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General Hospital Psychiatry 25 (2003) 324–331

General Hospital Psychiatry

Medical decision-making and information needs in end-stage renal disease patients

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Abstract

Health information and decision-making are increasingly important to patients with diverse illnesses. The aim of this study was to examine health information needs and decision-making in individuals with end-stage renal disease (ESRD) and to examine the influence of age and gender. A self-report survey was administered to 197 consecutive ESRD patients receiving renal replacement therapy. Their mean age was 52.8 years; 58.2% were male, 64.3% were on hemodialysis, and 35.7% on peritoneal dialysis. Actual participation levels in decision-making were not necessarily in agreement with the preferred degree of participation. Eighty percent of patients wanted the health care team (HCT) to make their treatment decisions for them, but only 40% of those who preferred autonomous and 30% of those who preferred shared decision making with their HCT reported that this was their actual experience. Consequently, many more patients perceived that their decision-making was made by their HCT than preferred this. No significant gender differences were observed; however, older participants preferred and experienced their HCT make their treatment decisions ($P<.05$). All patients wanted high levels of information with some differences by gender and age. HCT should strive to ascertain and meet the information needs and treatment decision-making roles preferred by individual patients. © 2003 Elsevier Inc. All rights reserved.

Keywords: Decision-making; End-stage renal disease; Information preferences

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1. Introduction

Patients, in their role as health consumers, are increasingly advocating for more information regarding their illness and treatment options, and for a more autonomous role in medical decision-making. Patients' participation in medical decision-making has several potential benefits for patients including decreased anxiety and depression [1], enhanced sense of hope [2], increased feelings of control over illness, increased self-efficacy, a better understanding of and commitment to their treatment, better compliance, and increased satisfaction with their physician [3]. End-stage renal disease (ESRD) is a special case of medical decision making, as choosing the mode of renal replacement therapy (RRT) is important because this decision may ultimately impact on survival and quality of life [4]. Decision-making for ESRD patients is difficult as the different dialysis modalities, hemodialysis (HD), peritoneal dialysis (PD), and renal transplantation (RT) may be associated with differences in quality of life, medical and rehabilitation outcomes, and limitations or disadvantages [5].

Medical outcomes vary according to different treatment modalities although conflicting data exist on which treatment modality is superior. Some studies have shown that better outcomes are associated with HD versus PD [6,7], while others showed no significant differences in survival between PD and HD [8,9]. Yet another study showed a small but significant advantage for patients whose original modality was PD [10]. However, the general consensus is that RT offers a higher quality of life than any other method of treatment [11–13], although, even this finding has been challenged as sociodemographic and physiological differences existed between treatment groups [14].

There are gender and age discrepancies in the type of RRT received. A Canadian study demonstrated that significantly more male (58.1%) than female (50.8%) patients received HD than PD [6]. American [15] and recent Canadian studies [16] found that females were significantly less

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0163-8343/03/$ – see front matter © 2003 Elsevier Inc. All rights reserved.
doi:10.1016/S0163-8343(03)00069-0

likely to receive kidney transplants than males. Women are also significantly less likely than men to receive any treatment for ESRD [17]. Older patients are significantly more likely to be denied dialysis [17] and less likely to receive a transplant [18].

What is not clear is whether these differences in treatment allocation for ESRD are due to differences in decision-making preferences by age and gender. Studies of other medical conditions have shown that there are age and gender-specific preferences regarding treatment decisions. Some studies have shown that age is the most important predictor of participation in decision-making, in particular, younger patients being more ‘active’, desiring greater involvement [2] and exploring more information resources [19]. With increasing age, there is a greater tendency to put the decision-making responsibility in the hands of the physician, and less belief in challenging the authority of the health care team (HCT) [20]. Few studies have examined gender issues in medical decision-making. One study reported that women are less willing than men to accept treatments that may disrupt their caregiving roles [21].

Other prominent factors that influence patients’ medical decisions are advice from sources such as family, friends, and the HCT. The ability to make an informed medical decision is also greatly affected by patients’ perceived level of knowledge regarding their illness and treatment options. These factors may also differ by age and gender. This knowledge is gained through exploring several forms of medical information and consulting health care professionals. The acquisition of knowledge and medical information by patients is empowering; it gives them the confidence to make autonomous medical decisions and affords them a certain level of control over their health [22].

