Published in final edited form as:
J Nephrol. 2014 October ; 27(5): 571–576. doi:10.1007/s40620-014-0061-4.

The Extent of Informed Decision-Making about Starting Dialysis: Does Patients' Age Matter?

Mi-Kyung Song, PhD, RN
School of Nursing Adult and Geriatric Health Division University of North Carolina at Chapel Hill

Sandra E. Ward, PhD, RN
School of Nursing University of Wisconsin-Madison

Abstract

Background: A growing number of elderly patients with end-stage renal disease start dialysis. We examined elderly (≥ 65 years) patients' views about their decision-making experience after starting dialysis in comparison with patients aged 50-64 years, and patients ≤ 49 years.

Methods: Ninety-nine patients from 15 outpatient dialysis centers in North Carolina, USA completed a semi-structured interview asking them about the context of decision-making and their decision-making experience, and a 10-item investigator-developed Informed Decision-Making (IDM) questionnaire with binary response options (yes/no).

Results: While IDM scores were low for all three groups (< 5 out of 10), they were significantly lower for the older group compared to the other two younger groups ($p = 0.02$). A significantly lower percentage of the older group said that the doctor explained underlying conditions that led to kidney failure ($p = 0.04$), the impact of dialysis on daily life ($p = 0.04$), and the life-long need for dialysis ($p < 0.01$), and that the doctor tried to make sure the patient understood the information ($p = 0.01$). Also a significantly higher percentage of elderly patients felt the decision was made by the doctor rather than on their own or with their family, or collaboratively with the doctor ($p = 0.04$).

Conclusions: Informed decision-making is significantly poorer in patients aged 65 years or older than in younger patients. Clinicians should communicate clearly about the benefits and burdens of dialysis to older adults and provide an opportunity for them to understand the significant trade-offs that dialysis may require.

Keywords

Age; end-stage renal disease; dialysis; informed decision-making; patient-provider communication

INTRODUCTION

A growing number of elderly patients with end-stage renal disease (ESRD) are starting dialysis [1]. In the United States, 111,460 new patients with ESRD began dialysis in 2010;

Corresponding author: Mi-Kyung Song Associate Professor University of North Carolina at Chapel Hill 7460 Carrington Hall Chapel Hill, NC 27599-7460 songm@email.unc.edu 919.843.9496.

of those, 50 % were 65 years of age or older [1]. Survival in the first year after starting dialysis is only 73 % among patients aged 65 years or older and 59 % among those over 75 years of age [1]. Furthermore, the effects of dialysis on quality of life are unclear at best and are associated with substantial declines in physical functioning for older adults [2-4]. Because of these declines, it is important for patients to be fully aware of the benefits and burdens when making decisions about starting dialysis.

Practice guidelines promote careful shared decision-making between clinicians and patients in the initiation and withdrawal of dialysis [5]. Also, the Medicare Improvements for Patients and Providers Act of 2008 (MIPPA) provides reimbursement for up to six sessions of educational services for people with stage IV chronic kidney disease (CKD) [6]. Nevertheless, studies show that patients at all ages with advanced CKD feel unprepared for dialysis initiation [7-9]. Further, elderly (≥ 65 years) patients with advanced CKD lack preparation for living with dialysis and rarely have discussions with their nephrologists about prognosis and illness trajectories [10]. These studies suggest there are significant gaps in clinicians' communication with CKD patients who face dialysis decision-making, particularly with elderly patients. However, it is not known whether physicians communicate differently with older patients than they do with younger patients, nor do we know how elderly patients' perceptions about clinician-patient communication during dialysis decision-making and the decision-making experience differ from those of younger patients.

In an earlier paper [11], we examined dialysis patients' perspectives on how decisions to start dialysis were made and found that some patients might not be receiving sufficient information about therapy options and about the limited likelihood that dialysis would restore health or prolong life, but we did not investigate age differences. Here we examine elderly patients' (aged 65 years or older) views about their decision-making experience in comparison with younger patients (aged between 50 and 64, and aged 49 years or younger).

SUBJECTS AND METHODS

Design

This paper reports a secondary analysis of data from a multi-center randomized controlled trial (RCT; NCT01259011) testing the effects of an end-of-life communication intervention on outcomes of dialysis patients and surrogate decision-makers. Here we used baseline data to examine how the decisions about starting dialysis had been made.

