

Chronic Kidney Disease Self-Management “Helps” and Hindrances in Older African-American and White Individuals Undergoing Hemodialysis:

A Brief Report

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This brief report summarizes chronic kidney disease self-management “helps and hindrances” among older African American and White individuals undergoing in-center hemodialysis. Qualitative data from 107 interviews were analyzed using steps of content analysis. Seven “helps” and five hindrances were revealed. The “helps” were: following treatment orders/adherence; a social network; exercise and physical activity; faith practices/beliefs; distractions during treatment; maintaining a positive attitude; and resting. The hindrances were: functional limitations; managing co-occurring conditions; diet and fluid restrictions; feeling fatigued on treatment days; and social network/social activities. The authors conclude with five practice recommendations for increasing self-management behaviors among individuals undergoing hemodialysis.

INTRODUCTION

Self-management, the active participation in one’s care, is important for overall management of chronic kidney disease (CKD), the person with CKD being viewed as central to the interdisciplinary treatment team (Washington, Zimmerman, & Browne, 2016). Self-management is prioritized in the Conditions for Coverage because people undergoing hemodialysis are encouraged to participate in their own care (Alt & Schatell, 2009; Browne, 2012). The benefits of chronic disease self-management are well documented. Self-management improves health behaviors, self-efficacy and health status, results in fewer visits to emergency departments (Lorig, Sobel, Ritter, Laurent, & Hobbs, 2000), lowers medical costs (Bodenheimer, Lorig, Hohman, & Grumbach, 2002), and improves physical, emotional, and social functioning (Heisler, Smith, Hayward, Krein, & Kerr, 2003). Moreover, participants in self-management programs experience decreased pain, improved functional status, and increased quality of life (Kwog, Au, & Li-Tsang, 2016). These benefits warrant further investigation of improved self-management among individuals with CKD.

Self-management is particularly important to older adults who carry the burden of living with multiple chronic conditions. Over two-thirds of older adults live with two or more chronic conditions (Centers for Disease Control & Prevention (CDC), 2013), and older adults represent the fastest-growing segment of the CKD population (Washington, Hilliard, & McGill, 2003). Self-management is complicated for adults of all ages; for example, navigating complex medication regimens (Tanner, 2004). Thus, increasing self-management behaviors among older adults living with chronic conditions is a public health priority (CDC, 2013)

Given the growing emphasis on self-management, particularly for older adults, and its benefits documented in the

literature, it is surprising that there have been few attempts to qualitatively investigate factors that facilitate and impede those behaviors among older adults with CKD and undergoing hemodialysis. The goal of the current study is to examine participants’ perceptions about factors that help and hinder successful CKD self-management. The findings in this brief report are part of a larger mixed methods self-management study with 107 participants with CKD, aged 50 and older (Washington, Zimmerman, Browne, 2016). The theory guiding the larger study is social cognitive theory which describes the influence of personal and environmental factors that predict health behaviors (Bandura, 2001).

METHOD

In-person interviews consisting of closed and open-ended questions, were conducted with 107 individuals aged 50 and older, and undergoing in-center hemodialysis. This brief report summarizes responses to two open-ended questions: “What helps you manage well?”; and “What gets in the way of your ability to manage well?” This study was approved by the University of North Carolina at Chapel Hill Institutional Review Board.

Data Analysis

Because the surveys yielded a small amount of qualitative, yet informative, open-ended responses, steps of content analysis were used to open code the data, then inductively place those codes into respective categories (Hsieh & Shannon, 2005; Kondracki, Wellman, & Amundson, 2002). Following the open coding process, the categories were grouped into “helps” or “hindrances.” The number of codes in each category were counted and reported accordingly; categories with four or fewer codes were grouped together into an “other” category.

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Table 1. Self-management “helps” and hindrances^a

| “Helps” | Count ^b |
|------------------------------------------|--------------------|
| Following treatment orders/adherence | 89 |
| Social network | 39 |
| Exercise and physical activity | 21 |
| Faith practices/beliefs | 18 |
| Distractions during treatment | 11 |
| Maintaining a positive attitude | 10 |
| Resting | 5 |
| Other ^c | 6 |
| Hindrances | Count ^b |
| Functional limitations | 16 |
| Managing co-occurring chronic conditions | 16 |
| Diet/fluid restrictions | 11 |
| Feeling fatigued on treatment days | 9 |
| Social network/social activities | 8 |
| Other ^d | 17 |

^aExample quotes excluded for brevity

^bCategories with 4 or fewer counts in “other” category

^cOther = weight management, education, treatment options, access care, other activities

^dOther = Emotional impact, loss of appetite, access care, limited transportation, limited travel opportunities, weight loss, time, death of others, caregiving

RESULTS

A total of 107 interviews were completed. Respondents were primarily African American (65%), and the mean age was 63. The number of men and women were nearly even (51% and 49%, respectively). Participants were undergoing in-center hemodialysis for an average of 7 years.

The content analysis revealed 7 “helps” and 5 hindrances to successful chronic kidney disease self-management (i.e., those receiving 5 or more counts). The “helps” were: following treatment orders/adherence (89), a social network (39), exercise and physical activity (21), faith practices/beliefs (18), distractions during treatment (11), maintaining a positive attitude (10), and resting (5). The hindrances were: functional limitations (16), managing co-occurring conditions (16), diet and fluid restrictions (11), feeling fatigued on treatment days (9), and social network/social activities (8). The categories and counts are listed in **Table 1**.

