number of words correctly remembered during each task; better performance is indicated by higher numbers of recalled words.

Now I'm going to read you a list of words. When I'm done, I want you to repeat as many of the words back to me as you can remember. Are you ready?

List 1

	Immediate	**10-minute Recall**
Orange		
Apple		
Banana		
Papaya		
Cucumber		
Carrot		
Spinach		
Lettuce		
Red		
Green		
Purple		
Blue		
Rose		
Sunflower		
Tulip		
Poppy		

Mark the box of each word the recall correctly.

California Verbal Learning Test

Participants are read a list of nine to sixteen words and are asked to recall as many of the words as they can. This task is performed twice – in the immediate recall task, participants are asked to repeat the list of words back to the administrator immediately after hearing the list. In the delayed task, participants are asked to recall the words after a ten-minute delay. Scores reflect the number of words correctly remembered during each task; better performance is indicated by higher numbers of recalled words.

Now I'm going to read you a list of words. When I'm done, I want you to repeat as many of the words back to me as you can remember. Are you ready?

List 2

	Immediate	**10-minute Recall**
Rectangle		
Square		
Triangle		
Hexagon		
Georgia		
Kansas		
Kentucky		
Mississippi		
Tennis		
Volleyball		
Football		
Hockey		
Plate		
Bowl		
Coaster		
Cup		

Mark the box of each word the recall correctly.

California Verbal Learning Test

Participants are read a list of nine to sixteen words and are asked to recall as many of the words as they can. This task is performed twice – in the immediate recall task, participants are asked to repeat the list of words back to the administrator immediately after hearing the list. In the delayed task, participants are asked to recall the words after a ten-minute delay. Scores reflect the number of words correctly remembered during each task; better performance is indicated by higher numbers of recalled words.

Now I'm going to read you a list of words. When I'm done, I want you to repeat as many of the words back to me as you can remember. Are you ready?

List 3

	Immediate	**10-minute Recall**
Computer		
Printer		
Clock		
Television		
Truck		
Car		
Window		
Headlight		
Strawberry		
Lemon		
Tomato		
Pear		
Grey		
Lavender		
Yellow		
Gold		

Mark the box of each word the recall correctly.

California Verbal Learning Test

Participants are read a list of nine to sixteen words and are asked to recall as many of the words as they can. This task is performed twice – in the immediate recall task, participants are asked to repeat the list of words back to the administrator immediately after hearing the list. In the delayed task, participants are asked to recall the words after a ten-minute delay. Scores reflect the number of words correctly remembered during each task; better performance is indicated by higher numbers of recalled words.

Now I'm going to read you a list of words. When I'm done, I want you to repeat as many of the words back to me as you can remember. Are you ready?

List 4

	Immediate	**10-minute Recall**
Celery		
Cabbage		
Peas		
Onion		
Badminton		
Golf		
Fencing		
Handball		
Recliner		
Love seat		
Dresser		
Cabinet		
Pennsylvania		
Oregon		
South Dakota		
Tennessee		

Mark the box of each word the recall correctly.

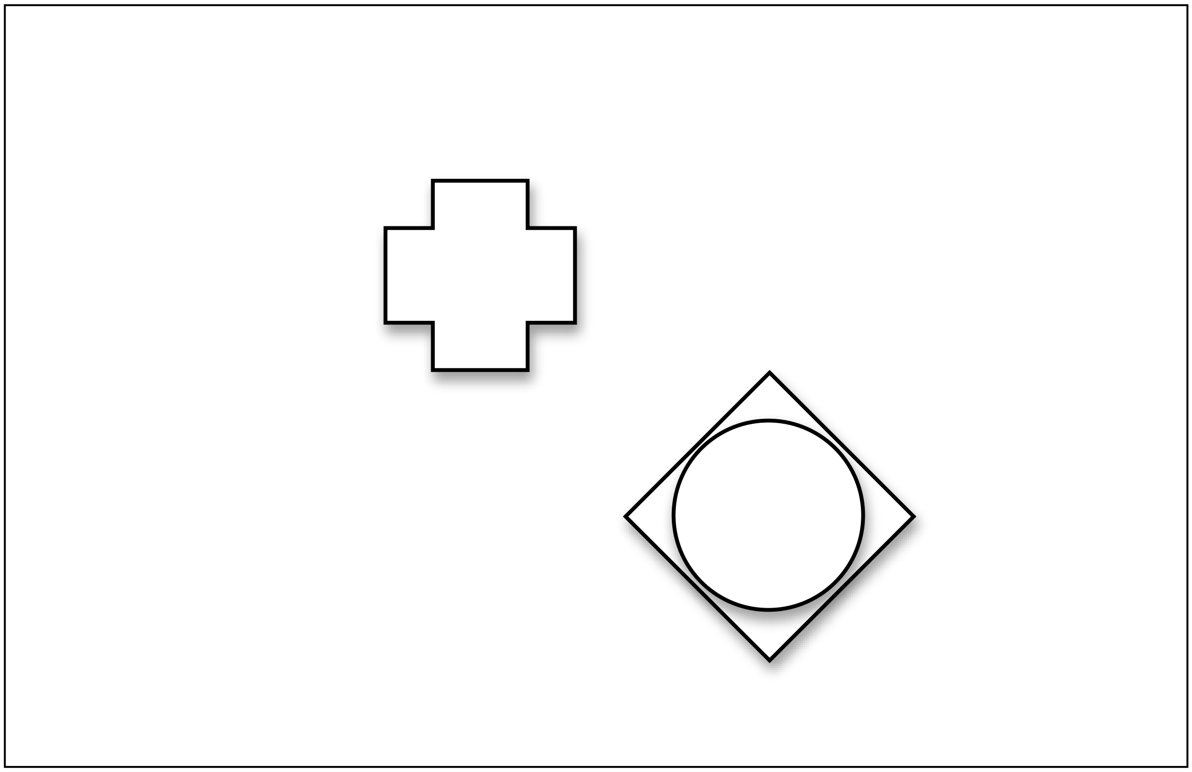
Benton Visual Retention Test

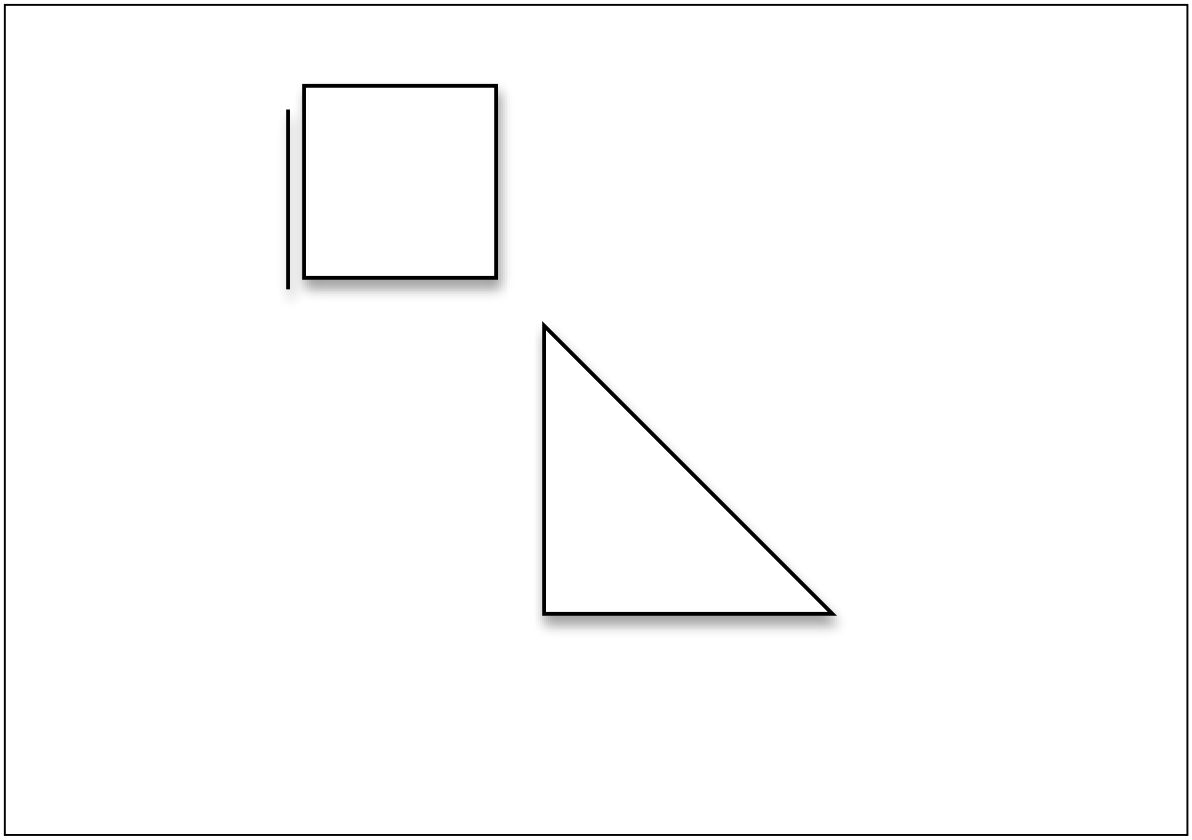
During the task, participants are shown a series of 10 designs (chiefly line drawings and basic shapes arranged in patterns) for five to ten seconds each and are asked to reproduce the images via recall. Scores are computed by totaling the number of correctly reproduced designs.

