

# Potential Impact of Peer Mentoring on Treatment Choice in Patients with Chronic Kidney Disease: A Review

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## Abstract

Chronic kidney disease (CKD) and the resultant end stage renal disease (ESRD) are associated with significant mortality, morbidity, and cost for the individual patient and society. CKD is among the major contributors to years of life lost (YLL) due to premature mortality. Also, while the disability adjusted life years (DALY) for many conditions decreased between 1990 and 2010, the DALY for CKD has increased by 69%. In addition to the physical disability, CKD is associated with high prevalence (27.9%) of major depressive episodes, associated with limitations of employment, and a significant negative effect on quality of life (QOL). A major determinant of QOL is satisfaction with treatment choice. There is consensus among investigators that patients who are actively engaged in their own care experience improved health outcomes. The shared decision making (SDM) approach allows patients and providers the opportunity to work in partnership to make decisions that are congruent with the patient's values, preferences, and distinct situations. SDM has been associated with improved outcomes among patients with various chronic disease states. Mentoring, particularly by trained peers, has been used as an approach to enhance SDM in several chronic conditions, including cancer and cardiovascular disease. In this review, we will focus on care of patients with CKD as a model for the study of the impact of peer mentoring on SDM and choice of treatment for ESRD.

**Keywords:** Caregiver, end stage kidney disease, illness burden, mentorship, peer group, quality of life

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## Introduction

End stage renal disease (ESRD) is a significant global public health problem. In 2011, the adjusted rates of prevalent and incident cases of ESRD in the US were 1,901 and 357 per million population, respectively. Approximately 113,000 patients began dialysis, and nearly 18,000 received a transplant.<sup>1</sup> Chronic kidney disease (CKD) is associated with significant mortality, morbidity, and cost for the individual patient and society. According to a report by the Burden of Disease Collaborators,<sup>2</sup> CKD is among the major contributors to years of life lost (YLL) due to premature mortality, leading to 60,000 deaths in 2010 in the United States. CKD has also indirectly contributed to 560,000 deaths due to cardiovascular diseases and 172,000 deaths due to cerebrovascular diseases. According to the same report, there has been a large increase (32.4%) in age-standardized YLL rate for CKD, as well as years lived with disability. Also, while the disability adjusted life years (DALY) for many conditions decreased between

1990 and 2010 (e.g., ischemic heart disease by 19%), the DALY for CKD has increased by 69%.<sup>2</sup> In addition to the physical disability, CKD is associated with high prevalence (27.9%) of major depressive episodes,<sup>3</sup> a potential hindrance to employment. Advanced CKD limits the capacity for gainful employment and is associated with significant direct and indirect cost to the individual patient and society. The percentage of working-age dialysis patients who are employed varies between 11% and 31%.<sup>4-7</sup> CKD has significant negative effects on quality of life (QOL),<sup>8,9</sup> which, in turn, has been correlated with mortality among CKD patients.<sup>10</sup> A major determinant of QOL is satisfaction with treatment choice.<sup>11-13</sup>

There is consensus among investigators that patients who are actively engaged in their own care experience improved health outcomes.<sup>14-16</sup> The shared decision making (SDM) approach allows patients and providers the opportunity to work in partnership to make decisions that are congruent with the patient's values, preferences, and distinct situations. SDM has been associated with improved outcomes among patients with inflammatory bowel disease,<sup>17</sup> cardiovascular disease,<sup>18</sup> multiple sclerosis<sup>19</sup> spine surgery,<sup>20</sup> various cancers,<sup>21,22</sup> and CKD.<sup>23</sup> Mentoring, particularly by trained peers, has been used as an approach to enhance SDM in several chronic conditions, including cancer<sup>24</sup> and cardiovascular disease.<sup>25</sup> In this review, we will focus on care of patients with CKD as a model for the study of the impact of peer mentoring on treatment choice for ESRD.

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## What are treatment choices for ESRD?

Patients progressing toward end stage renal disease (ESRD) must decide among multiple treatment options with varying characteristics. In-center-hemodialysis (ICH) is the most prevalent treatment for ESRD in most parts of the world. In comparison with ICH, home modalities (peritoneal dialysis; home hemodialysis) are associated with improved quality of life, decreased morbidity, and lower cost.<sup>26-28</sup> Compared with dialysis, transplant leads to improved survival, a better quality of life, and lower long-term costs. It is the treatment of choice for the majority of patients.<sup>29</sup> Most patients who undergo kidney transplant receive deceased-donor transplant after variable periods of dialysis.<sup>1</sup> Compared with deceased-donor transplant, pre-emptive transplant from a living donor is associated with fewer rejections, improved long-term graft and patient survival as well as less cost.<sup>30-32</sup> The insufficient utilization of preferred modalities has been attributed to ineffective education of patients regarding choices of therapy.<sup>33</sup>