2. Present study

The main focus of this study was to explore age and gender differences in RRT decision-making preferences and information needs. The following hypotheses were tested: 1) females will have a more passive role in their decision making than males; 2) older patients will have a more passive role in their decision making than younger patients; 3) there will be no significant differences between males and females in preferred role in decision making; 4) there will be no significant differences between older and younger patients in preferred role in decision making; 5) younger and male patients are more likely to have their preferred role in decision making; and, 6) more decisional self-efficacy will be associated with more independent decision making. We also examined the relationship of sociodemographic characteristics, perceived knowledge about illness and treatment, confidence in decision-making, and advice from others (family, HCT, etc.) with decision-making preferences. As an understanding of the information needs of patients is necessary to help develop interventions that will provide patients with the appropriate means to make knowledgeable decisions, we examined the type and the method of acquiring information used by ESRD patients to make medical decisions.

3. Methods

3.1. Patients

Patients with ESRD receiving HD (in hospital or satellite centers or home) or PD (continuous ambulatory or continuous cyclic) were recruited from a tertiary care university hospital in Toronto, Canada and asked if they were interested in completing a survey about treatment decisions for kidney disease. The study was introduced to patients by the investigators, informed consent was obtained, and self-report questionnaires were completed in private. Patients who could not provide informed consent were excluded from the study. Patients were excluded from the study if they were sleeping when approached on more than one occasion or were incapable of completing the questionnaire due to language barriers. Individuals with visual impairment completed the survey in interview format with the research assistant. Ethical approval for the study was obtained from the University Health Network’s Research Ethics Board. The final sample included 197 individuals (80%) response rate.

3.2. Instruments

A self-report survey was developed from items based on an extensive literature review [1–6,15–30], interviews with key physicians and patient informants, and standardized survey instruments indicated below (questionnaire available upon request). The survey was 19 pages long with 69 questions, and took approximately 30–60 min to complete. The survey was pretested on 7 patients, receiving both HD and PD, and 3 physicians and their feedback was incorporated into the final survey. Surveys were administered to patients receiving dialysis on consecutive clinic days.

The survey requested information regarding sociodemographic characteristics, medical information, knowledge of illness and treatments, and information preferences. Sociodemographic information included age, gender, highest level of education, and employment status. Medical information included underlying diagnosis, dialysis modality, and length of treatment. Questions regarding knowledge of illness and treatment included patients’ perceived knowledge of their kidney condition and the risks/benefits of dialysis and transplantation. Information preferences were assessed by inquiring about the type, source, and level of information (e.g., related to lifestyle concerns, information regarding disease progression, and treatment options) patients preferred before and during dialysis.

The main outcome variables were actual and preferred

Table 1
Demographic and treatment information of ESRD patients

Variable	Total sample	Female	Male	<53yr	≥53yr
n	197	81 (41.8%)	113 (58.2%)	100 (52.0%)	93 (48.0%)
Age (yrs, mean ± SD)	52.8 ± 15.63 range 21–86 yr	49.6 (16.9)**	55.1 (14.3)	—	—
Education					
≤high school	78 (40.4%)	39 (48.1%)	39 (34.8%)	51 (51.5%)	26 (28.0%)
>high school	115 (59.6%)	42 (51.9%)	73 (65.2%)	48 (48.5%)***	67 (72.0%)
Married	124 (63.9%)	42 (51.9%)**	82 (72.6%)	80 (80.0%)***	43 (46.2%)
Employment					
Full/part time	47 (24.4%)	18 (22.5%)	29 (25.6%)***	11 (11.0%)	36 (38.7%)***
not employed/student/homemaker/other	36 (18.7%)	21 (26.3%)	15 (13.3%)	17 (17.0%)	19 (20.5%)
retired	46 (23.8%)	15 (18.8%)	31 (27.4%)	46 (46.0%)	0
disability	64 (33.2%)	26 (32.5%)	38 (33.6%)	26 (26.0%)	38 (40.9%)
Treatment modality					
HD	126 (64.3%)	43 (53.1%)***	81 (72.3%)	59 (59.6%)	64 (68.8%)
PD	70 (35.7%)	38 (46.9%)	31 (27.7%)	40 (40.4%)	29 (31.2%)
Treatment duration (months, mean ± SD)	37.4 ± 41.67 range 0.25–240 mo	34.3 ± 37.3	40.1 ± 44.8	29.2 ± 24.8	47.0 ± 55.6***
Reasons requiring dialysis					
diabetes	73 (39%)	27 (34.6%)	46 (43.0%)	41 (44.1%)	32 (35.2%)
polycystic kidney disease	17 (9.1%)	6 (7.7%)	11 (10.3%)	7 (7.5%)	10.0 (11.0%)
glomerulonephritis	12 (6.4%)	6 (7.7%)	6 (5.6%)	2 (2.2%)	10.0 (11.0%)
hypertension	8 (4.3%)	4 (5.1%)	4 (3.7%)	7 (7.5%)	1 (1.1%)
autoimmune disease	4 (2.1%)	2 (2.6%)	2 (1.9%)	1 (1.1%)	3 (3.3%)
unknown cause	4 (2.1%)	2 (2.6%)	2 (1.9%)	2 (2.2%)	2 (2.2%)
other	69 (36.9%)	31 (39.7%)	36 (33.6%)	33 (35.5%)	33 (36.3%)
Transplant waiting list					
Yes	99 (52.4%)	40 (51.3%)	59 (53.2%)	41 (42.7%)	57 (62.0%)***
No	90 (47.6%)	38 (48.7%)	52 (46.8%)	55 (57.3%)	35 (38.0%)