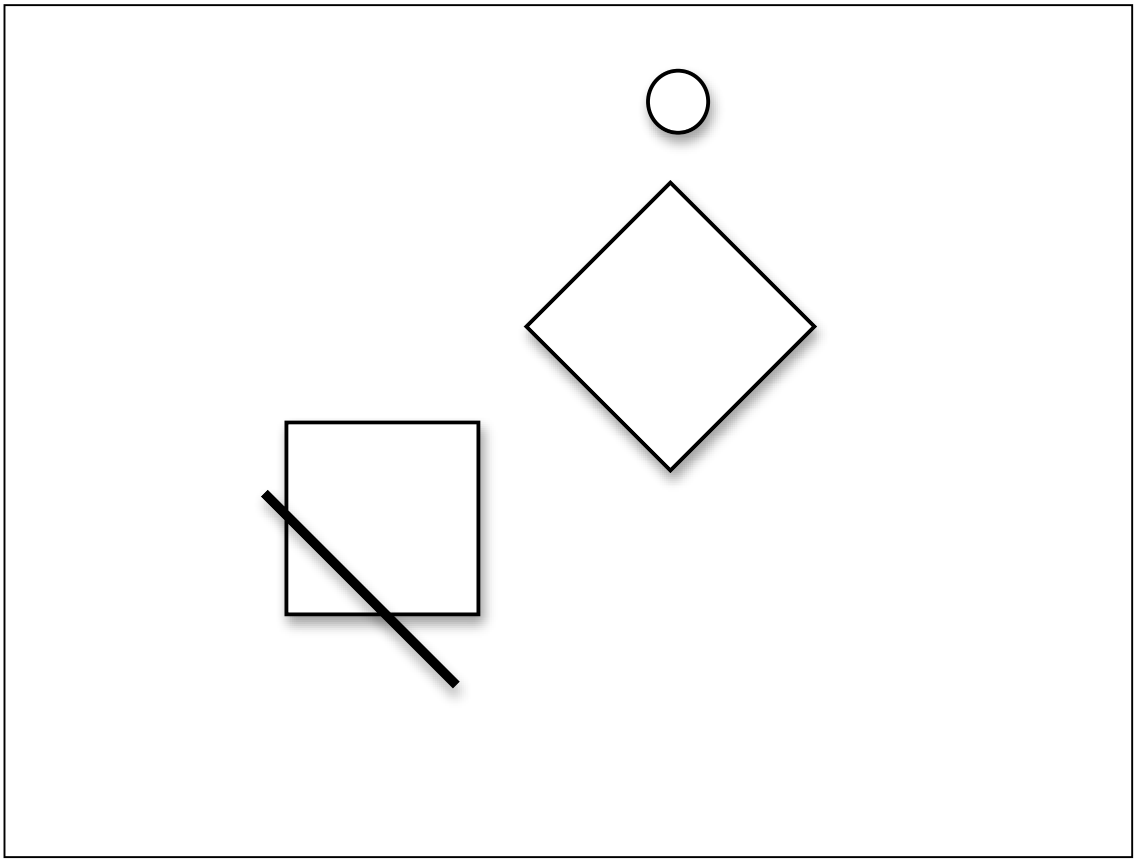
Now I'm going to show you some pictures, just for a few seconds. After I put each picture away, I want you to draw the picture you see on your own piece of paper. You will flip to a new page for each drawing. There will be 10 pictures total.

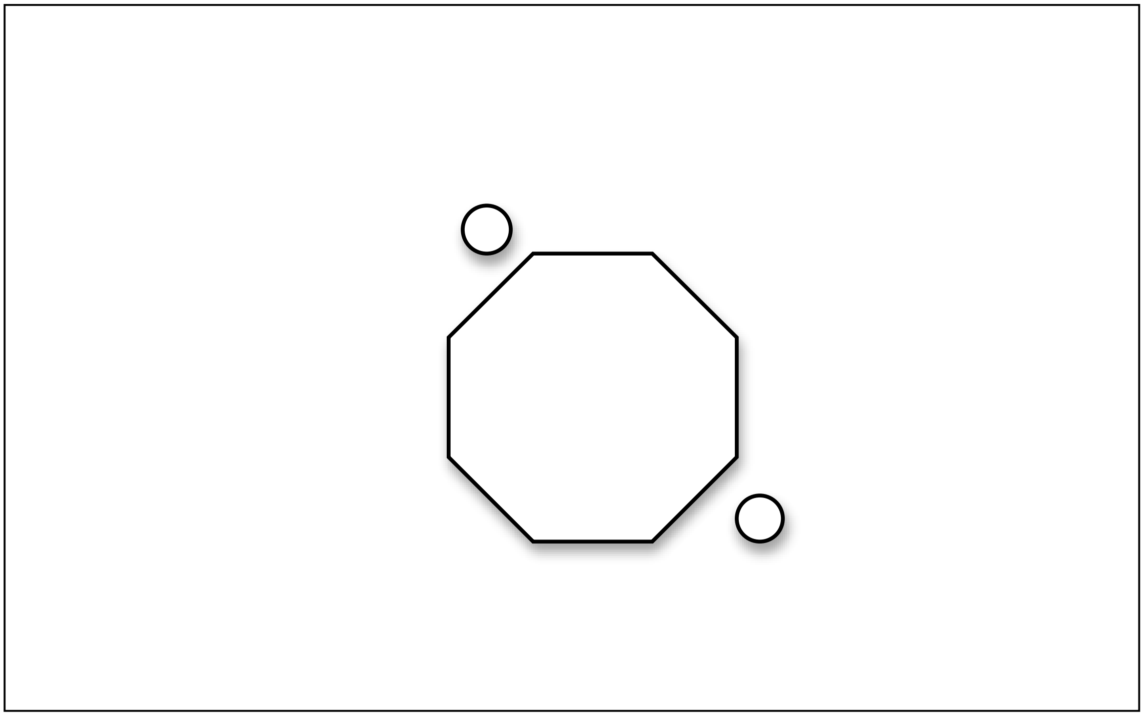
(HAND PARTICIPANT PAPER AND PENCIL)

