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## Volunteering Improves Adherence to Dietary Regimens and Outlook of People With Chronic Kidney Disease

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Bonnie G. Orlins, MSW, LISW, Fresenius Medical Center, Sidney, OH;

Susan T. Davis, PhD, University of Dayton, Dayton, OH;

Dee Ann Roman, RD, CDE, Pinehurst, NC

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*The research reported here builds on a corpus of studies that have found strong positive effects of volunteering on depression, self-esteem and adherence to medical regimens. Patients with chronic kidney disease at a community hemodialysis facility volunteered to act as participants in a control condition or an experimental (volunteer) condition that involved 1 hour/week volunteer service. The patients were matched with a volunteer activity from possibilities identified by the hemodialysis unit social worker and showed reliable increases in adherence as measured by control of fluid weight gain and potassium levels. In addition, qualitative analysis of pre- and post-experiment interviews with participants correlated well with measures of depression and self-esteem. Depression indicators declined for those in the volunteer condition but not for those in the control condition. Our discussion includes strong recommendations that volunteer opportunities developed and facilitated by the unit social worker for patients on dialysis are an investment of resources that produce a significant payoff in patient physical and psychological health.*

### INTRODUCTION

People who work daily with patients who have chronic kidney disease (CKD) observe common factors that have a negative impact on this large group of people. Social workers describe the continuing adjustment issues that are often reflected in patient needs, such as the need for self-esteem enhancement and help in alleviating depression (Cvengros et al., 2005; Kimmel, 2005; Kimmel & Peterson, 2005). Depression, for example, affects many with CKD; a recent study ( $n = 207$ ), estimated the prevalence of depression among patients with CKD to be nearly 20% (Cvengros et al., 2005), while Piraino et al. (2003) reported the incidence of depression to be as high as 25% for CKD patients beginning dialysis in a review of the literature. However, while all agree that depression is a major problem in this population, estimates can range from 5 to 50% depending on the instrument used to diagnose depression (Kimmel & Peterson, 2005). In addition to the need for addressing psychological factors is the need for the staff to address issues affecting physical health, such as patients' adherence to dietary restrictions (Bannister & Snelling, 2006). Dialysis patients have many co-morbid conditions (e.g., cardiovascular complications, infections, anemia, hypertension) and,

collectively, are immunocompromised (Fehr et al., 2004). Thus, the importance of health maintenance and patient adherence to prescribed dialysis regimen while undergoing dialysis cannot be minimized.

Vocational rehabilitation (VR), among other interventions, has provided a route for addressing some of these issues (Curtin et al., 2003). For these patients, psychological health still includes the need to feel as independent as possible and to be contributing members of society (Cvengros et al., 2005). VR is one way of achieving these independence and productivity goals. However, for various reasons, a number of patients are unable to participate in VR activities (Curtin et al., 2003; Dinwiddie, 2004). The goal of VR is gainful employment. Because of their illness, many CKD patients have a difficult time participating in traditional jobs. Other factors reduce the time available for VR and pursuance of job responsibilities, such as time spent on dialysis, sick days due to CKD and related health issues and numerous medical appointments. Finally, pragmatic issues such as accessibility to VR (e.g., travel from rural areas) and ability to drive (e.g., for home-bound patients) make VR logistically inconvenient.

Volunteerism has been shown to have an impact on health and affect in other medical conditions (Harris &

Thoresen, 2005; Musick & Wilson, 2002) and has been overlooked in CKD. Anecdotal evidence and more formalized examinations of volunteerism's benefits (e.g., Oman & Thoresen, 2000) indicate that people feel better, function better and are more compliant with medical regimens when they feel that they have a purpose in life and are having a positive impact on others around them (e.g., Morrow-Howell et al., 2003). However, volunteerism has not been specifically related to dialysis patients and their particular needs. The present research pursues the benefits of volunteerism to the enhanced health and positive outlook of dialysis patients.

## RESEARCH BACKGROUND

Research has documented the relationship between volunteerism and perceptions of well-being. Morrow-Howell and colleagues (2003) found that 8 of 10 volunteers reported experiencing an increase in well-being, having more friends and acquaintances and making more productive use of their time. Reports of other positive effects of volunteerism are that it "provides a sense of control over one's life and one's environment, thus alleviating depression," (Mirowsky & Ross, 1989) and that volunteerism increases "perceived self-efficacy, self-esteem, and positive affect" (Musick & Wilson, 2003).

Volunteering has been reported to be particularly beneficial for the elderly population (usually defined as over 60 years of age) because it can protect them from "the hazards of retirement, physical decline, and inactivity" (Fischer & Schaffer, 1993). Wheeler et al. (1998) reported in their meta-analysis of research examining the effects of volunteering on the elderly that, despite differences in socioeconomic status and physical health, there was a strong positive relationship between volunteering and life satisfaction. Aside from the fact that a large number of dialysis patients are in this age group, it seems that even many younger patients share some characteristics typically associated with the older group (Kimmel & Peterson, 2005). These include loss of employment and the self-esteem that comes from doing productive work, reduced participation in outside activities and increased loneliness, a preoccupation with health, the loss of ability to perform some previously mastered functions, a perceived loss of control over life and elevated levels of depression (see Kimmel & Peterson, 2005 for review).

Volunteerism, extensively studied in elderly populations, has produced opportunities for benefits that counteract or ameliorate some of these consequences. Based on a theory proposed by Lin et al. (1999), psychological

and social resources are mechanisms that can explain the relationship between volunteerism and health. A number of studies have examined processes related to these mechanisms and found (a) increases in self-assurance and confidence (Midlarsky, 1991); (b) increases in self-esteem and consequent well-being and decreases in depression (Wuthnow, 1991); and (c) reduction in loneliness and enhanced feelings of self-worth (Omoto et al., 1993). In each of these instances, and among others, volunteerism is the mediating link between improved involvement with psychosocial resources providing information and support and positive social interactions that counter the withdrawal seen in the elderly and those affected by chronic disease (Musick & Wilson, 2003).

