Designing Nephrology Social Work Interventions to Improve Self-Management and Adherence Based on the Dialysis Outcomes and Practice Patterns Study

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Along with other studies, the Dialysis Outcomes and Practice Patterns Study demonstrates that adherence to treatment has been shown to impact morbidity and mortality for people with chronic kidney disease. Dialysis treatment teams continue to seek ways to help patients understand the short- and long-term effects of nonadherence to medical recommendations. This article highlights nephrology social work interventions designed to improve patient self-management skills through cognitive behavioral techniques.

INTRODUCTION

Patient survival in Europe and Japan is better than the United States even after adjustments for age, gender, and diabetes (Saran et al., 2003). A detailed examination of practice patterns was undertaken in the Dialysis Outcomes and Practice Pattern Study (DOPPS) to try to understand this and many other questions regarding care outcomes. DOPPS I, an ongoing international, observational, and prospective hemodialysis study, was initiated in 1996. Countries included in this phase of the study include Japan, the United States, France, Germany, Italy, Spain, and the United Kingdom.

Nonadherence is a determinant of treatment outcomes including endpoint outcomes of morbidity and mortality. DOPPS data shows that skipping one dialysis treatment a month can increase mortality by 30% (Saran et al., 2003). Other research has shown similar trends (Leggett et al., 1998; Kimmel et al., 1995). Skipping dialysis once a month also leads to a 16% higher risk of hospitalization than for patients who did not skip (Saran et al., 2003). Prior to DOPPS, the risk of hospitalization associated with nonadherence had not been reviewed closely despite its effect on cost containment and patient morbidity.

Patient level predictors of nonadherence in DOPPS included younger age, female gender, African American race, employed status, living alone, smoking status, depression, marital status, and time on end-stage renal disease treatment. These predictors were associated with varying nonadherent behaviors including skipping and/or shortening treatment, weight gain between treatment, hyperphosphatemia, and hyperkalemia. Additionally, a high correlation was found among different measurements of nonadherence. In other words, when one measure of nonadherence was present, there was a statistically significant chance that other nonadherent behaviors would be found. The highest correlation was seen between shortening and skipping hemodialysis treatment (Saran et al., 2003). Larger facility size was associated with a higher probability of patients skipping treatment.

An important focus of nonadherence is large interdialytic weight gains, which can have an adverse impact on blood pressure, which in turn leads to increased cardiovascular risk (National Kidney Foundation/KDOQI Workgroup, 2005). Challenges to adherence include disease factors, treatment regime, and individual/family context (Linsk & Bonk, 2000). Determinants of successful adherence include access to resources and medications, social support, and adherence techniques such as increasing the capability of a patient and ensuring that patients understand the implications of nonadherence (Gallegos & Giddens, 2004).

The thought-provoking question is: How can social workers provide interventions that impact treatment outcomes in a time-efficient, effective manner?

NEPHROLOGY SOCIAL WORK INTERVENTION STRATEGIES TO IMPROVE ADHERENCE

Targeted psychosocial interventions provided by nephrology social workers who are part of the interdisciplinary team working with dialysis patients can improve outcomes by improving patient self-management (adherence to medical recommendations). The nephrology social worker's training in systems theory aids in the assessment of modifiable health risk behaviors. These health risk behaviors in dialysis patients include:

- treatment adherence (missed and shortened treatments)
- fluid adherence (interdialytic weight gains)
- dietary adherence (low salt, phosphorous, potassium, sugar)
- medication adherence
- lifestyle behaviors (smoking, exercise)
- social support
- depression management
- affect (stress and anger) management

As outlined in the CNSW "Outcomes Driven Model of Nephrology Social Work Practice" (National Kidney Foundation [NKF]/Council of Nephrology Social Workers [CNSW], 2006), social workers focus on four tenants that support adherence behavior: knowledge, resources, motivation, and life skills. Social workers must continually assess these four areas to understand the needs and strengths of the patient and achieve success.