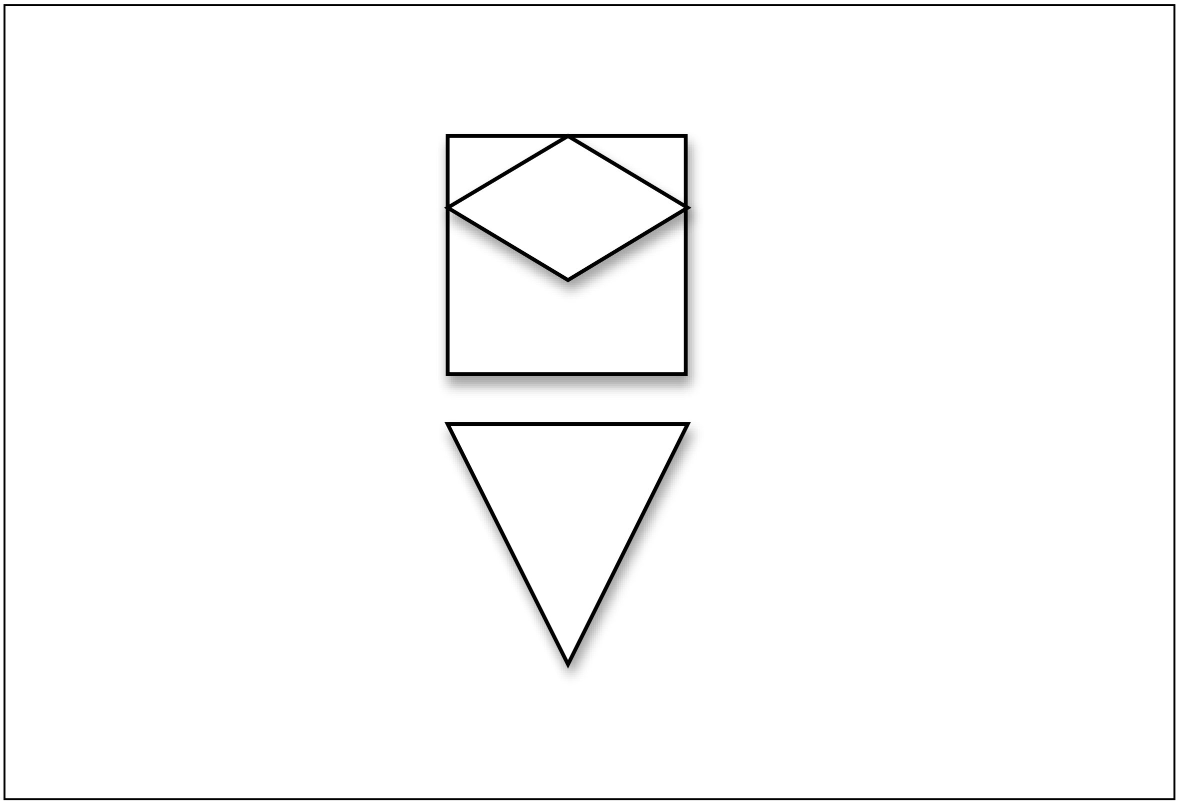
Are you ready to start?