## PRESENT RESEARCH

The purpose of the present research was to examine the experience of volunteerism for individuals with CKD undergoing hemodialysis. There were four specific research questions of interest:

1. Is there a relationship between volunteering and self-esteem?
2. Is there a relationship between volunteering and depression?
3. Is there a relationship between volunteering and adherence to a treatment regimen?
4. How does the experience of volunteering impact individuals on hemodialysis?

Specifically, the present study examined the positive effects of volunteerism in a self-selected sample of patients undergoing hemodialysis. Patients were matched with volunteer opportunities and monitored for adherence to dietary regimens and changes in depression and self-esteem. In addition to the evaluation of these quantitative variables, observations and interviews provided correlational evidence of the positive effects of volunteerism.

In summary, the present research hypothesized that the effect of volunteer activity would result in mood enhancement, an increase in feelings of self-worth and a concurrent increase in adherence to dietary restrictions.

## METHODS

### *Participants*

There were 15 individuals with CKD undergoing hemodialysis at a community hemodialysis center who volunteered to participate in the study. The total population undergoing dialysis at the center during the time of the study was 40 patients. The participants' ages ranged from 26 to 85 years with a median age of 57 years, and there were 8 women and 7 men. Two of the

participants had more than a high school education, and two participants had not completed high school. Of the sample, seven participants were married; the remaining participants were either single ( $n = 4$ ), divorced ( $n = 2$ ) or widowed ( $n = 2$ ). The participants in this sample lived in a rural, Midwestern community. Participants were randomly assigned to an experimental condition ( $n = 8$ ) in which they were given volunteer assignments (*volunteer*) or assigned to a *control* condition ( $n = 7$ ) in which they were not given volunteer assignments. Five of the participants in the experimental condition were on state-assisted Medicaid; however, all of these individuals became Medicaid eligible after beginning dialysis as the result of the many expenses associated with dialysis. Two of the participants in the control condition were on Medicaid; both became eligible after beginning dialysis. None of the participants were employed. The length of time that the participants had undergone hemodialysis ranged from less than 5 months to 14 years, as recorded at the onset of the study. Participation in the study was approved by each person's physician. All participants engaged in every aspect of the study and were given \$15 department store gift cards at the beginning and end of the study to reimburse them for gas money and interview time.

### Materials

Materials included the Center for Epidemiologic Studies Short Depression Scale (CES-D 10), the Rosenberg Self-Esteem Scale (SES) and an interview questionnaire developed by the investigators.

The CES-D10 is a 10-item version of the 20-item CES-D, and is available at no charge from the Stanford Patient Education Research Center. It serves as a self-report depression instrument with instructions for the respondent to indicate the frequency with which the feeling expressed in each item was experienced according to the stem, "During the past week ..." The CES-D 10 requests responses on a Likert-type scale, with 0 indicating *rarely or none of the time (less than 1 day)*, 1 indicating *some or a little of the time (1–2 days)*, 2 indicating *occasionally or a moderate amount of time (3–4 days)*, and 3 indicating *all of the time (5–7 days)*. An example of one of these items is, "I was bothered by things that usually don't bother me." Two of the items (nos. 5 and 8) are reverse-scored. The score on the CES-D 10 is the sum of the 10-item weights, with a score of 10 or greater indicating depression. Internal consistency (reliability) for the CES-D 10 is reasonably high at 0.84. In a test of the scale with 605 subjects with chronic disease (Lorig et al., 2001; Andreson et

al., 1994), the observed range was 1–30, with a mean of 12.9 (SD = 6.13).

The SES is one of the most widely used self-esteem measures in social science research (Greenberger et al., 2003). It is a self-report Likert-type instrument with 10 items answered on a 4-point scale ranging from *strongly agree* to *strongly disagree*. In the present study, for scoring five of the items, the labels were weighted such that *strongly agree* was assigned a value of 3, while *strongly disagree* was assigned a value of 0. An example of one of these items is, "I feel that I have a number of good qualities." The remaining five items are reverse-scored. An example of one of these items is, "I certainly feel useless at times." Thus, in this administration, the total score on the SES was the sum of the two sets of items, and could range from 0–30, with 30 indicating the highest score possible. Greater self-esteem is indicated by a higher score. Developers of the scale (see Blascovich & Tomaka, 1993; Rosenberg, 1986) report that it has high reliability, with test–retest correlations typically in a range of 0.82 to 0.88, and Cronbach's alpha ranging from 0.77 to 0.88 for a number of studies.

The interview questionnaire included six questions designed to encourage participants' self-disclosure of their general moods, feelings about themselves and attitudes about their medical conditions and hemodialysis treatments. The complete questionnaire can be seen in Appendix A.

### Procedure

Five volunteer activities were selected from a list identified by the social worker at the hemodialysis unit who made contact with a supervisor or coordinator at each of the volunteer sites. Sites included a food pantry in need of help stocking shelves, helping customers, cleaning, etc.; a literacy council in need of volunteers to read and audiotape books for clients; nursing homes in need of volunteers to write letters and/or visit shut-ins and mend clothes for the sick and elderly; and a hemodialysis unit renal dietician in need of a volunteer to clip coupons for patients. (See Appendix B for additional volunteer activities identified by the social worker.) Each volunteer was matched with an activity according to his or her health, mobility and interest. The volunteers committed to 1 hour of volunteer activity per week. Volunteers were given the option of being matched with a second volunteer activity if the first activity did not work out. One volunteer availed herself of this option.