Setting and sample

Patients from 15 outpatient dialysis centers in North Carolina, USA were determined eligible for the parent RCT if they: a) self-identified as African American or Caucasian because the intervention in the RCT had been pilot-tested with those groups; b) had been on dialysis for at least 6 months to ensure they had experienced life on chronic dialysis; c) scored ≥ 6 on the Charlson Comorbidity Index (CCI) or 5 if they had been hospitalized at least once in the last 6 months [12] (as it would have increased the possibility that they would die during the study period); d) were English speaking; and e) had two or fewer errors

on a cognitive screening test, the 10-item Short Portable Mental Status Questionnaire [13]. Of 155 eligible patients, 99 consented and participated.

Data collection procedures

A research staff member conducted telephone interviews (15-45 minutes) that included the following:

Context of decision-making—Patients were first asked to describe their perceptions of decision-making with a broad question, "Tell me how the decision to start dialysis came about." Follow-up questions explored their prior knowledge of progression to ESRD and the possible need for dialysis, the setting of decision-making (e.g. doctor's office or hospital), and the clinician who discussed with the patient about dialysis (e.g. a nephrologist or a non-nephrologist).

Informed Decision-Making (IDM)—Patients responded (yes/no) to an investigator-developed 10-item IDM tool that asked about communication with their physician during the decision-making process. The binary responses (1 vs. 0) to the items were summed to create the IDM score (range 0-10) with higher scores indicating being better informed. Internal consistency reliability was acceptable (KR-20 = 0.70) [14].

Perceptions of the decision-making experience—Patients were asked whether they felt decision making had been rushed (yes/no), whether they felt they had any choice about dialysis (yes/no), whether they felt the decision to start dialysis was made by the doctor, on their own or with their family, or collaboratively with the doctor.

Data analysis

Using content analysis [15, 16], words and phrases capturing patients' responses about the context of decision-making were formulated into codes. The coding scheme was created by team consensus on coding definitions and was critiqued for credibility at monthly meetings [17]. Inter-coder reliability between two coders was evaluated with 10 randomly selected transcripts. Cohen's Kappa was satisfactory (0.7–0.8) [18, 19]. χ^2 tests, Fisher's exact tests, and analysis of variation (ANOVA) were used for group comparisons.

RESULTS

Patient characteristics

Table I presents socio-demographic and clinical characteristics of the sample. A significantly higher percentage of patients aged 65 years or older were Caucasians compared to the two younger patient groups (χ^2 =11.85, $p < 0.01$). All patients were receiving hemodialysis except for two in the 50-64 year age group. The mean (standard deviation, SD) years on dialysis in patients aged 49 years or younger (7.26 [6.50]) was significantly longer than that of patients aged 65 or older (2.44 [2.21]; $F = 10.32$, $p < 0.001$).

Context of decision-making

A majority of patients in all three groups had been seen by a nephrologist prior to decision-making about dialysis and had been told that their CKD could progress to ESRD (Table II). Over 80 % of patients in all groups did not know what to expect with dialysis. Most of the patients aged 65 or older (84.4 %) made the decision to start dialysis after the enactment of MIPPA 2008 (χ^2 =16.26, p < 0.001).

Patients' perceptions about the extent of information received and decision-making experience

IDM scores were low for all age groups but were lowest for those aged 65 years or older even after controlling for race and education. Specifically, mean (SD) IDM scores were 3.63 (2.39) for those over 65 years, 4.67 (1.65) for those between 50 and 64 years, and 4.88 (1.75) for those 49 years or younger (F = 3.86, p = 0.02). Years of education did not differ among the groups, but IDM scores were significantly correlated with years of education (r = 0.24, p = 0.02). Neither whether the decision was made before or after MIPPA nor years on dialysis was associated with IDM scores.

Table III shows the number of patients who responded "yes" to each IDM item by age group. Compared to patients over age 65, a significantly higher percentage of younger patients said that the doctor explained what condition led to kidney failure (χ^2 = 6.46, p = 0.04), how daily life might change after starting dialysis (χ^2 = 6.73, p = 0.04), the life-long need for dialysis (χ^2 = 10.30, p < 0.01) and that the doctor tried to make sure they understood the information (χ^2=8.63, p = 0.01). Only one person over age 65 and none of the younger patients said the doctor offered the option of not starting dialysis and instead using palliative care.