## How are CKD patients currently making treatment decisions?

In the absence of absolute clinical contraindications, the treatment of choice should be the modality that is most consistent with the informed patients' preferences according to their activities and lifestyle. In a qualitative study, Lee *et al.* determined that flexibility, independence and feelings of security were key factors in determining choice of modality, with maintenance of a normal life being a major goal.<sup>34</sup> In many cases, treatment decisions are made without active patient involvement. Data indicate that many patients with CKD are inadequately informed about their disease and options for treatment. Information is typically presented late in the course of the disease and often immediately prior to initiation of renal replacement therapy (RRT), not allowing sufficient time for patient's understanding, active engagement and informed decision making.<sup>35,36</sup> Data about incorporation of patient preferences in decisions relating to CKD care are limited. In a qualitative study by Tong *et al.*, CKD patients believed they received insufficient information. They noted that treatment choices were based on lifestyle and family impact and felt that time was needed to comprehend the diagnosis, cope with uncertainty and to integrate the treatment into their daily routine. The authors concluded that more attention should be given to providing patient-level information and psychosocial and practical support.<sup>37</sup> There are significant differences between patient preferences and the medical care they receive. In a survey of 197 patients with ESRD, many more patients perceived that their decision was made by their healthcare team than they preferred.<sup>38</sup> Lack of sufficient information about alternative treatment options prior to initiation of RRT has been highlighted in a qualitative study involving CKD patients and their families.<sup>39</sup> Among 1,365 dialysis patients, the majority had not been presented with home dialysis modalities or transplant as options, prior to initiation of dialysis.<sup>40</sup> In a study of 676 patients with CKD, 35% reported very limited or no knowledge about their kidney disease or any therapeutic modality for ESRD. More than half of the respondents had no knowledge of transplant.<sup>41</sup>

## The gap between the desired and provided information

Educational programs for patients with CKD are now standard

practice but nearly all are based upon information perceived by professionals as important. Evidence suggests patients are often not fully informed about the availability of various forms of renal replacement therapy (RRT) options or how these options differ from one another.<sup>34,42</sup> In developing educational programs for patients with CKD, it is critical to recognize topics that are important to them. This will lead to identification of appropriate information that will enhance knowledge, promote independence and encourage patients to self-manage their illness. Patients seek transparent and unbiased information about the different forms of available RRT such as understanding the relative medical efficiency,<sup>43</sup> and the advantages and disadvantages of the different treatment options.<sup>44-50</sup> Patients want to fully understand the psychosocial impact of CKD and its treatment.<sup>42</sup> Patients on dialysis require information about the effect of treatment on leisure activities, hobbies and sports,<sup>47,48,51</sup> and the ability to travel,<sup>50,52</sup> particularly when retired.<sup>51</sup> Patients of all ages seek information about the ability to achieve a lifestyle as close to normal as possible,<sup>49,50,53</sup> maintaining and sustaining social relationships, networks, activities and commitments.<sup>50-52,54</sup> Younger patients, particularly, seek information about the possibility of selecting a dialysis option that increases the opportunity to find work.<sup>47,51,53,55</sup> Individuals equipped with a complete overview of all options are better prepared to make informed treatment choices that are most acceptable to them, which best suit their lifestyle and with which they will be content.<sup>49,56-58</sup>

## Active patient engagement and choice of CKD treatment

Treatment decisions made without active patient engagement lead to dissatisfaction with care and subsequent negative impact on QOL and life expectancy.<sup>59,60</sup> Among the CKD population, patient education has mainly consisted of presentation of information, lacking self-management education. While 61% of patients have reported that they had received education about PD, only 10.9% initiated PD.<sup>61</sup> The discrepancy between early education and utilization of the treatment modality might reflect the fact that despite education, there has not been engagement for choosing the modality. One of the barriers to implementing SDM and active patient engagement is late referral of patients with CKD to nephrologists.<sup>62</sup> The information and education that are provided to patients have traditionally been based upon clinical outcomes, often overlooking patients' information needs and QOL outcomes.<sup>42</sup> These modes of education have not necessarily led to improved patient engagement. Patients who are actively engaged in their own care are more likely to make well informed choices.<sup>23</sup> Shared decision making (SDM) is gaining significant interest as a potential tool that might help bridge the gap between the care patients want and the care they receive.<sup>63,64</sup> SDM is particularly important as patients decide about the timing and modality of dialysis, and timing and type of transplant. Among patients with CKD, educational interventions, particularly those aimed at active engagement, have improved discussion and active pursuit of living donor transplant and may improve their use of preemptive transplant.<sup>65</sup> The importance of the impact of patient engagement on choice of CKD treatment has been appreciated in few studies. Educational interventions, particularly those aimed at active patient engagement, have led to increased interest in choosing peritoneal dialysis and pursuing transplantation,<sup>66</sup> particularly living donor kidney transplant.<sup>65</sup> It is important to develop educational

programs based on the information needs identified by patients themselves. This will enhance knowledge, promote independence and encourage patients to self-manage their illness. In the realm of research, most studies have focused on the study of the impact of the informational dimension of education on outcomes with limited exploration of active patient engagement, particularly in a quantitative fashion.