* Note: not all raw numbers add up to 197 and not all percentages add up to 100 due to missing data; ** $p<0.05$, *** $p<0.01$. Significant p values are reported according to Chi square or t-test results

HD = Hemodialysis; PD = Peritoneal Dialysis; SD = Standard Deviation.

roles in decision-making, which addressed patients' actual level of participation in choosing the type of RRT modality they were currently receiving and their preferred level of participation. To assess actual level of participation, the following question was asked: "Who made the decision about the type of dialysis you are currently receiving?" To assess preferences for decision-making the following were asked: "How much did you want to participate in decisions about treatment of your kidney disease?" and "Did you participate in the decision to the extent you wanted in the treatment decision?" Possible answers ranged from completely independent to total control of decision-making by HCT.

The influences of medical (e.g., health care team opinion, disease-related issues) and social (e.g., religious/cultural beliefs, living circumstances and family role) factors on type of dialysis chosen and decision to be on a transplant list were assessed. The level of confidence in medical decision-making was tested by using the O'Conner Decision Self Efficacy (DSES), a standardized questionnaire [22].

3.3. Statistical analyses

The data were analyzed for any significant differences between gender and age groups (older versus younger, divided by mean age of the population) according to decision-making preferences; demographic information; reasons for dialysis; knowledge of kidney condition, dialysis and kidney transplantation; and information needs. Groups were compared by independent t tests for continuous variables and χ^2 analysis for categorical data. Results with a p-value of <0.05 were considered significant for the proposed hypotheses. The exploratory analyses applied a more stringent p value ($P<.01$) to control for multiple comparisons.

4. Results

4.1. Demographic and medical information

The demographic and medical information for the overall sample and according to gender and age are presented in Table 1. The sample population was divided into two groups by the mean age (52.8, approximated by 53 years).

4.1.1. Decision-making preferences

In the overall sample population, 34.6% of patients reported that they preferred to make their treatment decisions alone, 41.5% wanted equal responsibility with their HCT