Just prior to the onset of and at the conclusion of the 3 months specified for the volunteer activities for those in

the experimental condition, participants in each condition gave informed consent; demographic information including age, gender, educational level, relationship status with significant other and length of time on dialysis; and responses to the SES and the CES-D 10. Completion of the instruments was self-paced and required an average of 5 minutes each for the SES and the CES-D 10. Additionally, the interview questionnaire was administered to each participant in each condition at the onset and conclusion of the study. Interviews were conducted by a hired research assistant and tape-recorded for later transcription. On average, interviews took approximately 1 hour to complete. The research assistant was not previously known to the participants.

Adherence to treatment regimen was evaluated on the basis of two primary factors. First, adherence to prescribed dialysis diet was indicated by (a) phosphorous levels (adherence was represented by a monthly reading of less than 6 mg/dL); and (b) potassium (K) levels (adherence was represented by a monthly reading of less than 6 mEq/L as recommended by the National Kidney Foundation Kidney Disease Outcomes Quality Initiative guidelines). Second, adherence to prescribed fluid allotment was evaluated by the amount of fluid weight gain between dialysis treatments. Adherence was represented by a weight gain of less than fluid allotment. Fluid allotment was established as 3% of the patient's base (dry) weight or adjusted base weight for obese patients. Fluid weight gain was measured in kilograms on a calibrated standard scale at the dialysis center.

The hemodialysis unit dietitian recorded K and phosphorus ( $\text{PO}_4$ ) levels for each participant once per month, beginning 2 months prior to the onset and ending 2 months following the end of the volunteer period. The dialysis staff recorded fluid weight gain (in kilograms) three times per week, at each hemodialysis appointment.

## RESULTS

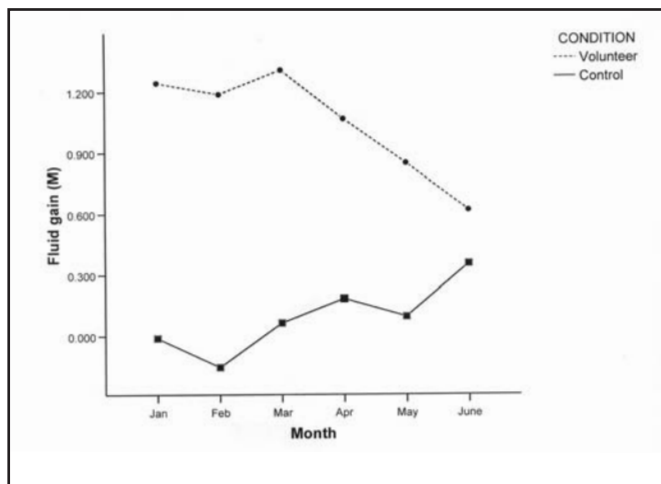
The data from one participant from the experimental condition who experienced a decline in health precluding his ability to act as a volunteer were not included in any part of the analyses. Thus, there were seven participants in the volunteer condition and six in the control condition who supplied complete data for the quantitative measures. Two patients were unable to complete the final interview; one participant from the control group received a kidney transplant, and one participant from the volunteer group died before the post-experiment interviews were conducted.

Examination of the findings from the quantitative measures revealed that they were consistent with the qualitative data from the interviews and suggests the reliability and validity of those measures for this sample. Of most importance for the quantitative analyses were those measures indicating adherence to dietary restrictions: fluid weight gain and K and phosphorus levels.

### Fluid Weight Gain

Figure 1 shows the mean fluid weight gain (loss) for volunteer and control conditions for each of the months prior to (January, February), following (June) and comprising (March–May) the experimental time period. As can be seen, overall fluid weight gain appears greater for those in the volunteer condition than for those in the control condition. Because a random assignment procedure was used, this outcome could not have been predicted and was consistent throughout the course of the experimental time frame. However, once the volunteer period began, amount of fluid weight gain appears to steadily decline for those in the volunteer condition while, concurrently, it appears to increase somewhat for those in the control condition. A 2 (condition)  $\times$  6 (months of the experiment) mixed (between subject  $\times$  within subject) ANOVA confirmed these observations. There was a statistically significant interaction between condition and the time course of the experiment,  $F(5, 60) = 3.701, p < 0.01, MSE = 0.160$ . The effect was strong as indicated by an  $\eta^2$  of 0.236. Likewise, there was a main effect of condition,  $F(1, 12) = 9.939, p < 0.05, MSE = 2.146, \eta^2 = 0.427$ . However, there was no main effect of time course of the experiment,  $F(5, 60) < 1.0$ .

**Figure 1. Mean fluid gain prior to, during and following the study**





Simple main effects analyses of the months March through June for the volunteer condition showed that the reduction in fluid weight gain was reliable for those in the volunteer condition,  $F(3, 18) = 4.233$ ,  $p = 0.02$ ,  $MSE = 0.144$ . The effect was strong as indicated by an  $\eta^2$  of 0.414. Paired samples  $t$ -tests were used to evaluate change between months and revealed that the greatest reduction in fluid weight gain took place from the beginning months to the end of the volunteer period (March–June and April–June),  $t(6) = 3.789$  and  $2.743$ , respectively,  $p < .05$ , while the change from month to month (March–April, April–May and May–June) was not statistically significant,  $t(6) = 0.835$ ,  $1.618$ , and  $1.944$ , respectively,  $p > .05$ .