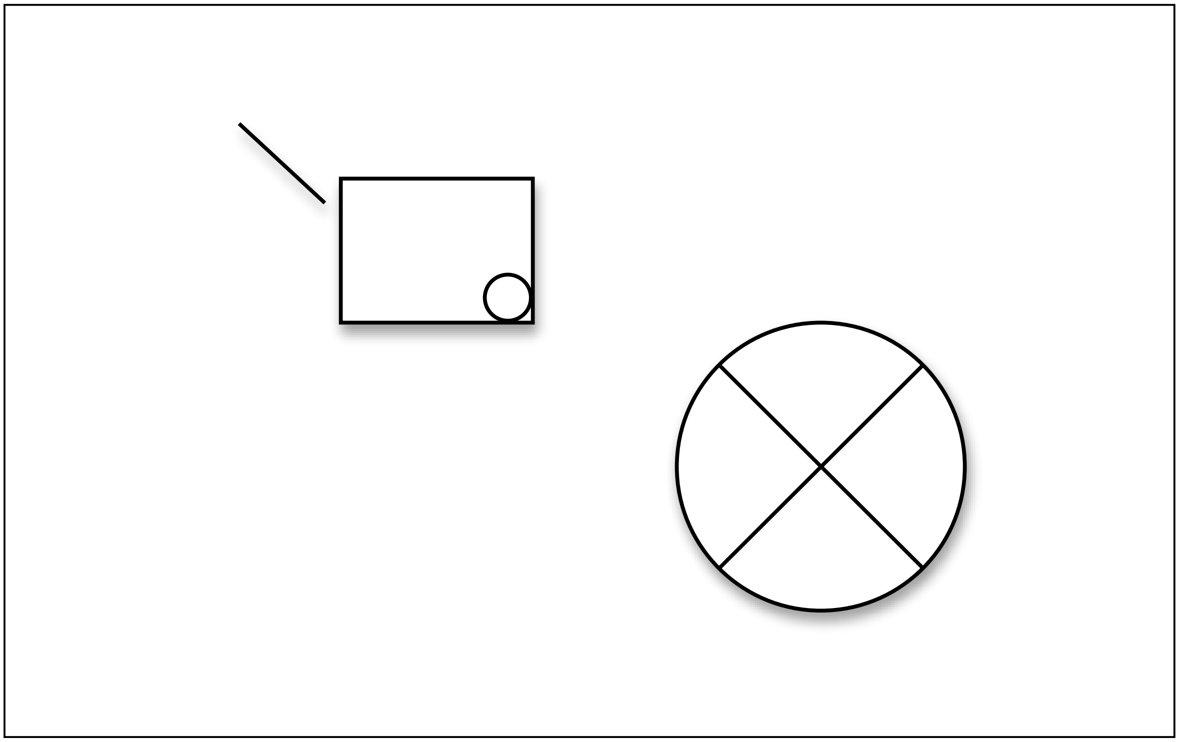


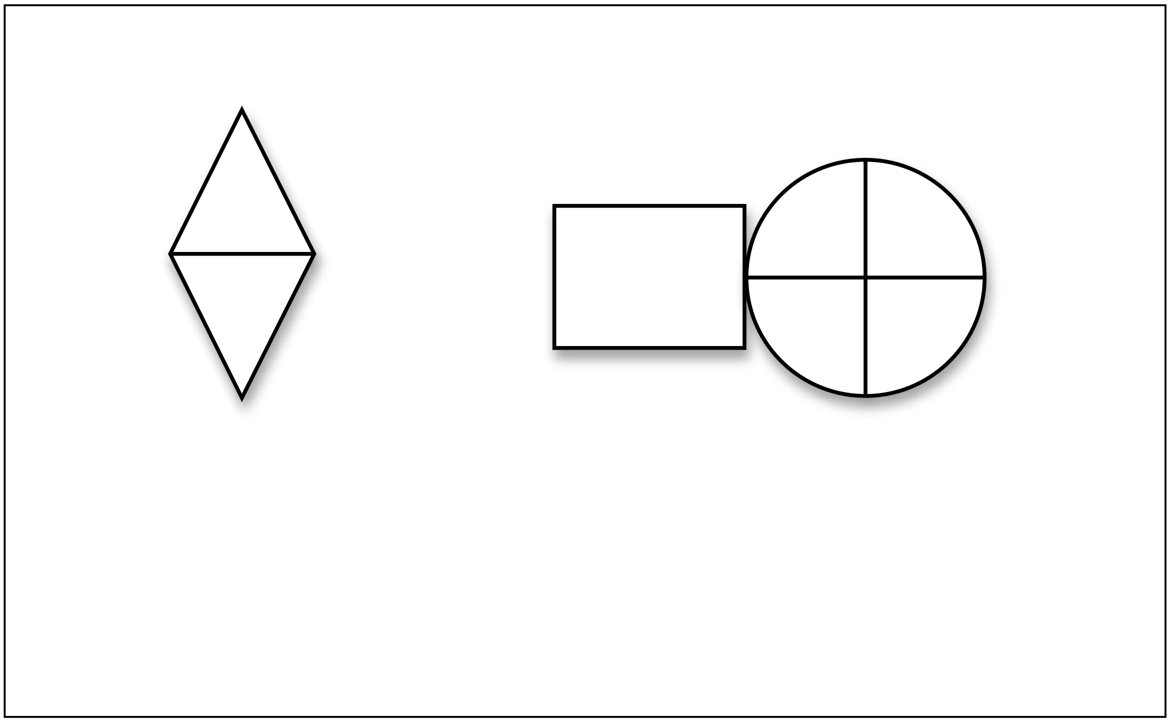


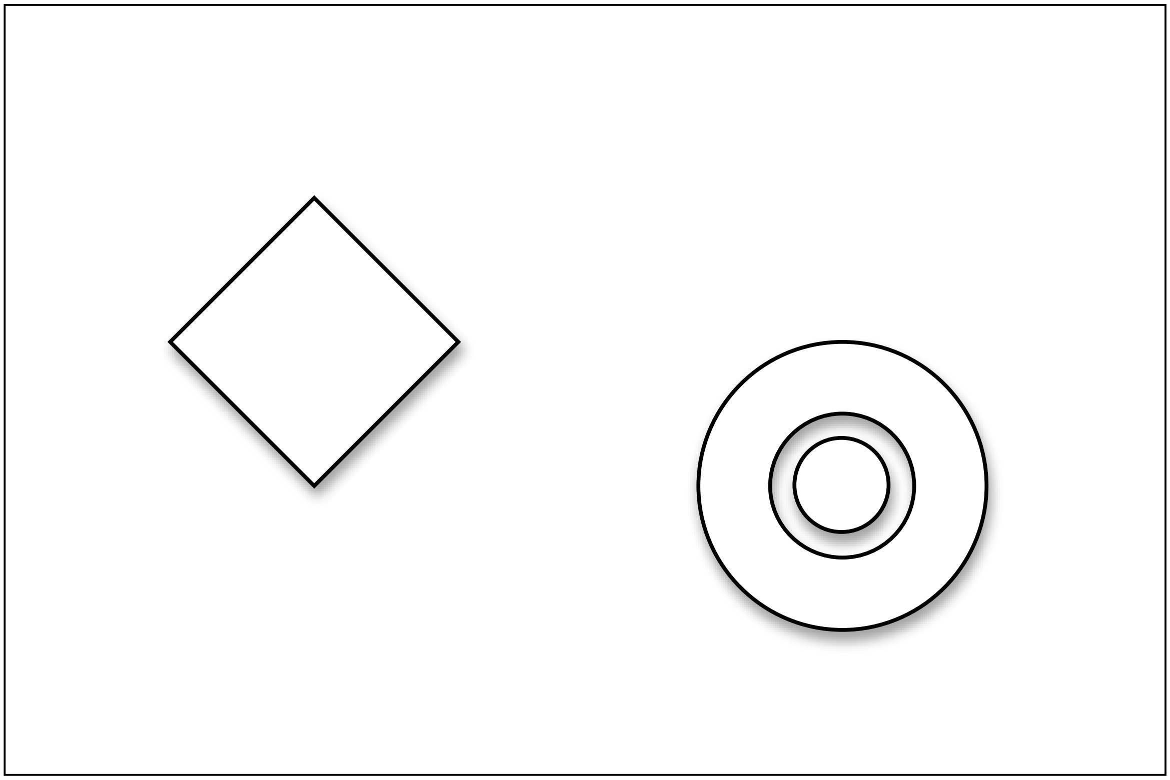


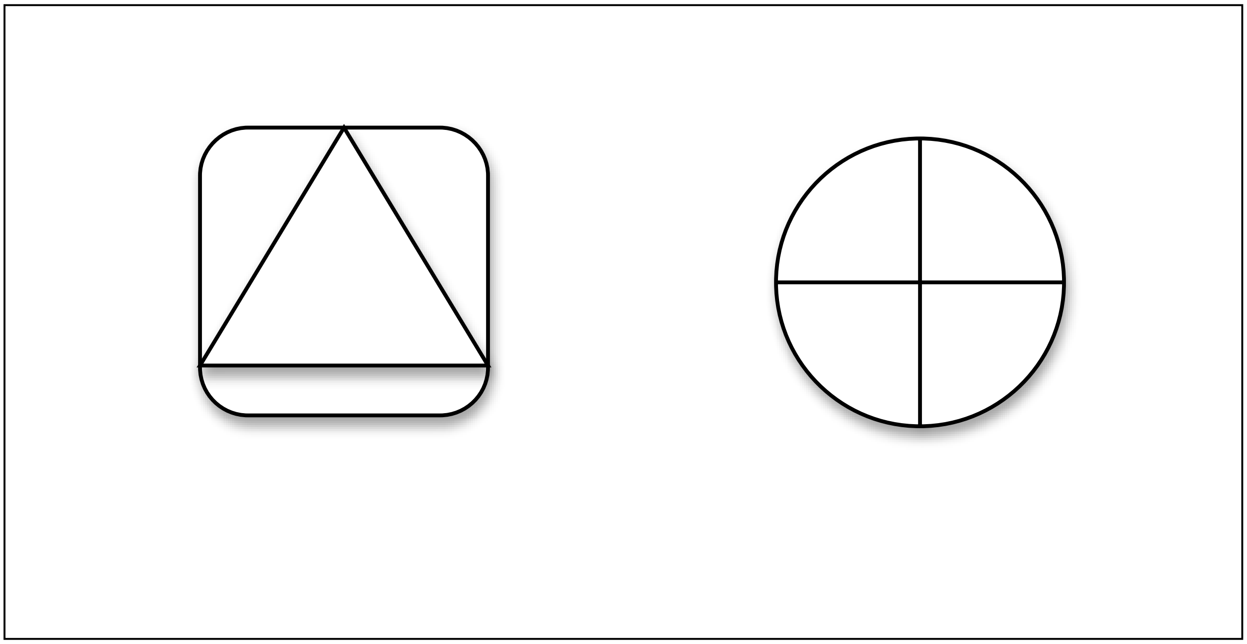


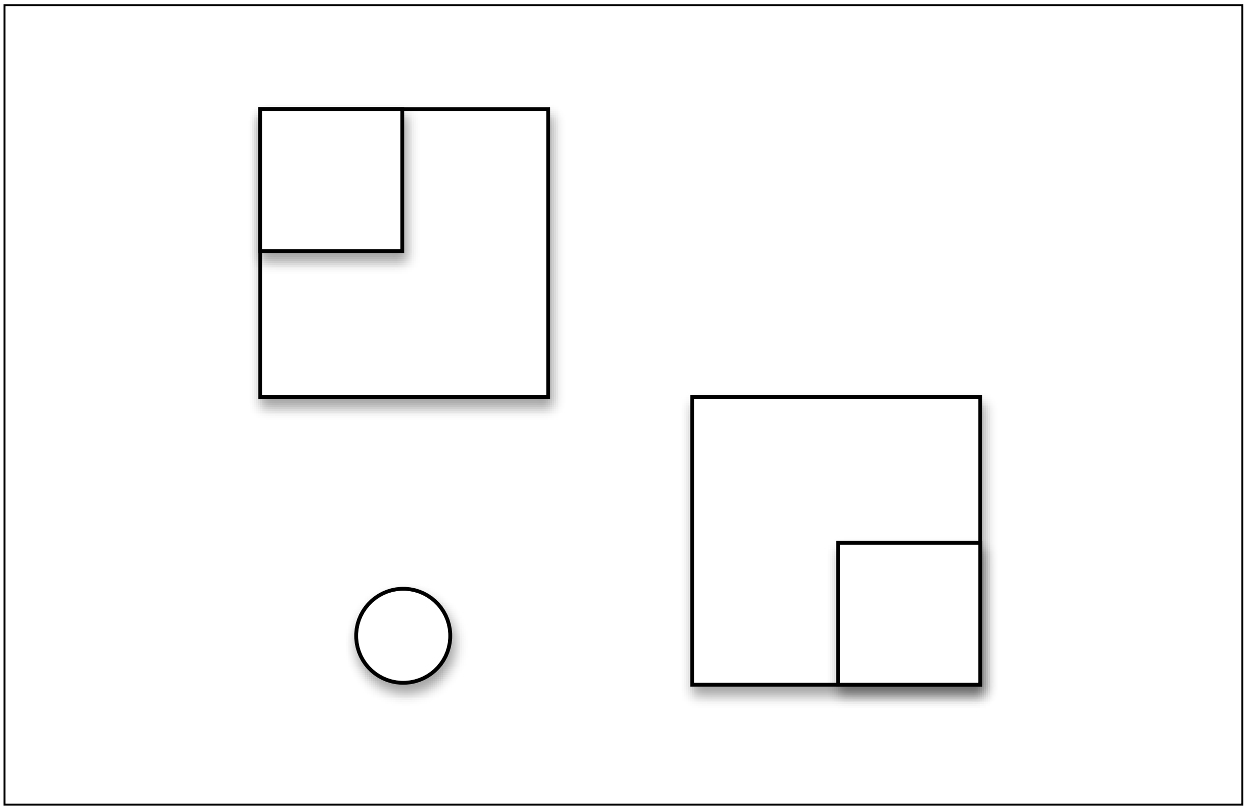












Trail-Making Test A

Now we're going to make some patterns on a piece of paper, a little bit like connect-the-dots. I'm going to time how long it takes you to finish each sheet. For the first task, you're going to trace a line to connect the numbers from 1 to 25. I'll show you how to do the task and then you'll try it. Are you ready?

DEMONSTRATE ON SAMPLE SHEET HOW TO COMPLETE TRAILS A TASK