Social workers are taught early in their graduate education to "begin where the client is." Patients' readiness to manage their disease is impacted by their phase of adjustment to chronic kidney disease, which can be divided into three phases (NKF/CNSW, 2006; Figure 1):

- Phase I: Diagnosis and/or initiation of renal replacement therapy
- Phase II: Chronic fluctuating illness
- Phase III: Physical decline/death

Patients may not be ready to struggle with adherence if it has only been 1 week since they learned that without dialysis they would no longer be able to live. Focused psychosocial assessment and intervention are key to facilitating improved understanding and adaptation to illness. To promote an effective intervention design that targets the identified health risk behavior, social workers must understand where the patient is in his or her adaptation to illness, what the patient gains if medical recommendations aren't followed, and what is given up if recommendations are followed. This gain and loss paradigm extends to the patient's support system. Adherence, therefore, is a lifelong management task that promotes wellness and survival by managing behaviors and risks that are impacted by psychosocial variables across the lifetime of patients and their support systems.

Figure 1

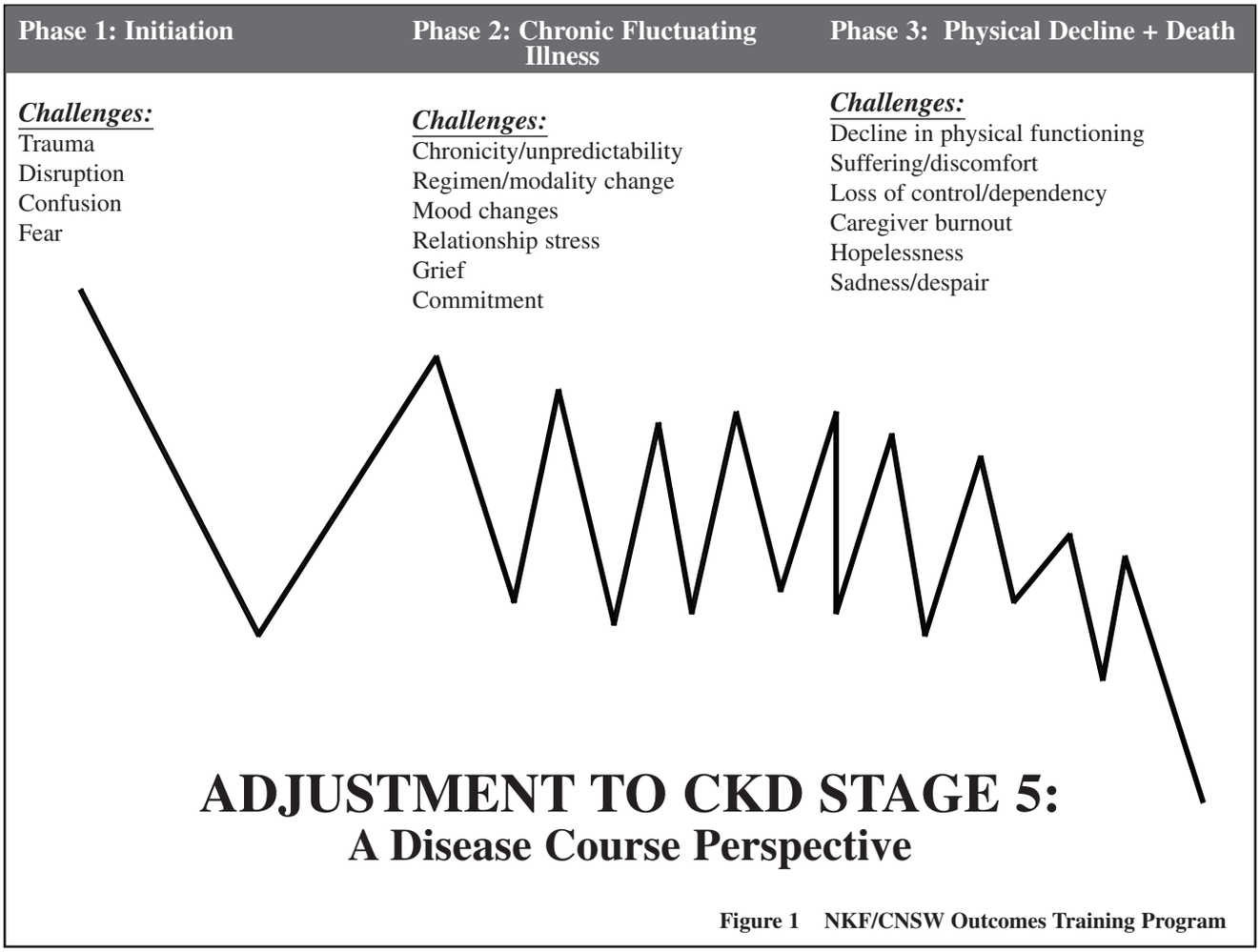


Figure 1 NKF/CNSW Outcomes Training Program

THE ADHERE MODEL AND NEPHROLOGY SOCIAL WORK INTERVENTION

ADHERE is an acronym for a model developed by Gallegos et al. (2004) that offers strategies to improve self-management success. Key words in this paradigm, which are discussed further in the following sections, are *assess, dialog, holistic, empower, reinforce*, and *evaluate*. Incorporating this approach in social work intervention promotes patient adherence.

Assessment is ongoing and essential to targeting interventions for patients. The Life Options Rehabilitation Advisory Council (LORAC) developed patient interest checklists that can be given to patients to ascertain their level of understanding on various aspects of kidney disease and treatment for different time spans during their adaptation process. In addition, LORAC offers fact sheets to help teach many of the topics patients are interested in learning (Life Options, 2006). For social workers wishing to develop their own surveys, an adherence assessment checklist might ask the following:

1. What do you know about dialysis? Fluid gains? Blood pressure control, etc.?
2. Who is part of your support system?
3. From where do you draw your personal strength?
4. What do you feel is the most challenging aspect of limiting your fluids?
   a. taking your phosphorus binders?
   b. coming to all of your dialysis treatments?
   c. staying for the full treatment, etc.?
5. What are your short- and long-term goals for treatment?

By identifying and prioritizing adherence problems in their dialysis populations, social workers become an integral part of continuous quality improvement and are able to determine appropriate questions for goal setting