A high percentage of patients felt they had no choice about starting dialysis (because the alternative would be death) or about the dialysis modality; 78.1 % of those age over 65, 66.7 % of those aged 50 to 64, and 55.9 % of those under age 49 (χ^2 = 3.67, p = 0.16). More patients 49 years or younger (32.4 %) had felt rushed to make a decision compared to patients between 50 and 64 years old (15.2 %) and patients 65 years or older (15.6 %; χ^2 = 3.85, p = 0.15).

Most patients said that the decision was made by themselves or with their family (61.8 % of patients aged 49 or younger, 48.5 % of patients aged 50-64 years, and 56.3 % of patients aged 65 years or older). While 27.3 % of patients between ages 50 and 64 felt the decision was made collaboratively between themselves and the doctor, only 8.8 % of patients 49 years or younger and 3.1 % of patients 65 years or older said this. The rest (29.4 % of the youngest patients, 24.2 % of patients 50-64 years old, and 40.6 % of the oldest patients) felt that the decision was made by the doctor. These differences were statistically significant (χ^2 = 9.93, p = 0.04).

DISCUSSION

In our data the three age groups were similar with respect to socio-demographic and clinical characteristics, except that the younger patient group included more African Americans and

had been on dialysis longer. Similarly, the decision-making context was comparable among the three groups, although more patients aged 65 years or older had made the decision about dialysis more recently than had younger patients.

However, perceptions about the extent of informed decision-making were significantly poorer in patients aged 65 years or older compared to younger patients. A lower percentage of elderly patients said they received information about the underlying condition that led to ESRD, the impact of dialysis on daily life, and a life-long need for dialysis before beginning dialysis, and that the doctor tried to make sure the patient understood the information. This lack of receipt or understanding of information might have contributed to the older patients' perceptions that the decision was made by the doctor rather than collaboratively and that they had no choice about starting dialysis or about the dialysis modality [11].

This age effect in patients' perceptions about dialysis decision-making supports concerns that dialysis may be provided to elderly patients after only limited consideration of the benefits and burdens [20, 21]. It also helps explain why many elderly patients report that they stepped into a life on dialysis without much understanding of the therapy [10] and subsequently considered withdrawing from dialysis [22, 23]. Furthermore, in contrast to national statistics that about 24 % of elderly patients have seen a nephrologist prior to initiation [1], roughly 70 % of elderly patients in our study had seen a nephrologist and had been warned about their kidney disease progressing to ESRD. This pre-ESRD care does not appear to have offered them the opportunity to be better informed about dialysis, pointing to significant gaps in pre-dialysis care for elderly patients. One might question whether these age differences could be cohort effects [24] rather than an indication that clinicians' practice differs by patients' age. However, assuming a trend in health care toward greater involvement of patients in decision-making, the cohort suggestion is not supported because those more recently faced with dialysis initiation (the older patients) perceived themselves as less well informed than the younger patients who began dialysis longer ago.

Our findings are based on patients' recollections of what happened during decision-making and we cannot determine what actually occurred. Their limited recollection of informed decision-making might be explained by cognitive impairment which is high among CKD patients [25-27], but we screened out patients with gross cognitive impairments. Additional limitations include the modest sample size, which might not be representative of the US dialysis patient population (e.g. it included few peritoneal dialysis patients). We did not measure health literacy that could influence patients' understanding of the information presented [28, 29]. Finally, the IDM was an investigator-developed tool that requires further validation.

The decision to start dialysis is complex and requires understanding significant trade-offs. We found that many patients, especially those who are older, had little understanding of dialysis prior to their decision. Most elderly patients with ESRD have multiple comorbid conditions. Clinicians should carefully review patients' multi-morbidity, consider prognosis, and communicate clearly about the benefits and burdens of dialysis. Although many patients felt there was no decision to be made because not starting dialysis meant foreseeable death, the extent of information about dialysis (e.g. dialysis modality options) provided by

clinicians may determine elderly patients' perceptions about the decision-making experience and influence their perception that the decision was made by the doctor. To identify ways to improve dialysis decision-making experiences, further studies are needed to examine physicians' perspectives on dialysis decision-making and factors (e.g. patients' decision-making preferences, ageism) that might contribute to age differences in patients' dialysis decision-making experiences.