In contrast, for those participants in the control condition, the increase in fluid weight gain (see Figure 1) was not statistically reliable,  $F(3, 18) = 1.215$ ,  $MSE = 0.097$ ,  $p > .05$ . Follow-up paired samples  $t$ -tests comparing the increase between months supported this conclusion; the one increase in fluid weight gain that approached significance was that between May and June,  $t(6) = -2.133$ ,  $p = 0.077$ ; all other resulting increases in fluid weight gain were not statistically significant,  $t \leq -1.298$ ,  $p \geq 0.242$ , in each case.

Simple interaction comparisons looked specifically for major differences in fluid weight gain between the volunteer and control conditions for those months in which the greatest changes appeared to take place—as participants had had sufficient experience with volunteering and following, April to May and May to June. As can be seen in Figure 1, the greatest difference between conditions was in fluid weight gain changes for each between May and June, at the conclusion of the volunteer period for this research. It was at this time that fluid weight gain was greatest for those in the control group while fluid weight gain was lowest for those in the volunteer condition,  $F(1, 12) = 8.318$ ,  $p = 0.014$ ,  $MSE = 0.050$ . The interaction was strong, as indexed by  $\eta^2$  at 0.409. In contrast, although there were different changes in fluid weight gain between those in the control and volunteer conditions, there was no reliable interaction between change and condition for the period April to May,  $F(1, 12) = 1.134$ ,  $p = 0.308$ ,  $MSE = 0.202$ .

### K Levels

Initially showing higher levels of K than those in the control condition, the participants in the volunteer condition showed progressively lower levels of K over the course of the volunteer period. As can be seen in Table 1, all seven participants in the volunteer condition showed improvement in their K levels; this was indi-

cated by a decline in levels to the acceptable range of 3.5 to 6.0 mEq/L from the first to the last month of the experimental time period. In contrast, only two participants in the control condition showed improvement in K levels as demonstrated by a decline to the acceptable range, while most (four participants) actually showed an increase in K levels above the acceptable range. These differences in response for the volunteer and control conditions were reliable,  $\chi^2(2) = 7.778$ ,  $p < .05$ .

**Table 1. Percent Change in Potassium Level as a Function of Experimental Condition**

Change in Potassium Level (% of condition)			
Condition	Improved	Same	Worse
Volunteer	100	0	0
Control	29	14	57

### Phosphorus Levels

As can be seen in Table 2, results were mixed for improvement in maintaining appropriate phosphorus levels for those in the experimental condition. Improvement in adherence as indicated by maintaining phosphorus levels in an acceptable range of 3.5 to 5.5 mg/dL was attained by three of the patients and three showed an increase beyond the acceptable range. On the other hand, six of the patients in the control condition showed an increase beyond the acceptable range. However, these differences between conditions were not statistically significant,  $\chi^2(2) = 3.00$ ,  $p > 0.05$ . In contrast to the thrice-weekly measures of fluid weight gain, measures of K and phosphorus were made on a monthly basis. It should be noted that a small sample size with few repeated measures of a variable can result in more error variability that contributes to the statistical test and less power in the data for detecting real effects.

**Table 2. Percent Change in Phosphorus Level as a Function of Experimental Condition**

Change in Phosphorus Level (% of condition)			
Condition	Improved	Same	Worse
Volunteer	43	14	43
Control	14	0	86

### Depression and Self-Esteem

Of additional interest for the quantitative analysis were differences in response to pre- and post-experiment measures of depression and self-esteem. Scores on depression decreased overall from the first to the second administration of the CES-D 10 for participants in both

the volunteer and control conditions. While the decrease in depression appeared to be greater for those in the volunteer condition ( $M = 9.57$  versus  $7.43$ ,  $SD = 2.37$  and  $4.79$ , for the first and second CES-D 10 administration) than for those in the control condition ( $M = 8.83$  versus  $7.67$ ,  $SD = 5.71$  and  $6.02$ , first and second administration), there was no interaction,  $F(1, 11) < 1.0$ ,  $MSE = 18.17$ , nor was the difference between conditions reliable,  $F(1, 11) < 1.0$ ,  $MSE = 28.70$ . Finally, the apparent overall reduction in depression was not reliable,  $F(1, 11) < 1.0$ ,  $p > 0.05$ ,  $MSE = 18.17$ .

There was no reliable change in self-esteem for either of the two conditions, as assessed by the SES. Examination of the mean pre-experiment SES scores for participants in the volunteer and control conditions showed little difference between the two; the mean SES scores for the volunteer and control conditions, respectively, were  $20.50$  ( $SD = 4.76$ ) and  $20.83$  ( $SD = 4.26$ ). The changes to mean SES scores of  $19.67$  ( $SD = 3.20$ ) and  $19.83$  ( $SD = 5.85$ ) for those in the volunteer and control conditions, respectively, on the post-experiment administration were not significant. Neither was there an interaction between time of administration of the SES and condition, nor were there main effects of change in SES scores or condition,  $F(1, 11) < 1.0$ , for each effect. Note that self-esteem, according to one definition (Bem, 1967) is considered by many (e.g., Watson et al., 2002) to be a relatively stable personality characteristic and, as such, rapid change may not be observed easily by scales such as the SES. On the other hand, the definition of self-esteem as used in the present research—pride in self, self-respect, and self-worth (based on Bandura, 1997)—may be more sensitive to subtle changes that are better detected in the longer interview process (analysis to follow).

In general, although the examination of scores for the pre- and post-experiment administrations of the SES and CES-D 10 indicate no reliable changes related to the volunteer experience, the numbers in each condition were small and probably did not produce adequate power to detect an effect. In addition, there were only two administrations of these instruments—immediately before and at the end of the experimental period (6 months later). However, a trend toward a reduction in depression was indicated. This, considered along with the data from the pre- and post-experiment interviews of participants in this study, provides evidence for a role of volunteerism in achieving psychological improvement for patients in dialysis.