Figure 2

Fitting Treatment Into Your Lifestyle

• My eating habits	⟹	When and how many times a day you eat?
• My sleeping patterns	⟹	When and how well to you sleep?
• My regular exercise	⟹	Walking, aerobics, dancing, weights, cleaning house, gardening.
• My social supports	⟹	Family, friends, spiritual organization, support group, dialysis center.
• My work/financial situation	⟹	Will my job be flexible with my hours, is home dialysis a choice, should I file for SSDI to have a steady income?

Adapted from AIDS Action Committee, MA 2003

and targeted interventions. Prioritizing issues and the need for intervention may come from awareness of a trend in the clinic setting, industry standards, or corporate needs/requests.

Using the ADHERE model, assessing patients' knowledge and readiness for change moves social workers into a dialog with patients about their health beliefs and options. Dialog in the ADHERE model helps to clarify the possible consequences of nonadherence and reviews self-care strategies. Through this dialog, which may include motivational interviewing, social workers come to understand what gains and losses the patient perceives through adherence to medical recommendations.

A holistic approach includes looking at a patient's environment, culture, resources (internal and external), and support system to promote the best treatment outcome. "Fitting Treatment Into Our Lifestyle: A Worksheet" was developed by the AIDS Action Committee (Gallegos et al., 2004) as part of the ADHERE model. This worksheet was easily adapted for patients with kidney failure (see Figure 2). Taking a holistic approach allows a review of the person-in-environment fit and targeting of social work interventions as indicated to improve treatment outcomes.

Nephrology social workers empower patients by encouraging them to be active participants in disease management and treatment. Using the strengths perspective and motivational interviewing in teaching may increase the likelihood that patients will more effectively manage or adhere to medical recommendations. The strengths perspective focuses on the dignity of every human being and builds on people's strengths and capacities rather than focusing on their deficits, disabilities, or problems. Emphasis is placed on uncovering, reaffirming, and enhancing the abilities, interests, knowledge, resources, aspirations, and hopes of individuals, families, groups, and communities (Saleebey, 1996). Motivational interviewing is a patient-centered, directive method for enhancing intrinsic motivation to change by exploring and resolving ambivalence. It seeks to help create a collaborative relationship within which social workers can skillfully use directive listening techniques to address patient reluctance to change and to determine the patient's personal motivations to initiate and persist with behavior change (Miller & Rollnick, 2002; Rose, 2006).