Ready to try on your sheet?

GIVE PARTICIPANT TRAILS A WORKSHEET

Okay, you can start when I say "Go." Ready? Go!

TIME HOW LONG IT TAKES THE PARTICIPANT TO GET FROM 1 to 25.

Trail-Making Test B

In the next task, you're going to connect the dots again, but this time, you're going to combine numbers and letters. So, for example, you will trace a line starting with 1, then A, then 2, then B, and so on. I'll show you how to do the task and then you'll try it. Are you ready?

DEMONSTRATE ON SAMPLE SHEET HOW TO COMPLETE TRAILS A TASK

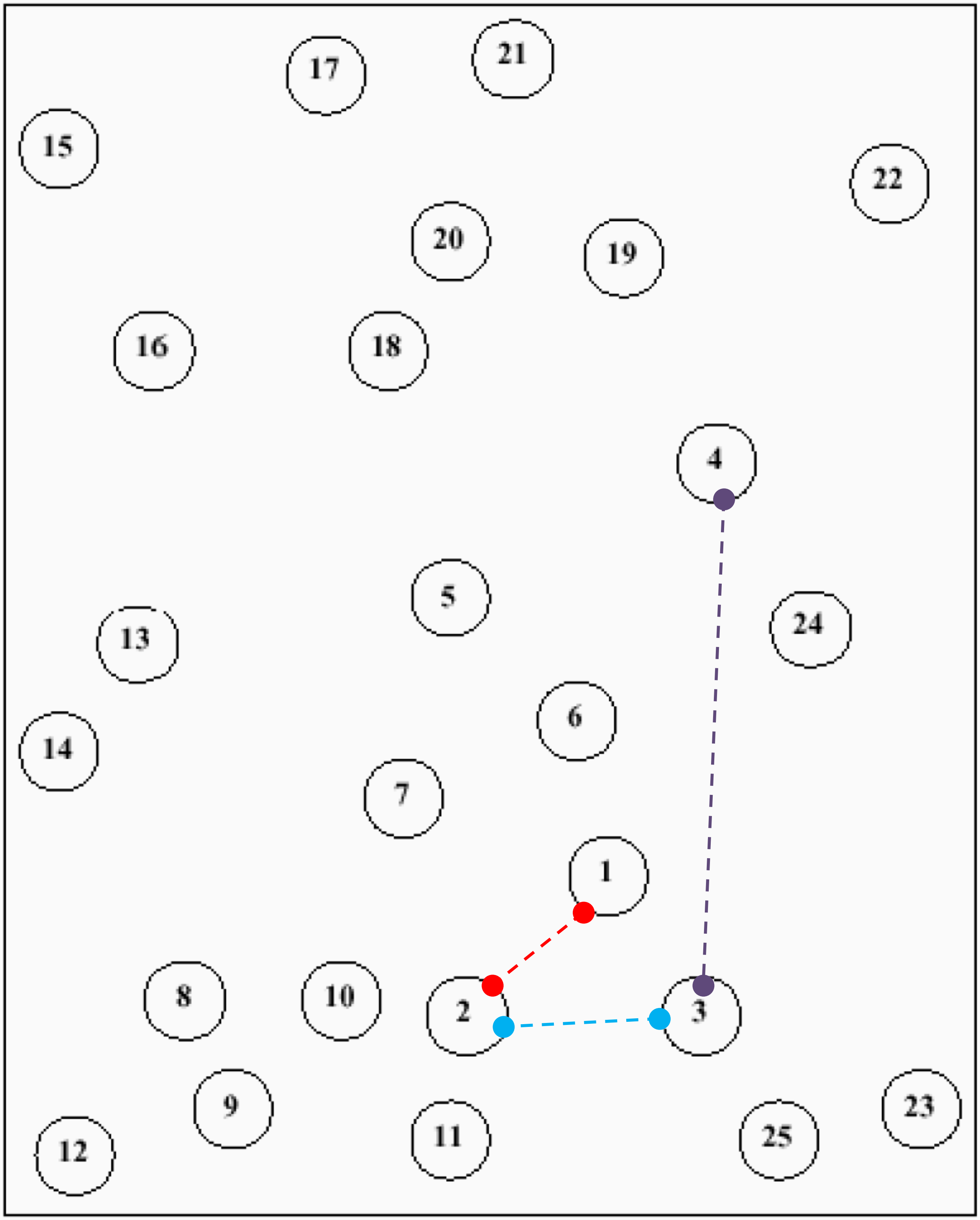
Ready to try on your sheet?