### Role of patient empowerment through education in the choice of treatment modality for ESRD

Interventions focusing on changing health beliefs and on increasing awareness are effective in empowering patients to participate in positive health behaviors.<sup>67,68</sup> The Health Belief Model,<sup>69–71</sup> consisting of five components (perceived susceptibility, perceived severity, self-efficacy, social support, and perceived barriers), along with protection motivation theory,<sup>72</sup> and the theory of planned behavior<sup>73,74</sup> have been successfully used within the context of health education programs in a variety of health conditions. Among patients with ESRD, pre-dialysis group education leads to improved understanding of the illness and enables patients to choose treatment modality.<sup>46</sup> A survey of patients admitted to 229 dialysis units concluded that an incomplete presentation of treatment options within the context of pre-ESRD education is an important contributor to under-utilization of home dialysis therapies and may also delay access to transplantation.<sup>40</sup> Available evidence suggests that race and gender differences in electing transplant may disappear or be diminished when patients are fully informed of ESRD treatment options.<sup>75</sup>

### Peer-led mentoring is an effective strategy in patient education and engagement

Mentoring by trained peers has the potential of reinforcing self-management skills and activities. Having led to enhanced patient engagement, peer mentoring has particularly resulted in improved outcomes among patients with chronic conditions. Heisler has proposed seven models of peer support which include: professional-led group visits; peer-led self-management training; peer coaches; community health workers; support groups; telephone-based peer support; and web- and email-based programs.<sup>76</sup> Mentoring, particularly by trained peers, is an effective model to provide individualized, patient-centered information, decision and self-management support to improve outcomes for patients with chronic conditions. Relationship-centered peer mentoring is a potentially robust approach which can establish trust and has the potential of decreasing disparities in health care outcomes.<sup>77</sup> The success of peer mentoring has been attributed to the non-hierarchical, reciprocal relationship that is created by sharing similar experiences.<sup>78</sup> Bypassing the socioeconomic strata of the provider-patient relationship, peer to peer mentoring is more likely to result in a relationship that is consistent with the individual's social and cultural beliefs. Peers who have experience in managing their CKD may be in a better position to communicate knowledge and confidence to a recently diagnosed patient in a more personalized manner than most healthcare professionals. Peers with the same chronic disease share knowledge and experience to which others often cannot relate.<sup>76</sup> Patients with CKD have indicated the desire to visit the dialysis units and to meet other patients.<sup>46,50,52,56,79</sup> They

are interested in the experiences of others, not as a source of medical information<sup>47</sup> but to discuss ideas on how to cope.<sup>46</sup> Comparing themselves with their peers will reassure them of their own situation and will reduce sense of isolation.<sup>49,80</sup> Seeking information is a common coping strategy.<sup>46</sup> Providing CKD patients with information alleviates anxiety, enables the individual to cope, facilitates awareness, increases adherence and leads to improved self-management adherence.<sup>45,81</sup> Mentoring goes beyond providing information. Patients are interested in obtaining an unbiased perspective of available treatment and learning about different coping strategies from independent organizations, such as support groups or patient organizations.<sup>45,46,52</sup> It is well known that patients who are actively engaged experience improved health outcomes.<sup>15,41,82</sup> A peer-led CKD educational program could incorporate important patient-centered information and better engage patients.

### Discussion

Patients with chronic diseases are constantly faced with treatment decisions. This necessitates a re-evaluation of the patient-provider partnership and innovative approaches to improve shared decision making and self-management by patients. Controlled trials have provided evidence that programs aimed at teaching self-management skills are more effective than information-only patient education in improving clinical outcomes.<sup>83</sup> Self-management training for chronic illness has been suggested as an essential part of high-quality primary care.<sup>84</sup> Optimizing the shared decision-making process will empower patients to actively participate in making knowledgeable choices based on an understanding of the disease condition and personal values and preferences. Mentoring by trained peers has the potential of reinforcing self-management skills and activities. Having led to enhanced patient engagement, peer mentoring has particularly resulted in improved outcomes among patients with chronic conditions. Educational programs for patients with CKD are now standard practice but nearly all are based on information perceived by professionals as important.<sup>79</sup> While researchers have focused on “hard” clinical outcomes, patients with ESRD have mentioned flexibility, independence and feelings of security as key factors in determining choice of modality.<sup>34</sup> It is, therefore, imperative to provide patients with adequate information to allow them to select a treatment option most in line with their key factors. Earlier education geared towards improved shared decision making is more likely to be associated with choice of treatments associated with improved outcome, such as pre-emptive transplant and home dialysis.<sup>35</sup> In this paper, we have highlighted a peer-led CKD educational program as a novel process which can incorporate important patient-centered information into the education, leading to increased patient engagement and improved outcomes. It is important to emphasize that strategies such as peer mentoring are not intended to replace traditional education, but to complement it. While traditional education provides information and skills, novel strategies are needed to teach problem-solving strategies. Racial and geographic variations in awareness of treatment options for ESRD have been well-described.<sup>41,61</sup> These variations, along with the lack of availability, or shortage, of some of the modalities of treatment, such as peritoneal dialysis and transplant, are likely contributors to disparities in kidney transplant among minority groups. Strategies utilizing culturally sensitive communication and interventions can ameliorate disparities and improve access to transplant.<sup>85</sup>

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