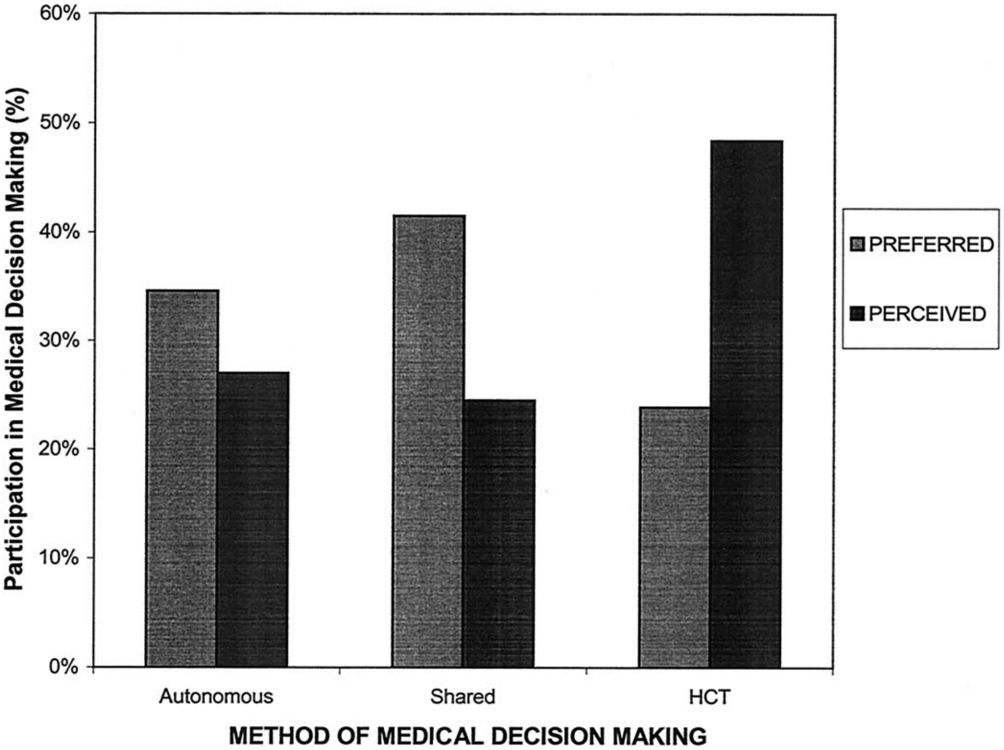


Fig. 1. Preferred vs. perceived participation in medical decision making overall.

for decision-making, while 23.9% preferred the HCT to mostly make the final decision. The actual levels of participation reported in decision-making were 27% made the decision alone, 24.5% shared responsibility, and 48.4% had the HCT make the decision (see Fig. 1).

We compared preferred with perceived (actual) degrees of participation reported in decision-making. χ^2 analysis reported a significant difference between these variables in the overall sample (χ^2=33.8, $P<.001$), which remained when analyzed for each of the age groups. Younger people who preferred independent decision-making were significantly more likely to actually make their decisions alone versus older patients (54% vs. 27%, $P<.05$). Within each decision-making preference group, we determined whether or not they received their preference. A majority of patients (80%) whose preference was for the HCT to make their decision (23.9% of the overall population) reported that the HCT made their decision. Only approximately 30% of those who wanted to share their decision with their HCT (41.5% of the overall sample) did so. Approximately 40% of the overall sample who wanted to make their treatment decisions alone (34.6% of the overall population) actually did.

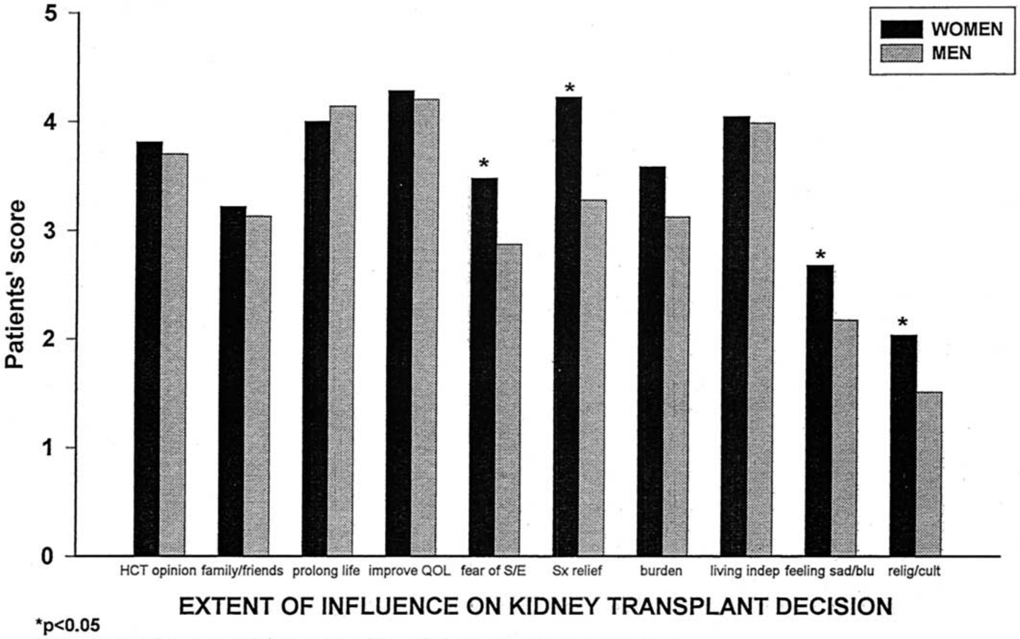
Contrary to hypothesis 1, there was no significant difference by gender in actual level of participation in medical decision-making. Hypothesis 2 was supported, as older patients were significantly more likely to have their health care team make their treatment decision for them ($P<.05$). There were no differences by gender in preferred level of decision-making (confirming hypothesis 3). Hypothesis 4 was not supported, as a greater proportion of older patients preferred to have their HCT make their treatment decisions for them ($P<.05$). The sample size was not adequate to test hypothesis 5, whether an interaction between age and gender existed, as men made up a larger proportion of the older age group (68%).