GIVE PARTICIPANT TRAILS B WORKSHEET

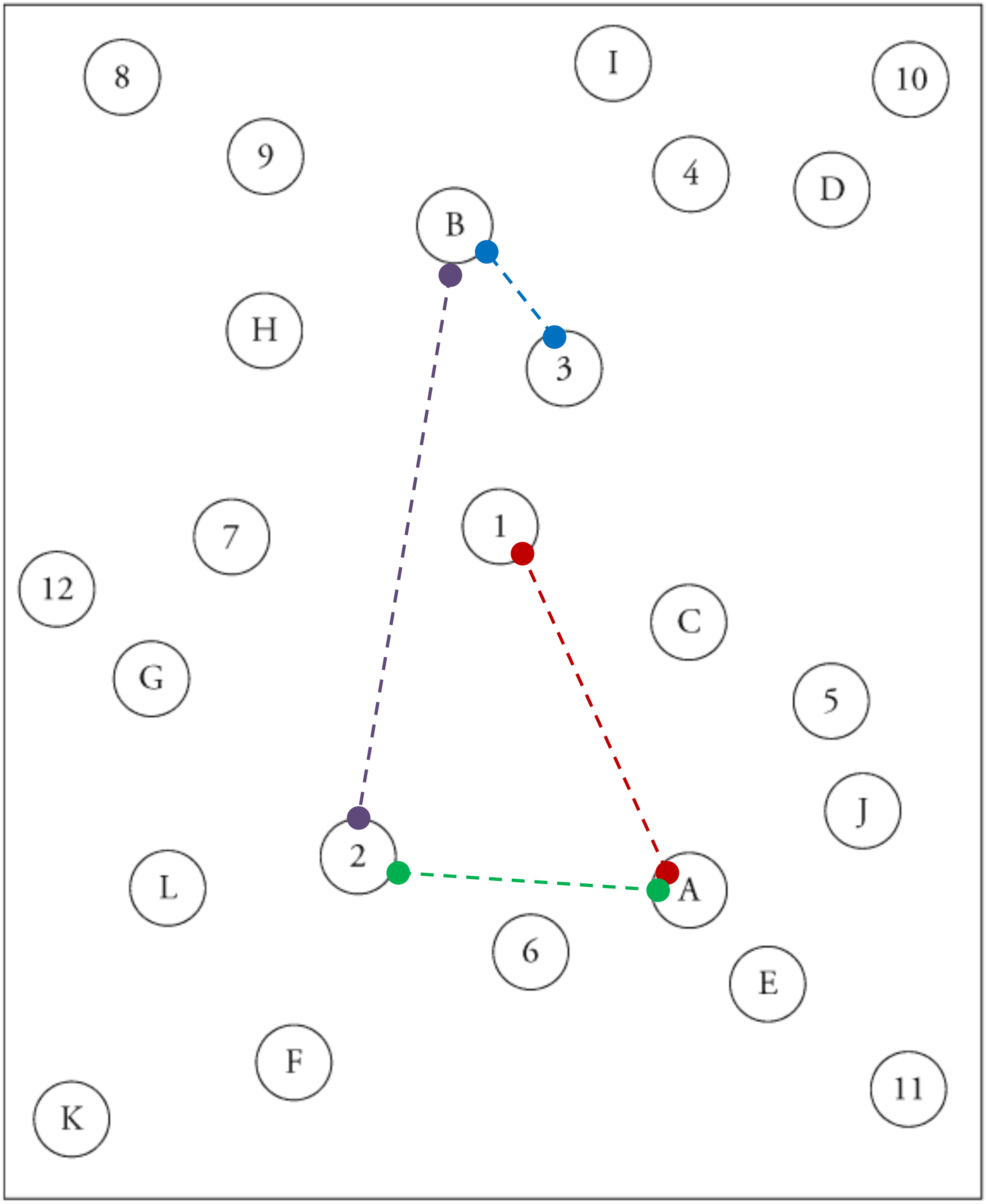
Okay, you can start when I say "Go." Ready? Go!

TIME HOW LONG IT TAKES THE PARTICIPANT TO GET FROM 1 to 25.