### Qualitative Analysis of Interviews

The qualitative analysis focused primarily on the transcripts of semi-structured interviews conducted pre- and post-experiment. The analysis was conducted by two evaluators, independent of each other, and examined changes for each participant in the experimental and control conditions. However, indicators of change were also identified in informal observations of participants throughout the project by dialysis staff, revelations from participants' families and by participant verbalizations outside the interviews. In addition, observations were also recorded by the research assistant who called each participant twice throughout the project. In both pre- and post-experiment interviews, six questions were asked (see Appendix A).

Changes between pre- and post-experiment interviews were categorized using the following criteria:

1. Mood—for example, affect, more positively worded phrases, energy level and body language as observed by interviewer
2. Self-esteem—for purposes of this project, self-esteem is defined as pride in self, self-respect, and self-worth (Bandura, 1997; dictionary.com, n.d.)
3. Relationships—participant's relationships with people significant in his/her life
4. Sense of control—participant's sense of control over own life; sense of control regarding the adherence to dialysis regimen
5. Attitude toward dialysis—how positively or negatively a participant views his/her dialysis treatment and the necessity to integrate it into his/her life
6. Ability to make a difference—sense of generativity, self-efficacy or sense of capability (see Bandura, 1997)

Each of these six criteria were used by the evaluators to give a rating of change of *decreased or declined*, *stayed the same*, or *increased or improved*. What follows are summaries for each criterion across patients, including examples of statements indicating change. The examples given are not exhaustive. Participants in the study were given codes to facilitate reference to their comments and behavior; those in the experimental condition were coded with letters A, B, F, G, H and I and those in the control condition were coded with letters C, D, E, J, K and L. The examples that best illustrate the criteria came from all six participants in the experimental condition. However, only participants C, D and E, in the control condition provided comment or examples illustrating the criteria for their condition.

### Mood criteria

Both evaluators found that all six participants in the experimental condition improved. The research assistant who conducted the interviews reported more positive body language and more desire to talk in the post-experiment interviews in participants in the experimental condition. Of those in this condition, she noted greatly improved eye contact for participant A, who also commented that “I can do a lot more that I used to” in the post-experiment interview as contrasted with “I wish I could do more” in the pre-experiment interview. Participant B expressed pride that, for the first time in years, she had the energy to weed her garden.

Of those participants in the control condition, both evaluators agreed that, according to the criteria, three participants declined in mood, two stayed the same and one improved. Participant C’s improvement was indicated by changes such as her saying, “There are lots of things I can’t do anymore” in the pre-experiment interview to talking about going out of her house more often in the post-experiment interview. Of the three participants who were noted to decline in mood, participant D stated, for example, “My moods are not too bad” in the pre-experiment interview as contrasted with, “I’m depressed. I get down and blue and depressed more than before” in the post-experiment interview. Both evaluators noted that participant E seemed less enthusiastic and more blasé toward life in the post-experiment than in the pre-experiment interview. The tone of his voice was not as animated in the post-experiment interview. Further, participant E stated, “Things are going beautifully” in the pre-experiment interview as compared with, “Things are going good” in the post-experiment interview.

### Self-esteem criteria

One evaluator found that all six participants in the experimental condition improved. The second evaluator found that five participants improved and one stayed the same. In the post-experiment interview, participant F said, “Reading books on tape [the volunteer assignment] makes me feel smart.” In the post-experiment interview, participant G said in a strong voice interpreted by the interviewer as reflecting pride, that “I stock a whole shelf in an hour. They seem to like me quite well.” Previously, this participant was noted as showing hesitancy about even volunteering in a placement away from home. The research assistant noted during the interviews that participant H displayed a more self-assured body posture (e.g., sitting up straighter, shoulders not drooping) in the

post-experiment interview as compared to that observed in the pre-experiment interview.

Of those participants in the control condition, both evaluators rated one participant as having declined, four as having stayed the same and one as having improved. Participant C, who both evaluators rated as improved in self-esteem said, “I have been getting out more and doing more things” in the post-experiment interview. However, in this case, an explanation for this improvement is offered by her concerns expressed in the pre-experiment interview about a particular relative; on the basis of her comments at the time of the post-experiment interview, this concern had been resolved.

### Relationship criteria

Both evaluators rated one participant in the experimental condition as having stayed the same and five as having improved their relationships. Participant G said, “I get along reasonably well with my wife” in the pre-experiment interview as contrasted with saying, “I get along real well with my wife” in the post-experiment interview. Participant I stated having good relationships with children both in the pre- and the post-experiment interviews.

Of those participants in the control condition, both evaluators noted one participant as having declined in the quality of relationships, four as having stayed the same and one as having improved. Participant D, for example, noted by both evaluators as having declined, said, “I enjoy my relative because I ain’t by myself anymore” in the pre-experiment interview as contrasted with, “I wish I could live by myself” in the post-experiment interview.

### Sense of control criteria

Of those in the experimental condition, both evaluators rated one participant as having stayed the same and five as having improved; however, a different participant was rated by each evaluator as having stayed the same. Both evaluators agreed on the improvement of participant A, who said in the pre-experiment interview, “I have a little trouble with phosphorous.” In the post-experiment interview, this participant said, “I’m doing better with phosphorous. I can control my diet.” In the pre-experiment interview, participant G said, “Fluid is a big problem” as contrasted with the post-experiment interview in which he said, “I limit myself to so much fluid per day.”