Overall, higher decisional self-efficacy (DSES) scores, representing greater self-efficacy and confidence in engaging in treatment decisions, were associated with experiencing more independence in decision-making (r=−0.22, $P<.01$), thus supporting hypothesis 6. Younger patients obtained a higher score on the DSES scale (46.68±7.63 vs. 43.46±112.47; $P<.05$) but there were no significant gender differences.

Factors which were more important for women's compared to men's decision to be on a transplant list included fear of side effects ($P<.05$), relief from other symptoms ($P<.05$), feeling sad or blue ($P<.05$), and religious/cultural beliefs ($P<.05$, see Fig. 2). There were no significant gender differences in the role played by the HCT opinion, relationship with family and friends, prolongation of life, improvement of quality of life, fear of being a burden to others, and ability to live independently on their decision to be on a transplant list (see Fig. 2).

There were a similar number of males and females on the transplant waiting list; however, transplantation was suggested more often by the HCT to younger patients than to older patients (85.9% vs. 48.9%; $P<.01$) and more patients in the younger age group were on a transplant waiting list (62.0% vs. 42.7%; $P<.01$).

Factors that were significantly more influential in wom-



*p<0.05
Mean reported, measured on a scale of 1=no influence to 5=great influence

Fig. 2. Influence on kidney transplantation by gender.

en's choice of treatment included fear of dialysis procedure, fear of side effects of dialysis, and transportation considerations ($P<.01$). A significant difference in treatment allocation according to gender existed with significantly more men (72.3%) than women (53.1%) receiving HD ($P<.01$, see Table 1).

The sources of information used (e.g., doctor, nurse, social worker, friends/family) to obtain information about their illness or treatment did not significantly differ between genders. However, in both age groups, the major information resource consulted before agreeing to initiate dialysis was their physician but more younger than older people also used their nurse and other renal patients as sources of information before deciding to initiate dialysis. Also, the opinions of family members ($P<.01$) had a significantly greater influence on the type of dialysis chosen by older people.

4.1.2. Perceived level of knowledge

All patients wanted high levels of information. Younger patients (age$<$53) perceived themselves as having significantly more knowledge than older patients regarding the types of dialysis available ($P<.05$), the reasons for requiring a transplant ($P<.05$), the risks of transplantation ($P<.05$), and the benefits of transplantation ($P<.01$; see Fig. 3). No gender differences in knowledge were observed. No relationship was found between level of perceived personal knowledge about their illness and treatment and decision-making preferences.