An overall definition of self-management was also identified. The following quote best represented the day-to-day tasks individuals with CKD must undertake to manage their condition while undergoing hemodialysis:

Well, other than taking my medications, coming to the dialysis center, and making my doctor appointments, I just do what I normally did before I started dialysis. Like if I have work to do around the home. You can't eat like a normal person and you can't plan like a normal person. Other than that, you're really living a normal life. I actually feel better than I have in the last two years and that means a lot to me.

DISCUSSION

This brief report summarizes “helps” and hindrances of chronic kidney disease among older African American and White individuals undergoing hemodialysis. The qualitative data in this study were previously coded by four specific self-management tasks: cognitive symptom management, exercise, fluid adherence, and diet adherence (Washington, Zimmerman, Browne, 2016); this study extends those findings by pinpointing factors that facilitate and impede self-management. Regarding “helps,” the interviews revealed that adherence to treatment orders and the presence of a social network aided in successful self-management.

About hindrances, respondents overwhelmingly described functional limitations and the management of other chronic conditions. This finding is not surprising given that over two-thirds of older adults live with more than one chronic disease (CDC, 2013). For instance, discomfort from co-occurring conditions were described as more painful than the effects of kidney disease, and oftentimes pain medications were used to obtain a tolerable level of comfort. Moreover, people complained about not being able to exercise and or do strenuous activities because of the pain and discomfort associated with co-occurring illnesses. These findings suggest co-occurring conditions negatively impact quality of life, even more than the discomfort associated with CKD. Thus, management of multiple chronic conditions is paramount if individuals with CKD are to achieve a desirable quality of life, and is also essential for decreased healthcare utilization and medical expenditures (Wolff, Starfield, & Anderson, 2002).

Interestingly, two categories overlapped as “helps” and hindrances. Nearly all participants recognized the importance of following treatment orders (e.g., attending all treatments, managing fluid intake, taking medications as prescribed, and eating proper foods); however, diet and fluid restrictions were seen as a hindrance to successful self-management. Also, the presence of a social network was identified as both a help and hindrance, especially when describing social activities such as managing food choices when visiting others, as evidenced by the following quote:

Table 2. Comparison to Clark et al. study (1991)

| Self-management task in Clark study | Current study |
|--------------------------------------------------------------|---------------|
| Recognizing and responding to symptoms | |
| Using medicines | X |
| Managing acute emergencies | |
| Maintaining nutrition and diet | X |
| Maintaining adequate exercise/activity ^a | X |
| Giving up smoking | |
| Using relaxation and stress-reducing techniques ^b | X |
| Interacting with healthcare providers | X |
| Seeking information and using community services | |
| Adapting to work | |
| Managing relations with significant others ^c | X |
| Managing emotions and psychological responses to illness | X |

^aReported in Washington, Zimmerman, & Browne (2016)

^bOr cognitive distractions

^cAs identified by social networks in current study

This weekend, I probably ate and drank more than I should. When you're in someone's house, you don't want to tell them you can't eat or drink.

When asked, "What helps you manage well?" many participants named individuals who helped them on a daily basis. Some named their spouses, others named their children and grandchildren, and others discussed social support associated with faith practices. This finding is consistent with previous self-management research with older adults who have

other chronic conditions and who found family and friends to have both positive and negative influences (Gallant, Spitze, Prohaska, 2007).

Clark et al. (1991) were among the first to document common self-management tasks in older adults living with chronic conditions (i.e., heart disease, asthma, COPD, and diabetes). This research sought to connect self-management to psychosocial coping in older adults by explicating intrapersonal and interpersonal processes (Clark et al., 1991). For comparative purposes, the authors were interested in knowing how similarly the participants in this study described their self-management behaviors when compared to participants in the Clark study. The comparison is detailed in **Table 2**.

CONCLUSION

It is important to note that some people expressed no hindrances or concerns, as evidenced by the following two quotes:

I'm still doing the same things I was doing before. I eat good, watch what I eat, and watch my weight. I eat plenty of fruits, vegetables, and meats.

Honestly, too much doesn't get in my way. When challenges come, you just deal with it and do what you have to do.

Nephrology social workers may consider the overall findings in this brief report when employing self-management interventions. Opportunities exist to develop and implement interventions that help individuals with CKD their existing behaviors, and introduce them to new behaviors that have been successful with other chronic conditions. To aid in this consideration, the authors conclude with five practice recommendations and corresponding examples in **Table 3**. Nephrology social workers may consider implementing these strategies to increase self-management among individuals with CKD.

Table 3. Five practice recommendations to increase CKD self-management

| Recommendation | Example(s) |
|------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1. Use technology for patient engagement | Send weekly text message reminders to patients; use group chat or video conferencing for patient support groups; regularly showcase exercise apps; start a patient social media page |
| 2. Implement innovative activities | Allow patients to create self-management vision boards to hang throughout the facility |
| 3. Distribute monthly pocket cards | Find ways to remember to take your binders; self-cannulation tips and techniques |
| 4. Identify patient mentors | Hold annual elections for two or three patient mentors to serve as "self-management coaches" |
| 5. Offer self-management incentives | Enter care plan attendee names into drawings for a small monetary gift card (e.g., \$5 to a grocery store or "kidney-friendly" restaurant) |

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