Social workers can enhance interventions focused on improving adherence by reviewing Prochaska et al.'s six-stage process in their book *Changing for Good: A Revolutionary Six-Stage Program for Overcoming Bad Habits and Moving Your Life Positively Forward* (1994). The six stages are:

1. precontemplation
2. contemplation
3. preparation
4. action
5. maintenance
6. relapse or recurrence of target behavior

As social workers understand a patient's readiness to contemplate change, interventions can be more effectively shaped to the needs of the patient and reinforced. An example of this might be blood pressure management, which in patient John Brown's case, demonstrates that his blood pressure is totally out of control. The team is focused on instructing him to take his medications. Mr. Brown does not understand why this is such a big problem. He knew it was important to try to keep his blood pressure down before dialysis, but now that he's started dialysis, his kidneys are gone and he thinks "What's the use?" As a social worker, it is important to understand what Mr. Brown gains by not taking the medications—better sexual function, fewer dollars spent, increased control or fewer demands because he's not having to take medication. It is also important to understand what he might not like about needing antihypertensive medications—the staff nagging him, headaches, etc. At this point, Mr. Brown does not understand the long-term health complications related to uncontrolled blood pressure, such as stroke.

As Mr. Brown's readiness for change is assessed, it is important to understand what he might lose by starting to take blood pressure medications. This could be money and/or sexual relationships, which in turn might lead to loss of self-esteem, depression, etc. It also needs to be determined if Mr. Brown can identify anything good about starting to take his blood pressure medications. As his ambivalence to change is assessed using the diagram in Figure 3, he may increase his awareness in a number of areas, including his understanding of the risks associated with his behavior and the positives associated with a potential change. As a professional, the social worker will become better able to target an effective intervention because his resistance to change is understood. Through use of the Prochaska model, teaching can be reinforced throughout the process but teaching is approached knowing that there will likely be relapses during any stage or all stages of the process (Figure 4). Knowing that relapses are a possibility allows the social worker to proactively plan to continually reinforce changes in behavior.

Figure 3

Am I Ready for Change?

Adapted from Gary Rose, PhD, "Motivational Interviewing." NKF 2001 Spring Clinical Meetings, NKF/CNSW Outcomes Training Program

What I like about fluid is:
- It makes me feel better right away.
- Easier

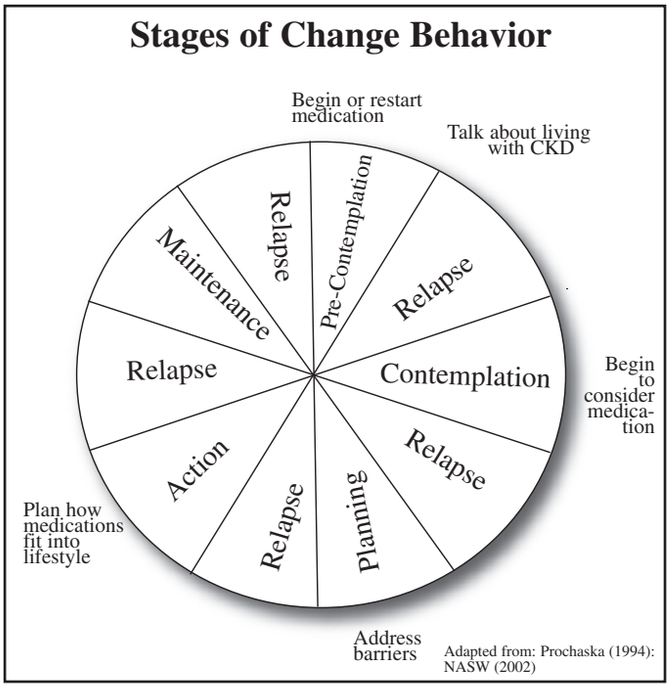
If I changed, the good thing might be:
- I would have easier tx.s.
- Feel better about myself.