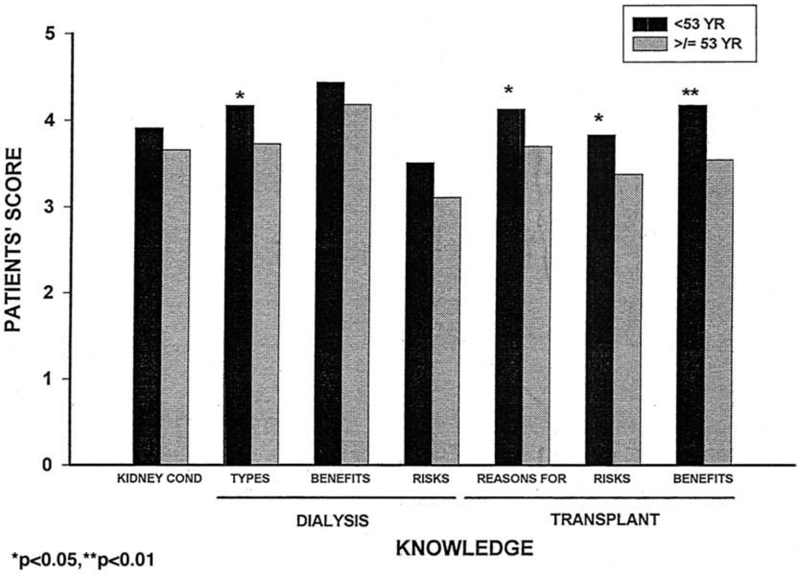
4.1.3. Information preferences

Men desired more information than women about the effect of dialysis on sexual activity ($P<.01$). While both men and women wanted a similar amount of information about kidney disease, different information formats were preferred by each gender. The preferred format for information was books for women and the information binder distributed by the Kidney Foundation for men.

Both age groups requested similar amounts and types of information regarding dialysis. The older group wanted more information than the younger population ($P<.01$) about the possibility of death resulting from dialysis refusal. Younger patients wanted more information about their ability to work while on dialysis ($P<.01$), effect of dialysis on sexual activity ($P<.01$) and physical appearance ($P<.01$), flexibility in the dialysis schedule ($P<.01$), and the effect of dialysis on usual social activities ($P<.01$, see Fig. 4). Both groups considered it equally important to know about whether refusing dialysis would affect their medical care, ability to have a normal life on dialysis, life span if left untreated, and the effect of dialysis on ability to care for oneself. Both age groups reported using information from general print media, Kidney Foundation publications, books, television and radio to a similar extent, but younger people relied more on information obtained from the Internet ($P<.01$) and CD-ROMs ($P<.01$) than older people.

5. Discussion

Our study highlights the complex decision-making process associated with ESRD treatment selection, which helps to explain the broad range of participation levels preferred by our patients, ranging from totally independent to passive roles. The sample population in our study is representative of ESRD patients in Canada as it resembles the patients in



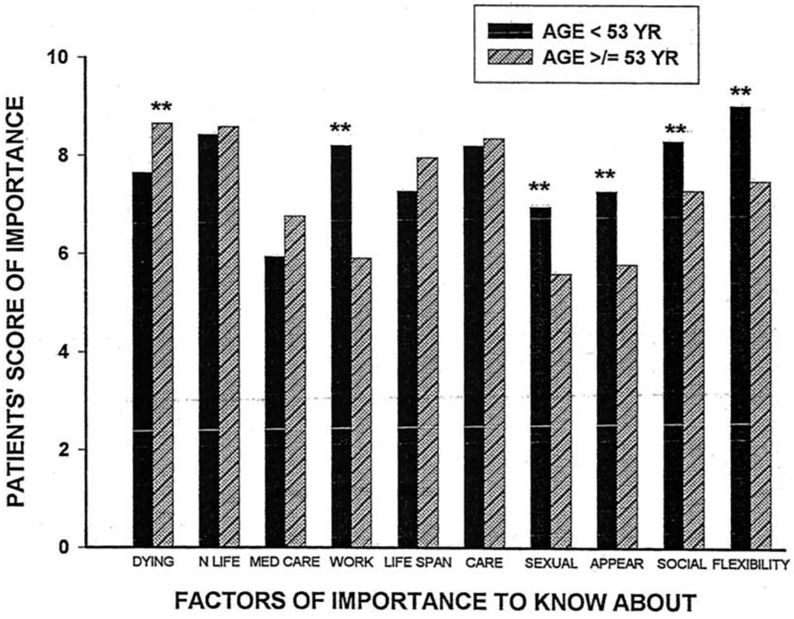
*p<0.05,**p<0.01

Mean reported, measured on scale of 1=do not know much about it to 5=know a lot about it

Fig. 3. Patients' knowledge according to age.

the Canadian Organ Replacement Registry [31] regarding sociodemographic, illness, and treatment variables. Our analyses demonstrate that preferred and actual levels of participation in decision-making are not necessarily correlated especially for patients who wanted a more autonomous or shared role. The strongest correlation existed in the group who wanted to pass on their decision-making responsibility to their HCT, as the HCT ultimately made the treatment choices for 80% of those patients (as well as for many patients who preferred more shared or autonomous roles).