Of those participants in the control condition, both evaluators rated two participants as having decreased,



three as having stayed the same and one as having an increase in sense of control. In the pre-experiment interview, participant E did not disclose any specific problems following the dialysis regimen, whereas in the post-experiment interview, he said, “I forget to take my pills every once in awhile.”

#### Attitude toward dialysis criteria

One evaluator categorized all participants in the experimental condition as having improved in their attitude towards dialysis. The second evaluator rated two participants as having stayed the same and four as having improved. Participant F was noted by both evaluators as having improved. When asked about dialysis in the pre-experiment interview, she said, “God is mad at me for something” as contrasted with the post-experiment interview when she said, “God is giving me a second chance.” Participant A, who was rated by both evaluators as having improved in her attitude toward dialysis, said in her pre-experiment interview, “I have a fear of how my disease will progress” as contrasted with the post-experiment interview when she said, “My health is pretty good.” In the pre-experiment interview when asked about his dialysis treatments, participant G talked about problems with fluid weight gain and feeling “achy and just plain tired all the time.” In the post-experiment interview, participant G said, “Dialysis is going real good. They’re giving me good dialysis.”

Of those participants in the control condition, one evaluator rated two participants as having declined in attitude toward dialysis, three as having stayed the same and one as having improved. The other evaluator rated three participants as having declined, two as having stayed the same and one as having improved. Participant C, who both evaluators found to be improved, said in her pre-experiment interview, “Dialysis is a big stumbling block.” In her post-experiment interview, she said, “I don’t like it, but I can accept it.” Participant E, rated as having declined by both evaluators, said in the pre-experiment interview, “I like having a health care person” as compared with his statement in the post-experiment interview, “It is hard having a health care person come to my home every morning.” This same participant said in his post-experiment interview, “It is hard coming to dialysis three times a week,” whereas there were no negative comments about dialysis in the pre-experiment interview. In the pre-experiment interview, when asked about how he felt about dialysis, participant D said, “I have come to live with it. It doesn’t get me down anymore.” In the post-experiment interview, this participant said his medical condition “worries me.”

#### Ability to make a difference criteria

Both evaluators rated all participants in the experimental condition as having shown improvement in this category. The noted increase in self-efficacy for participant F was dramatic. In the pre-experiment interview, she was noted as expressing hesitancy. In the post-experiment interview, she said, “I’d like to learn another language—maybe be an interpreter.” In the post-experiment interview, participant A said “My volunteering helps people. I feel a little better about myself.” All participants in the experimental condition seemed energized—as observed by the research assistant during the interview and by participant comments—when talking about their volunteer experiences; all indicated that they were making a difference. Five of these participants expressed a desire to continue volunteering after the conclusion of the research project.

Of those participants in the control condition, one evaluator rated one participant as having declined in feelings of self-efficacy and being able to make a difference, three as having stayed the same and two as having improved in their feeling that they could make a difference. The second evaluator rated one participant as having declined, four as having stayed the same and one as having improved. In the post-experiment interview, one participant asked if what he had done in the study had made a difference. Partway through the study, this same participant asked if he could help transport another dialysis patient to treatments if this would not interfere with study results, as he was in the control condition. The desire to help transport never occurred because the patient to be transported died before the study participant was able to obtain his driver’s license. One participant was rated by both evaluators as having declined in level of self-efficacy and perceived ability to make a difference. In the pre-experiment interview, this participant seemed to perceive himself as not being capable of making a difference; but, in the post-experiment interview, his expressed feelings of not being able to make a difference seemed intensified. The research assistant noted that he had a flatter affect in the post-experiment interview as he talked about not being able to perform his previous job anymore and sometimes feeling “hopeless.” He said, “I worry about what I can’t do anymore.”

#### Observations by staff and others

The identities of participants in this research were not formally revealed to the dialysis staff; however, because of the small number of patients in the unit and the pride outwardly verbalized by the participants of the study



while in the unit, many of the participants made their participation known. Informal observations of participants by staff members and verbal disclosures from participants and their family members to the principal investigator (PI) and the research assistant conducting the interviews were also considered. Five of the six participants in the experimental condition were noted as being more open and communicative at the dialysis center during and following their volunteer experiences. In support of this, all six were also noted by the evaluators as being more open and communicative in the post- as compared with the pre-experiment interviews. Another example: Before the start of the study, a participant in the experimental condition had requested an extended weekly time period with the social worker to discuss marital issues. Following the onset of the study, this participant was satisfied with a brief "hello" from the social worker. He reported that things were going well with his marriage and that his spouse approved of his volunteer experience. This participant's spouse also requested continued volunteer experiences for the participant and expressed an increased respect in her view of the participant. When asked about setting up an appointment on a certain day, the participant responded, "I volunteer on that day." The participant had originally requested a home-based clerical volunteer activity but, as this was not available, he agreed to try a placement outside his home. He continued successfully with this placement throughout the project.

A second participant in the experimental condition was not satisfied with the first volunteer experience outside her home. As her dissatisfaction became evident to the PI and the research assistant, she responded positively to the offer of a placement change. Following this change, she was noted by staff as becoming more talkative, open, self-assured and positive in attitude. After the start of the study, a third participant in the experimental condition was noted by the social worker as consistently offering handshakes in greeting. This behavior had not been noted prior to the study. The participant and spouse also verbalized enhanced marital satisfaction following the onset of the study. A fourth participant in the experimental condition, who had verbalized tendencies to show volatile behavior prior to the study, was seen to present a calmer affect following the onset of the study. A fifth participant in the experimental condition, who staff observed as being more communicative and open than ever observed before the onset of the study, expressed the desire to involve another family member in a volunteer experience. On the other hand, of the participants in the control condition, only

one participant was observed following the onset of the study as displaying a more positive attitude while in the dialysis unit.