"Ambivalence"

What I don't like is:
- Doctor/nurses lecture me.
- Shortness of breath/ cramps
- I feel ashamed

What I might lose by giving it up is:
- Less feeling of control
- Less social freedom
- Comfort (I might be very thirsty.)

Figure 4



Fluid management is often a significant challenge for people on dialysis and is an issue that lends itself to a group approach. An example of a three-session class based on cognitive behavioral, motivational, and paradoxical interventions is as follows (Johnstone, 2003):

Class 1:
- The story of Joe (someone with a fluid problem)
- Why the nurses get so upset (the risk of cardiovascular disease to the patient)
- Feeling "bad" is not good for you!
- Reframe: struggling and learning
- The decisional matrix (refer to Figure 3)
- Look at the fluid tracker (Figure 5), but don't make any changes

Figure 5

30-DAY "Fluid Tracker"

DIRECTIONS: Measure the fluids you use every day.

	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Week 1							
Week 2							
Week 3							
Week 4							

Taken from CNSW Research Project: Living Longer, Living Better, 2001. (Johnstone & Callahan)

Class 2:
- Cycle of a craving
- Craving control toolbox
- Continue fluid tracking

Class 3:
- Results of playful experimentation with tool box
- Fluid control journey is forever
- Preparing for and responding to relapse
- Review of class
- Readiness to set small goals

Finally, social workers need to continuously monitor intervention outcomes by evaluation as noted in the ADHERE model. Outcomes can be measured in a myriad of ways, which include treatment records, lab reports, surveys, scaling by patient, quality-of-life measurements, and pill counts. Evaluating outcomes is often difficult for social workers because of high caseloads, inexperience with evaluation, etc. However, evaluating interventions does not have to be formal. It can be as basic as asking Mr. Brown if he perceives a difference in his day-to-day activities since he decided to try to take his medications for a period of 4 weeks. If there is no follow-up and measurement of the outcome, improvement in adherence cannot be determined. If follow-up and reporting outcomes are recorded in progress notes,

care plans, even perhaps as a small continuous quality improvement project, it becomes a part of everyday practice—something that becomes easier to do each week.

Focusing on improving adherence may seem a daunting task. However, the key is to start small. Identify two patients with similar adherence issues, plan a 10-minute intervention, deliver the intervention, and measure the outcome.

SOCIAL WORK INTERVENTIONS WITH STAFF REGARDING ADHERENCE

Struggling with patient nonadherence to medical recommendations is often very difficult for dialysis treatment staff as well. Social workers can assist with the team's reaction to nonadherence and help support management in shaping the culture of the setting. The focus with staff is to help them identify how they feel and why they feel as they do when Ms. Green comes in with an excessive interdialytic weight gain. Is the staff concerned that Ms. Green may die if she continues excessive weight gains? It may be helpful to have short (10-minute) sessions with staff to discuss "if/then" and help them sort out their reactions in a non-stressful environment. The fear is often, "What if she dies?" It can also be helpful to think through transactional analysis concepts with the staff (parent/child, child/child, adult/adult) and how this might be impacting their communication with patients and affecting the outcome of self-management. Are staff members talking to patients as if they were children or with dignity and respect as adults? Rehearsals are fun and can be a great source of learning if time allows.

Social workers can also improve adherence by helping the staff understand changes in contemporary treatment of health risk behavior, such as:

- focusing on patient strengths
- remaining in patient-centered treatment
- shifting away from labeling
- forming partnerships for change
- using empathy rather than authority and power
- focusing on stage-specific interventions, such as the Prochaska Model, that help the patient progress to greater self-management (U.S. Department of Health and Human Services, 1999)

CONCLUSION

When planning targeted social work interventions to improve self-management and adherence or teaching staff to understand change, remember that change is a process. Other key points are:

- Motivation is a continuum of "readiness to change."
- Change occurs naturally.
- Change occurs in steps or stages and occurs over time.
- Patients move back and forth and cycle between stages of change.

Cognitive-behavioral interventions targeted to improve adherence and help patients become more capable of change, focus on their strengths, and make them feel empowered. Focused nephrology social work interventions make a powerful impact on the health and well-being of patients with CKD. Start small, but start!

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