The benefits of autonomy in making decisions regarding one's personal health care have been documented extensively in the literature [1–3]. Despite these benefits, patients who preferred more autonomous or shared decision-making were less likely to actually make an autonomous or shared decision. This discrepancy between preferred and actual participation levels may be due to factors such as availability of different treatment modalities, patient co-morbidities or other medical factors, physicians' expert knowledge about patient condition and available treatments, and re-



**p<0.01

Fig. 4. Information needs by age.

stricted hospital budgets and resources. Although direct cost to the patient is not a limiting factor in patients' treatment decisions in Canada and in US patients covered by Medicaid, it may influence physician decisions because of the unavailability of treatments. Regardless of treatment offered, informed consent from patients would be required before administration and no difference between the two countries regarding this issue would be expected, as international standards for informed consent exist.

Age is an important a factor in the degree of involvement in medical decision-making as evidenced by the more independent role and greater self-efficacy and confidence in making treatment decisions in younger compared to older patients in this study. This confidence may result from the higher education level and greater overall perceived knowledge that younger patients possessed about the types of dialysis, reasons for/risks of/ and benefits of transplantation compared to older patients. The more educational resources (internet, CD-ROM) consulted by this younger population may also play a role.

On the other hand, older patients reported a more passive role as reflected by their reliance on their HCT to make the ultimate decision for them and the great influence that their HCT's opinion had on their choice of treatment modality. The passive role of older people observed in this study conforms to the traditional doctor-patient expectations and the description of "delegators" in decision making [25]. "Delegators" are described as people who prefer to delegate their decision-making to their physicians, to God or to fate versus "activists" who prefer to have a voice in the decision-making process.

Despite the fact that older patients wanted less participation in their treatment-related decisions, they nonetheless wanted a similar degree of information about all aspects of dialysis, demonstrating that wanting information and making decisions are different [27] and that older patients still want to be kept informed despite their passive role in decision making [2,28,29]. There were also significant age differences in information needs (e.g., older patients wanting information about the possibility of death and younger patients querying the ability to maintain employment). These data should be considered in predialysis programs as providing appropriate information to different populations, according to their individual preferences, will facilitate patients in making more informed and confident decisions regarding their health care management.

This study had some limitations. In particular, the survey administered did not contain a test of knowledge and, therefore, patients merely reported their 'perceived' level of knowledge regarding topics related to their illness and treatment. Furthermore, we acknowledge that multiple comparisons were performed on the data set, increasing the likelihood of achieving statistically significant comparisons. Due to the varying length of time patients had been receiving treatment at the time the survey was administered, recall bias is another potential limitation of this study. In addition, it would be interesting to see the extent to which patient perceptions of role in decision-making is in agreement with professional perceptions about patient role. Specifically, professionals may feel that patients actually had a more independent role in treatment decisions than patients perceive.

In conclusion, this study explored decision-making preferences and its influencing factors in ESRD patients overall and according to gender and age. ESRD patients prefer to participate in their health care decisions to varying degrees, ranging from none or very little to total participation. Many more patients perceived that their decision-making was made by their health care team, than preferred this. Confidence in decision-making is directly related to independence in decision-making, while perceived knowledge regarding one's illness and treatment options was not. Several age and gender differences in decision-making were noted in this study. In particular, age and gender differences existed in the specific factors influencing treatment choices. With respect to overall self-perceived knowledge about one's condition and treatments, no significant gender differences existed, but younger patients declared more knowledge than older ones. Also, different gender and age groups prefer different types of information and modes of acquiring information, which is important for patient educational purposes. Younger patients comprise a more independent group than older patients, possessing greater confidence in decision-making. Older patients, on the other hand, have a greater reliance on their HCT for making medical decisions. However, these statements should be regarded as generalizations, and treatment should be individualized to the patient. Indeed, there may be older patients who want a great deal of participation in their medical decision-making and younger patients who desire a more passive role. As a whole, the results of this paper demonstrate the multifactorial nature of decision-making in ESRD patients which health care providers must be aware of as they assist patients through their medical decision-making.

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