Acknowledgments

This study was funded by the National Institutes of Health, the Office of the Director (R01NR011464-03S1, Song). The sponsor had no role in the design, methods, subject recruitment, data analysis, and preparation of the paper.

REFERENCES

1. U.S. Renal Data System. USRDS 2012 Annual Data Report: Atlas of End-Stage Renal Disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases; Bethesda, MD: 2012.
2. Kurella, Tamura M.; Covinsky, KE.; Chertow, GM.; Yaffe, K.; LandefeldCE McCulloch, CS. Functional status of elderly adults before and after initiation of dialysis. N Engl J Med. 2009; 361:1539–47. [PubMed: 19828531]
3. Li M, Tomlinson G, Naglie G, Cook WL, Jassal SV. Geriatric comorbidities, such as falls, confer an independent mortality risk to elderly dialysis patients. Nephrol Dial Transplant. 2008; 23:1396–400. [PubMed: 18057068]
4. Cook WLSV Jassal. Functional dependencies among the elderly on hemodialysis. Kidney Int. 2008; 73:1289–95. [PubMed: 18354381]
5. Renal Physicians Association. Shared decision-making in the appropriate initiation of and withdrawal from dialysis: Clinical practice guideline. 2nd. Renal Physicians Association; Rockville, MD: 2010.
6. Medicare Improvements for Patients and Providers Act of 2008, in Public Law 110-2752008. United States Government
7. Morton RL, Tong A, Howard K, Snelling P, Webster AC. The views of patients and carers in treatment decision making for chronic kidney disease: systematic review and thematic synthesis of qualitative studies. BMJ. 2010; 340:c112. [PubMed: 20085970]
8. Mehrotra R, Marsh D, Vonesh E, Peters V, Nissenson A. Patient education and access of ESRD patients to renal replacement therapies beyond in-center hemodialysis. Kidney Int. 2005; 68:378–90. [PubMed: 15954930]
9. Fadem SZ, Walker DR, Abbott G, et al. Satisfaction with renal replacement therapy and education: the American Association of Kidney Patients survey. Clin J Am Soc Nephrol. 2011; 6:605–12. [PubMed: 21330485]
10. Schell JO, Patel UD, Steinhauser KE, Ammarell N, Tulsky JA. Discussions of the kidney disease trajectory by elderly patients and nephrologists: a qualitative study. Am J Kidney Dis. 2012; 59:495–503. [PubMed: 22221483]
11. MK, Song; Lin, F-C.; Gilet, CA.; Arnold, RM.; Bridgman, JC.; Ward, SA. Patients' perspectives on informed decision-making surrounding dialysis initiation. Nephrol Dial Transplant. In press.
12. Charlson M, Szatrowski TP, Peterson J, Gold J. Validation of a combined comorbidity index. J Clin Epidemiol. 1994; 47:1245–51. [PubMed: 7722560]
13. Pfeiffer E. A short portable mental status questionnaire for the assessment of organic brain deficit in elderly patients. J Am Geriatr Soc. 1975; 23:433–41. [PubMed: 1159263]
14. Nunnally JCIH Bernstein, Psychometric theory1994. McGraw-Hill; New York, NY:
15. Hsieh HFSE Shannon. Three approaches to qualitative content analysis. Qual Health Res. 2005; 15:1277–88. [PubMed: 16204405]