Trail Making Test – A

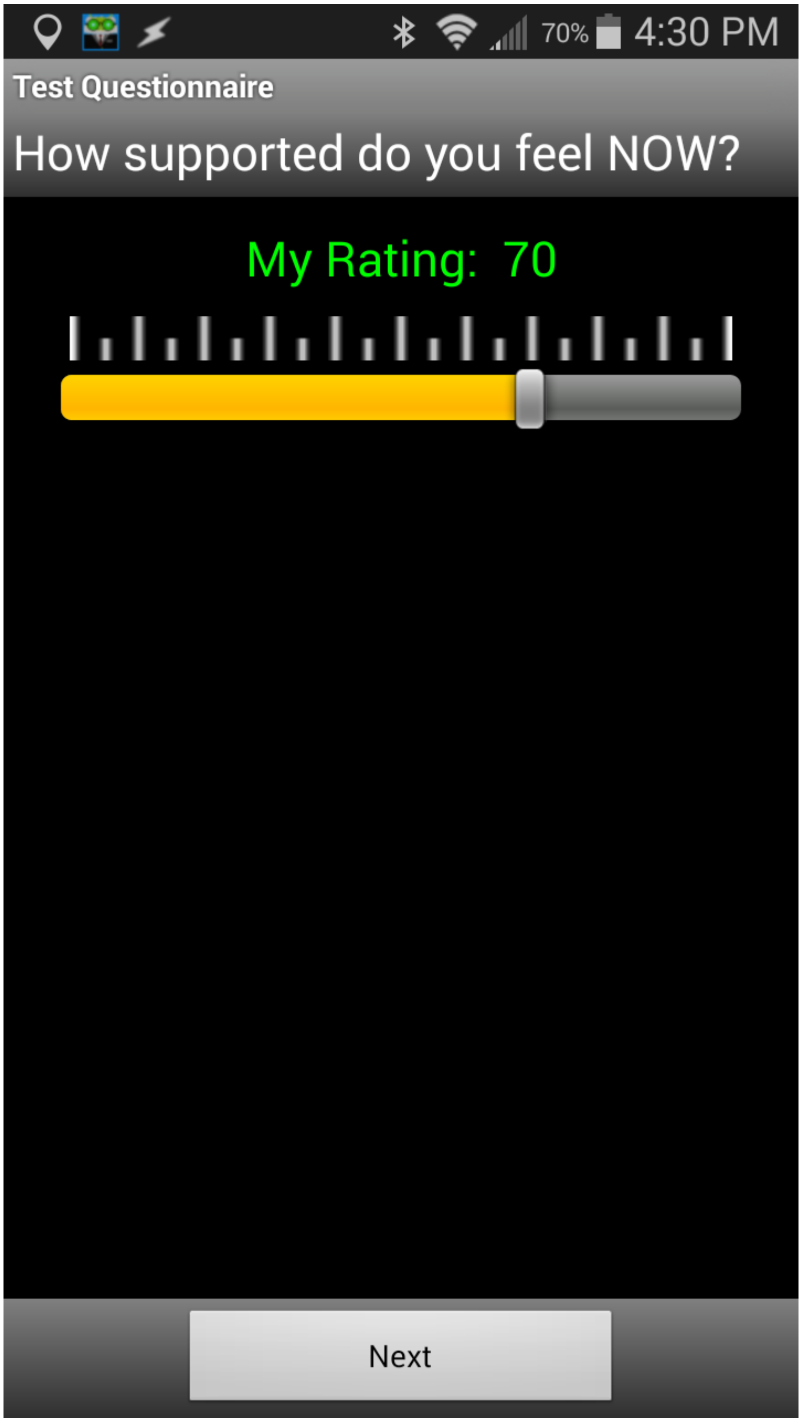


Trail Making Test – B



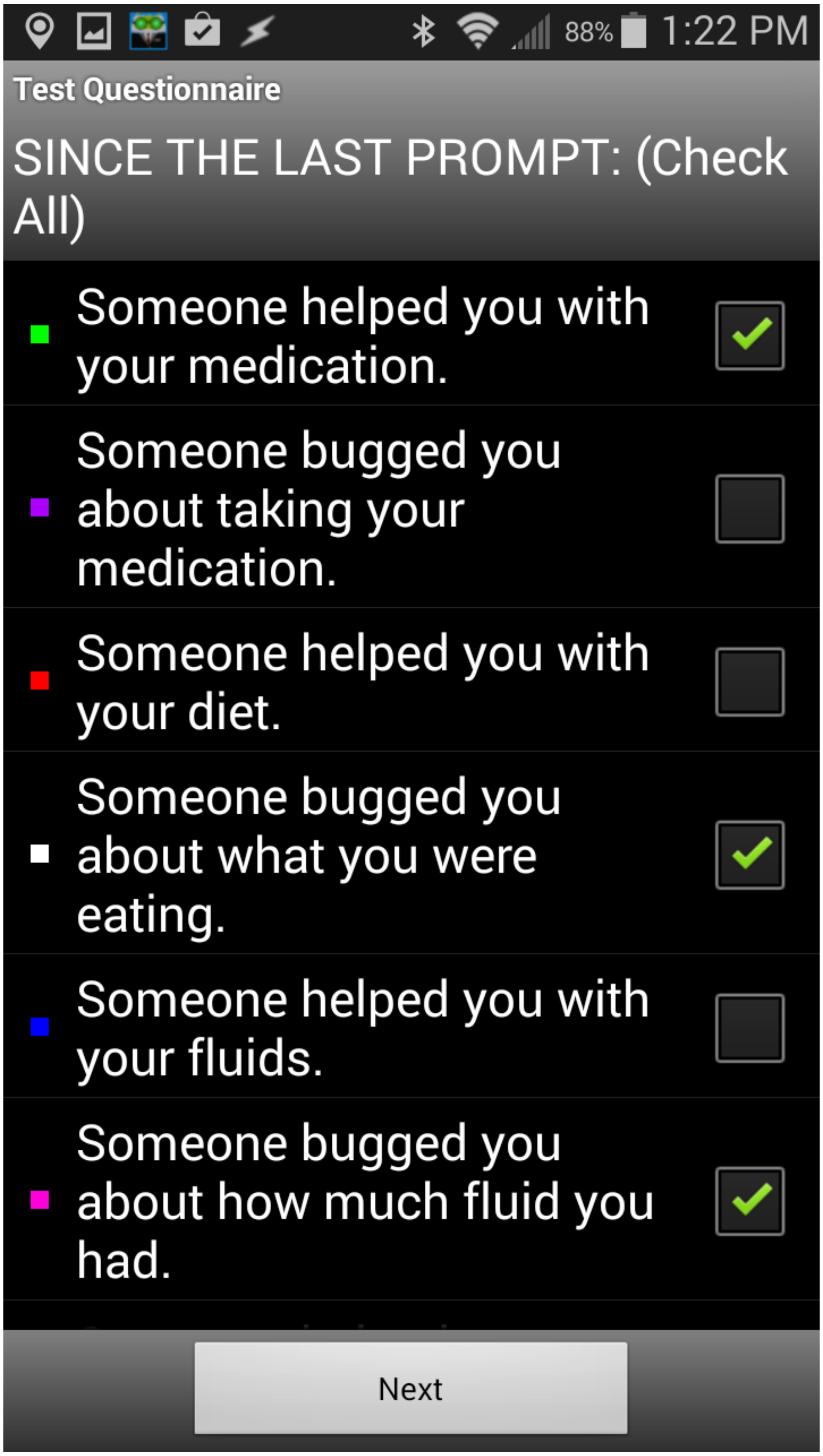
Selected Items from the Electronic Diary

Overall Support



How supported do you feel NOW?

My Rating: 70

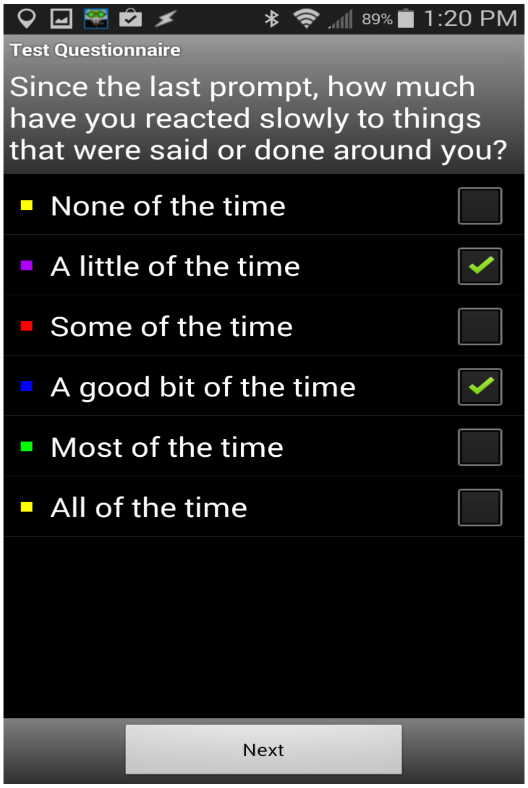


Test Questionnaire

SINCE THE LAST PROMPT: (Check All)

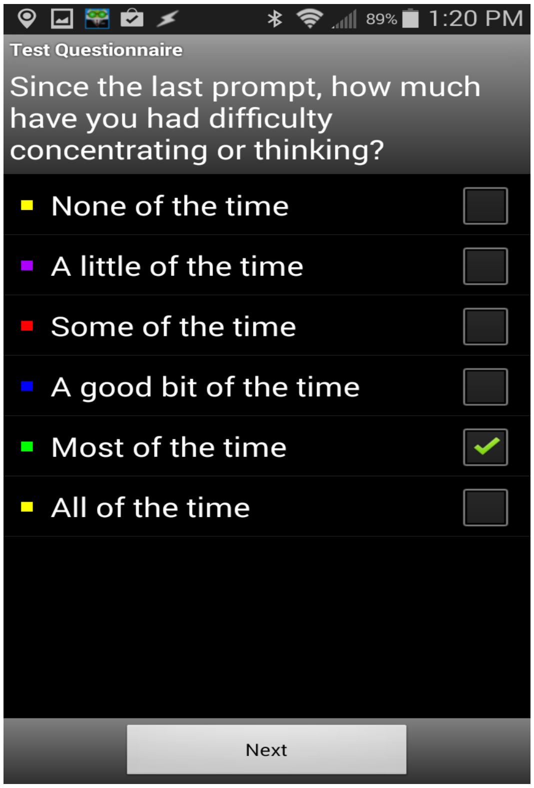
- 🟩 Someone helped you with your medication. ☑
- 🟪 Someone bugged you about taking your medication. ☐
- 🟥 Someone helped you with your diet. ☐
- ⬜ Someone bugged you about what you were eating. ☑
- 🟦 Someone helped you with your fluids. ☐
- 🟪 Someone bugged you about how much fluid you had. ☑

Cognitive Dysfunction



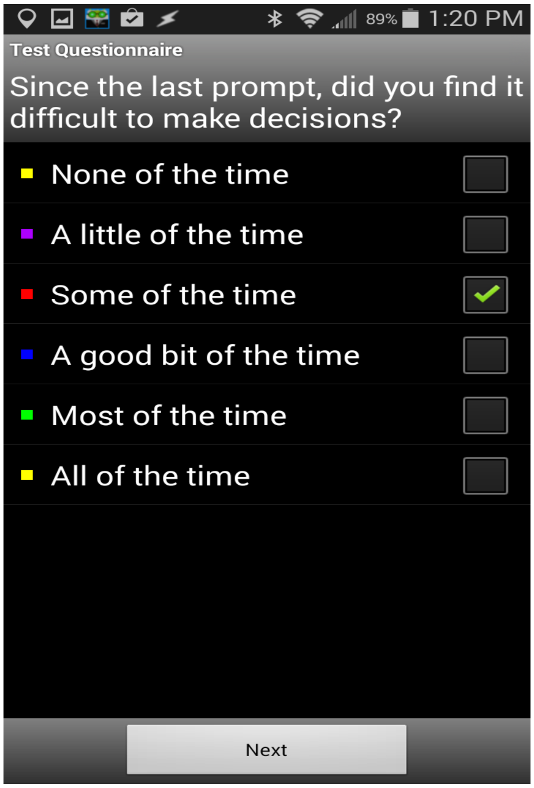
Since the last prompt, how much have you reacted slowly to things that were said or done around you?