## DISCUSSION

Volunteerism is an area that has not been investigated in the CKD population but has been shown to have demonstrable effects in elderly and chronic disease populations other than CKD (e.g., Musick & Wilson, 2003; Harris & Thoresen, 2005). The present study was intended to be exploratory and to contribute data upon which further research could be based and from which implications for practice can be considered. The findings of the present study show that volunteerism is an understudied phenomenon that can have a tremendous positive impact on dialysis patients. Those in the experimental condition of this study who volunteered weekly for 3 months showed significant improvement in adherence to dietary regimen, while those in the control condition who did not volunteer, as a group, did not improve on this measure of adherence to a dietary regimen that is critical to successful CKD treatment. Fluid weight gain, which is measured at each dialysis treatment, is most readily available to staff and patient and, thus, changes are very salient to patients. Further, it is a more accurate measure and more sensitive to patient dietary adherence than other measures. However, K and PO<sub>4</sub> levels are only measured monthly; while these are accepted measures and monthly measures are an accepted schedule for measurement, they are, consequently less reliable as an indication of adherence. Quantitative analysis of self-esteem and depression measures showed trends toward greater improvement for those in the experimental than in the control condition; these differences were not statistically reliable. However, the data from the quantitative analyses showed similar differences and indicate that a quantitative difference could be found in a larger sample than that observed in the present research.

The impact of volunteering was reported positively by all six participants in the experimental condition and was also observed in the affect, behavior and body language of a number of these volunteers. Five of the six participants in the experimental condition expressed a desire to continue volunteering after the project ended. Some talked about getting other people involved. All expressed enhanced self-perceptions of empowerment.

All participants in the experimental condition improved in their perceptions of their abilities to make a difference and self-efficacies. The resulting increase in sense of control over life is congruent with past studies of self-efficacy in that a belief that one can produce desired

effects provides the incentive to act on these effects (Bandura, 1997). Accordingly, there was a significant improvement in adherence to dietary regimen by those in the experimental condition as compared with those in the control condition as shown by measures of fluid weight gain and K. Better adherence has a probable effect of improved patient outcomes and, thus, better results for dialysis providers.

The enhancement of relationships shown by those in the experimental condition resulted in creating more outside support for the participants. This likely played a role in helping them to deal with their illness as was indicated by the improved attitude toward dialysis shown by this group of patients. The participants were found to be more accepting and hopeful regarding their treatment. One participant volunteered along with his spouse. This created an opportunity for this couple to enhance their relationship by doing something meaningful outside the dialysis unit instead of being as focused on the participant's illness. Another participant's spouse requested that the participant volunteer even more in the future.

Aside from showing strong benefits of volunteering as it relates to the criteria measured in the study, there were also some unexpected benefits that resulted from the study. The dialysis unit studied, which was an independent unit at the start of the study, was incorporated by a large dialysis provider during the study. Many patients in the unit expressed anxiety about unknown and imagined changes and concerns surrounding this incorporation. At the time of the incorporation, there was concern by the PI, research assistant and consultant that the added stress expressed might influence the results of the study.

Instead, participants in the experimental condition demonstrated an ability to "weather" the stress and not let it affect their control of fluid intake, for example, as indicated by continuously improving lab results for April through June. Participants in the control condition showed a decline in their lab results for those months, which could likely be interpreted as a response to stress and the ensuing loss of control of their lives. Volunteer work was the single identified independent variable that was consistent in the lives of those in the experimental condition while not a factor in the lives of those in the control condition. This study indicates that volunteerism may have an added unexpected benefit of helping an individual to deal with stress.

Another unexpected positive byproduct of the present study was the noticeable decline in demand of extended

social work time from the participants in the experimental condition. Prior to the study, two of the original seven participants in this condition routinely expressed marital dissatisfaction and requested frequent and lengthy social work intervention to help deal with these concerns. From the onset of the project, neither of these two participants expressed any marital concerns. Dialysis patients are faced with an inordinate amount of stress surrounding health concerns, loss of control and independence, loss of kidney function as well as relationship, financial and transportation concerns, among others. One effect of volunteering may be to provide a buffer to stress, which, in turn, may translate into less demand on the time of social workers and other staff members.

Benefits to society as a result of these participants' volunteer activities were also noted. A volunteer site representative from a nursing home shared how excited a resident was to have a weekly visit from one of the participants in the study. A representative from another volunteer site asked for permission to include appreciation for our volunteer in a newsletter. A highlight of the study was when a student at the Literacy Council, with the help of a tutor, wrote a personal note of appreciation to a study participant. Along with the note was a picture of his child—a child who, with the help of this project, has been able to enjoy her father reading a book to her.

As this study progressed, issues evolved that needed to be addressed to ensure its success. The PI was in contact with a representative from each volunteer site at the beginning of the study and as needed throughout the study. The research assistant was in periodic contact with each participant throughout the study. These planned contacts afforded participants the opportunity to express their level of satisfaction with their placements. When it was eventually realized that a participant in the experimental condition was unhappy with her placement, she took advantage of the opportunity to switch to another placement that was much more satisfactory to her. She continued her volunteer work after the fulfillment of her commitment to the project. This participant had not shared her dissatisfaction with the first placement until the site representative told the PI that attendance at the site had been sporadic. This information precipitated conversation with the participant, who then shared her concerns.

It was difficult finding home-based placements for those participants who preferred such placements. Of the original seven participants in the experimental condition, four requested home-based placements. A home-based participant who mended clothing in her home for an extended care facility (i.e., nursing home) needed

someone to pick up and deliver the clothing. The PI created a partnership with a local Literacy Council that invited participants to read books on tape. There was a need to provide participants with books and cassette tapes and then deliver the finished product.