16. Yardley, Marks DFL. Research methods for clinical and health psychology. SAGE; Thousand Oaks, CA: 2004.
17. Teddlie, Onwuegbuzie AJC. A framework for analyzing data in mixed methods research. In: Teddlie, C.; Tashakkori, A., editors. Handbook of mixed methods in social & behavioral research. Sage; Thousand Oaks, CA: 2003. p. 351-383.
18. Burla L, Knierim B, Barth J, Liewald K, DuetzT Abel M. From text to codings: intercoder reliability assessment in qualitative content analysis. Nurs Res. 2008; 57:113–7. [PubMed: 18347483]
19. Everitt, B. Making sense of statistics in psychology: A second-level course. Oxford University Press; Oxford, UK: 1996.
20. Badzek LA, Cline HS, MossSC Hines AH. Inappropriate use of dialysis for some elderly patients: nephrology nurses' perceptions and concerns. Nephrol Nurs J. 2000; 27:462–70. [PubMed: 16649321]
21. Kurella Tamura, Winkelmayer WCM. Predialyis nephrology care of older individuals approaching end-stage renal disease. Semin Dial. 2012; 25:628–32. [PubMed: 23173891]
22. Russ AJ, Shim JK, Kaufman SR. "Is there life on dialysis?": time and aging in a clinically sustained existence. Med Anthropol. 2005; 24:297–324. [PubMed: 16249136]
23. Russ AJ, Shim JK, Kaufman SR. The value of "life at any cost": Talk about stopping kidney dialysis. Soc Sci Med. 2007; 64:2236–47. [PubMed: 17418924]
24. Keyes KM, Utz RL, Robinson W, Li G. What is a cohort effect? Comparison of three statistical methods for modeling cohort effects in obesity prevalence in the United States, 1971-2006. Soc Sci Med. 2010; 70:1100–8. [PubMed: 20122771]
25. Stevens LA, Viswanathan G, Weiner DE. Chronic kidney disease and end-stage renal disease in the elderly population: current prevalence, future projections, and clinical significance. Adv Chronic Kidney Dis. 2010; 17:293–301. [PubMed: 20610356]
26. Post JB, Jegede AB, Morin K, Spungen AM, Langhoff E, Sano M. Cognitive profile of chronic kidney disease and hemodialysis patients without dementia. Nephron Clin Pract. 2010; 116:c247–55. [PubMed: 20606486]
27. Tsai CF, Wang SJ, Fuh JL. Moderate chronic kidney disease is associated with reduced cognitive performance in midlife women. Kidney Int. 2010; 78:605–10. [PubMed: 20571474]
28. James BD, Boyle PA, Bennett JS, Bennett DA. The impact of health and financial literacy on decision making in community-based older adults. Gerontology. 2012; 58:531–9. [PubMed: 22739454]
29. Marks R. Ethics and patient education: health literacy and cultural dilemmas. Health Promot Pract. 2009; 10:328–32. [PubMed: 19574584]

Table I

Sample characteristics by age group

Characteristic	Adults ≤ 49 years old (n = 34)	Adults 50–64 years old (n = 33)	Adults ≥ 65 years old (n = 32)
Age, mean years (SD), range	41.1 (8.8)	57.6 (4.5)	71.1 (6.7)
	20 – 49	50 – 64	65 – 85
Female	21 (61.8)	14 (42.4)	17 (53.1)
Race/ethnicity *			
African American or black	28 (82.4)	30 (90.9)	18 (56.3)
Caucasian or white	6 (17.6)	3 (9.1)	14 (43.8)
Educational level			
Less than high school	5 (14.7)	8 (24.2)	7 (21.9)
High school or equivalent	21 (61.8)	20 (60.6)	16 (60.0)
At least some university/college	8 (23.5)	5 (15.2)	9 (28.1)
Marital status			
Currently married or with a partner	7 (20.6)	14 (42.4)	14 (43.7)
Never married	10 (29.4)	3 (9.1)	2 (6.3)
Widowed or separated	14 (41.2)	16 (48.5)	16 (50.0)
Total gross annual income			
< $20,000	19 (56.5)	16 (49.4)	18 (56.3)
$20,000-$49,999	12 (35.3)	12 (36.4)	8 (25.0)
$50,000 or higher	2 (5.9)	3 (9.1)	6 (18.8)
Refused to answer	1 (2.9)	2 (6.1)	0
Religion			
Protestant	22 (64.7)	23 (69.7)	26 (81.3)
Other	9 (26.4)	7 (21.2)	4 (12.6)
None	3 (8.8)	3 (9.1)	2 (6.3)
Dialysis modality			
Hemodialysis	34 (100)	31 (93.9)	32 (100)
Peritoneal	0	2 (3.0)	0
Years on dialysis, mean (SD)	7.26 (6.50)	4.46 (2.80)	2.44 (2.21)
Comorbid conditions			
Myocardial infarction	10 (29.4)	12 (36.4)	10 (31.3)
Congestive heart failure	20 (58.8)	22 (66.7)	19 (59.4)
Peripheral vascular disease	14 (41.2)	15 (45.5)	8 (25.0)
CVA	15 (44.1)	13 (39.4)	5 (15.6)
COPD	10 (29.4)	12 (36.4)	12 (37.5)
Diabetes	32 (94.1)	28 (84.8)	28 (87.5)
CCI score, mean (SD)	7.6 (2.0)	8.8 (2.0)	8.8 (1.6)

Numbers indicate n (%) unless indicated otherwise. Due to rounding, some of the percentages may not add up to 100.