- None of the time ☐
- A little of the time ☑
- Some of the time ☐
- A good bit of the time ☑
- Most of the time ☐
- All of the time ☐



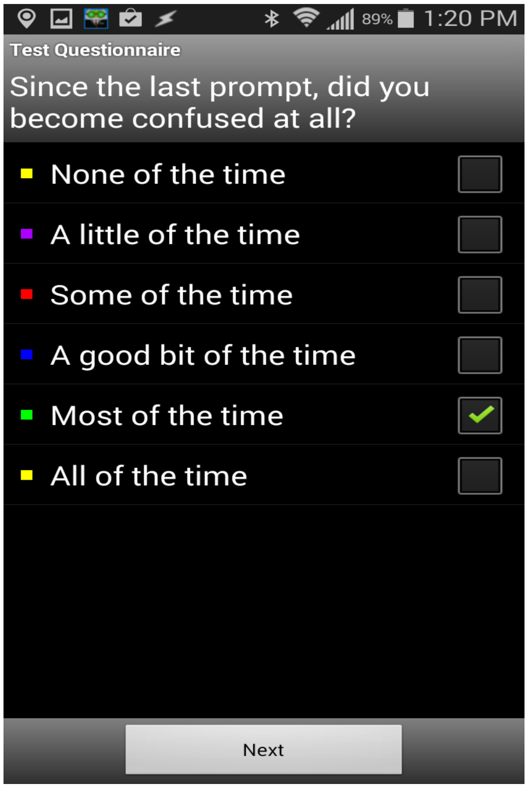
Since the last prompt, how much have you had difficulty concentrating or thinking?

- None of the time ☐
- A little of the time ☐
- Some of the time ☐
- A good bit of the time ☐
- Most of the time ☑
- All of the time ☐



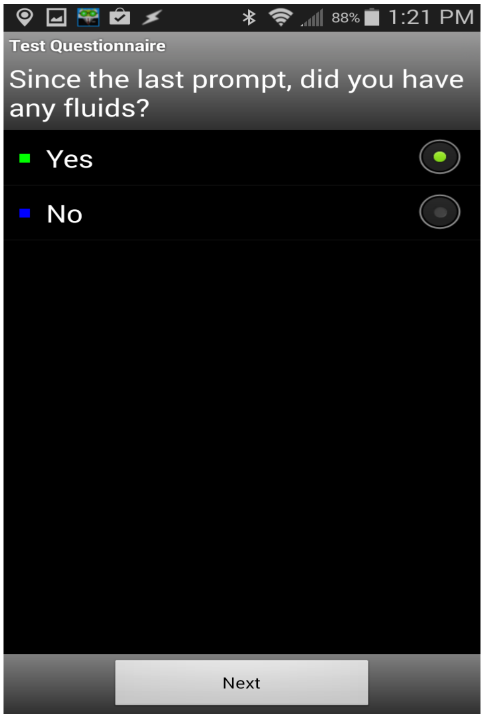
Since the last prompt, did you find it difficult to make decisions?

- None of the time ☐
- A little of the time ☐
- Some of the time ☑
- A good bit of the time ☐
- Most of the time ☐
- All of the time ☐



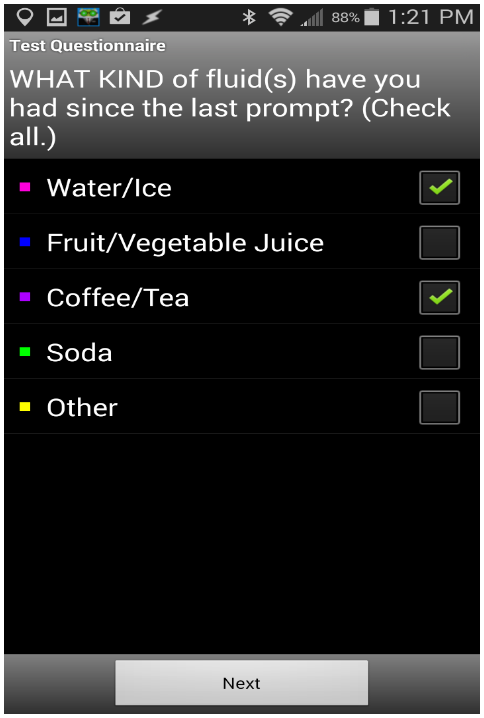
Since the last prompt, did you become confused at all?

- None of the time ☐
- A little of the time ☐
- Some of the time ☐
- A good bit of the time ☐
- Most of the time ☑
- All of the time ☐



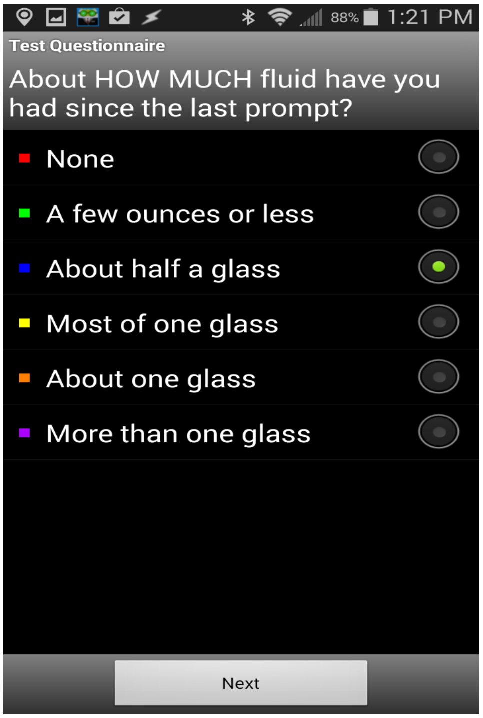
Since the last prompt, did you have any fluids?

- Yes ●
- No ○



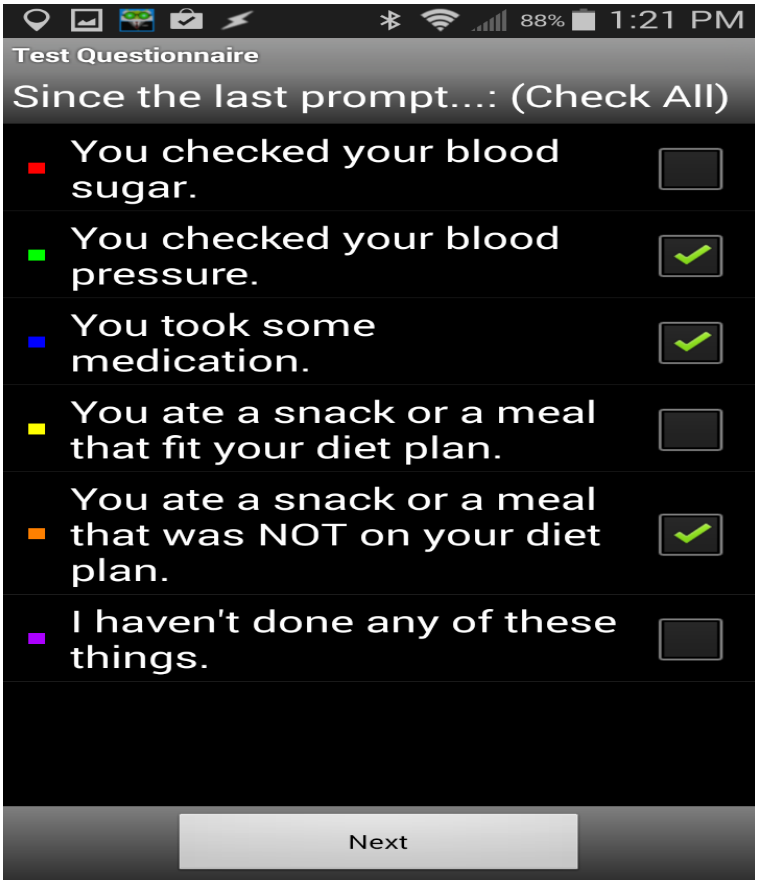
WHAT KIND of fluid(s) have you had since the last prompt? (Check all.)

- Water/Ice ☑
- Fruit/Vegetable Juice ☐
- Coffee/Tea ☑
- Soda ☐
- Other ☐



About HOW MUCH fluid have you had since the last prompt?

- None ○
- A few ounces or less ○
- About half a glass ●
- Most of one glass ○
- About one glass ○
- More than one glass ○



Since the last prompt...: (Check All)

- You checked your blood sugar. ☐
- You checked your blood pressure. ☑
- You took some medication. ☑
- You ate a snack or a meal that fit your diet plan. ☐
- You ate a snack or a meal that was NOT on your diet plan. ☑
- I haven't done any of these things. ☐