### *Limitations of the Study*

The study had a small sample size. Thus, generalizations to any larger dialysis population are constrained. Additionally, the small sample size affects the reliability of the results. Examination of the findings from the quantitative measures in combination with the qualitative data from the interviews, however, suggests that the measures are valid. Volunteerism is an area that has received minimal attention for the CKD population and, consequently, this initial systematic attempt to examine its effect is important. In addition, there is a need for continued study of psychosocial determinants of adherence to dietary regimens for dialysis patients (Kutner, 2001; Pang et al., 2001). The indications of a positive effect of volunteering on adherence to dietary regimens and psychosocial health, even in a small group of patients, make the results of the present study invaluable.

### *Implications for Future Research*

The Centers for Medicare and Medicaid Services (CMS) within the Department of Health and Human Services has revised requirements for Medicare certification for dialysis facilities ([http://www.cms.hhs.gov/CertificationandCompliance/05\\_DialysisProviders.asp#TopOfPage](http://www.cms.hhs.gov/CertificationandCompliance/05_DialysisProviders.asp#TopOfPage)). Rehabilitation is a critical component of the proposed revisions and addresses the need to restore “the mind and body to encourage the individual to maintain as full and active a life as possible.” Moreover, the text suggests rehabilitation can benefit the patient, family and society in a myriad of ways that extend beyond simple return to employment. Examples indicate that rehabilitating the patient can allow a support person to return to the workforce, and that the improvement in the patient’s quality of life may prevent long-term care facility placement and, ultimately, reduce medical costs. Findings from the present study support earlier claims that the volunteer experience has a positive impact on both the physical and mental health of older people in areas of general health decline and everyday functioning, depression and mortality rates (Lum & Lightfoot, 2005). It also supports previous claims that volunteering “can improve the health and mindset of those who do it” and that it can also “help people have better self-esteem at any age.” One participant in the study perhaps best described the impact of

volunteering when asked about her volunteer experience. She said, “It keeps my mind off me. I can’t get down in the dumps trying to think about somebody else. I feel a little better about myself.”

The findings of this study also suggest that volunteerism benefits a larger dialysis population. Findings also suggest the need for further research on the impact of volunteerism on the stress experienced by the CKD population, as well as on the reduction of time demands on staff to deal with patient concerns. Furthermore, previous research with other populations (e.g., Musick & Wilson, 2003) suggest a positive relationship between volunteerism and other physical factors, thus encouraging future research on the impact of volunteerism on physical factors experienced by dialysis patients (e.g., chronic pain, disability, mortality). The present exploratory study provides insight into the promising impact of a low-cost intervention on these critical issues. Further, the effects of various kinds of volunteer experiences (e.g., home-, community- and religious-based) were investigated. Finally, this study will assist in the development of an instrument to examine the impact of interventions on this population. It has already revealed areas important to these patients previously uninvestigated in the context of volunteerism.

### *Implications for Future Practice*

The findings from this study about the benefits of volunteerism suggest that future dialysis social work interventions be expanded to include volunteerism activities as a standard of practice rather than an exploratory intervention as reported here. The present study suggests the addition of earmarked hours for either social workers or another individual with projected functions of promoting the benefits of volunteerism, locating volunteer opportunities, matching patients with appropriate volunteer placements, periodically monitoring the experiences and changing placement, if necessary. Findings from this study indicate that the additional time spent by staff in coordinating volunteer activities for patients may be more than compensated for by patients being less demanding of staff time because the patients feel more in control of their lives, experience elevated mood and decreased depression, enjoy increased social support resulting from improved relationships and are more adherent to their dialysis regimens. As an integral part of the dialysis team, social workers have specific functions, such as assisting patient adjustment to dialysis and the physical, psychological and social life changes that accompany the dialysis regimen. Social workers continually search for ideas and resources to help



patients to continue to have a purpose in life, enhance their perceived control over their lives and function as productively as possible. It is frustrating for social workers to encourage patients to engage in traditional VR programs or apply for traditional employment at the same time that these patients need to wrestle with problems typical of dialysis, such as time commitment for dialysis, days of not feeling well and so forth. Unlike paid employment opportunities, volunteer opportunities are more likely to have a flexible time commitment that can incorporate dialysis treatment and frequent sick days.

Other possible benefits of volunteering may be that if patients gain more skills (social, technical, etc.), more confidence and enhanced feelings of self-efficacy from their volunteer experiences, they may become more marketable in the employment world. Thus, there may also be a byproduct of volunteerism leading to a desire on the part of some patients to enter more traditional VR programs and paid employment activities. Volunteerism can be either a viable alternative or an addition to traditional VR and paid employment activities. In short, when it comes to volunteering, "Nobody can do everything but everyone can do something."


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**APPENDIX A***Interview Questions*

1. How are things going for you?
2. How do you feel about your medical condition?
3. Tell me about taking care of yourself as the dialysis staff recommends.
4. How have your moods been lately?
5. How have you been getting along with the people in your life who matter to you?
6. How are you feeling about yourself?

**APPENDIX B***Volunteer Opportunities*

- Answering phones for a local helping organization
- Calling shut-ins to check that they are doing “OK”
- Helping at a local food bank/pantry: stocking shelves, helping customers, cleaning, etc.
- Visiting a lonely resident at a local nursing home
- Teaching or making a craft
- Audiotaping books for clients of a literacy council
- Writing letters to residents of nursing homes, prisons and schools
- Mending clothes for the sick and elderly
- Clipping coupons for patients in the hemodialysis unit, the elderly or a school or church