CVA, cardiovascular accident; COPD, chronic obstructive pulmonary disease; CCI, Charlson comorbidity index.

* $p < 0.01$.

Table II

Context of dialysis decision-making by age group

Context	Adults ≤ 49 years old (n = 34)	Adults 50–64 years old (n = 33)	Adults ≥ 65 years old (n = 32)	χ^2 and p value
Had prior knowledge of progression to ESRD				1.46 p = 0.48
Yes	19 (55.9)	23 (69.7)	21 (65.6)	
No	15 (44.1)	10 (30.3)	11 (34.4)	
Where was told about the need for dialysis				2.79 p = 0.25
Doctor's office	16 (47.1)	16 (48.5)	21 (65.6)	
Hospital	18 (52.9)	17 (51.5)	11 (34.4)	
The need for dialysis was told by				2.23 p = 0.33
Nephrologist	28 (82.4)	31 (36.0)	27 (84.4)	
Non-nephrologist	6 (17.6)	2 (6.1)	5 (15.6)	
Has/had a family or a friend on maintenance dialysis				1.51 p = 0.47
Yes	13 (38.2)	14 (42.4)	9 (28.1)	
No	21 (61.8)	19 (57.6)	23 (71.9)	
Knew what to expect with dialysis				2.91 p = 0.23
Yes	2 (5.9)	6 (18.2)	6 (18.8)	
No	32 (94.1)	27 (81.8)	26 (81.3)	
When decision was made				16.26 p < 0.001
After the enactment of MIPPA	13 (38.2)	15 (45.5)	27 (84.4)	
Before the enactment of MIPPA	21 (61.8)	18 (54.5)	5 (15.6)	

Numbers indicate n (%) unless indicated otherwise. Due to rounding, some of the percentages may not add up to 100.

ESRD, end-stage renal disease; MIPPA, Medicare Improvements for Patients and Providers Act.

Table III

Number (%) of patients responding "yes" to each item of the investigator-developed Informed Decision-Making (IDM) tool, by age group

	Content of Item	Adults ≤ 49 years old (n = 34)	Adults 50–64 years old (n = 33)	Adults ≥ 65 years old (n = 32)	χ^2 and p value
Did the doctor inform you about…					
1.	The condition that led to kidney failure?	24 (70.6)	16 (48.5)	13 (40.6)	6.46 p = 0.04
2.	How long you would live with or without dialysis?	19 (55.9)	15 (45.5)	11 (34.4)	3.08 p = 0.22
3.	Dialysis options, such as peritoneal dialysis and hemodialysis?	20 (58.8)	22 (66.7)	17 (53.1)	1.25 p = 0.54
4.	Benefits and burdens associated with each type of dialysis?	11 (32.4)	12 (36.4)	9 (28.1)	0.50 p = 0.78
5.	Did the doctor ask your values and preferences for those dialysis options?	8 (23.5)	5 (15.2)	7 (21.9)	0.81 p = 0.67
Did the doctor explain…					
6.	How your daily life might change after starting dialysis?	21 (61.8)	13 (39.4)	10 (31.3)	6.73 p = 0.04
7.	The need for dialysis for the rest of your life unless you receive kidney transplantation?	32 (94.1)	29 (87.9)	21 (65.6)	10.30 p < 0.01
8.	That not starting dialysis could be an option?	0	0	1 (3.1)	-
9.	Did the doctor try to make sure you understood what he/she told you?	28 (82.4)	28 (84.8)	18 (56.3)	8.63 p = 0.01
10.	Did the doctor try to understand what was important to you?	20 (58.8)	23 (69.7)	15 (46.9)	3.49 p = 0.18