Why Is It Difficult for Staff to Discuss Advance Directives with Chronic Dialysis Patients?1

Erica Perry, Richard Swartz,2 Linda Smith-Wheelock, Joan Westbrook, and Catherine Buck

ABSTRACT

General experience and reported data show that a substantial number of patients, at least 10% in many surveys, eventually choose to withdraw from chronic dialysis. There are additional studies suggesting that discussing and completing advance directives (AD) can promote more acceptance and less acrimony for patients, families, and staff when patients die. Even so, surprisingly few AD are completed, and dialysis staff often shun discussion of AD with patients. Thus, in this study, a survey of approximately 400 dialysis staff from 12 representative Michigan dialysis facilities was undertaken both to determine the beliefs, attitudes, and life experiences that might influence such discussions, as well as to guide future strategies aimed at encouraging the discussion and meaningful execution of AD. More than 50% (210) of the distributed questionnaires were completed. Overall results show that respondents report having discussed AD with only 30% of patients on average and that as many as 40% of respondents report never having done so. Among the professional disciplines responding to this survey, social workers report the largest percentage of patients with whom they discussed AD (60%), physicians a smaller percentage (38%), licensed practical (30%) and registered (25%) nurses even fewer patients, and dialysis technicians (20%) and dietitians (4%) the least. Across all disciplines, staff reported discussing AD with a larger percentage of patients when staff had experienced significant losses within their own personal lives, discussed such issues with friends or family, or had prepared their own AD. In rating specific barriers that correlated strongly with reported discussion of AD, each professional discipline had characteristic responses reflecting the approach of the discipline to addressing AD. The survey results suggest that the interdisciplinary variations observed are attributable to: (1) important differences not only in training, but also in the customary roles taken by each discipline; (2) inherent cultural differences, suggested by the findings among nonwhite staff of a lower reported frequency of having discussed AD with patients and of more concern over the barriers to doing so; and (3) a lack of support from supervisory and physician staff within the dialysis team. In conclusion, this survey shows, not surprisingly, that personal experiences and intrinsic cultural differences influence the attitudes of dialysis staff toward discussing AD with patients. The results of this survey underscore important differences between individual professional disciplines that affect both the perceived barriers to, as well as the likelihood of, discussing AD with patients. It seems that emotional issues such as death and dying stress interdisciplinary team interaction and amplify discomfort. However, it may be possible to increase the level of comfort in talking to patients about AD for each professional discipline by addressing the findings from this study (role differences and barriers) through focused interventions and by facilitating mutual support among the distinct members of the dialysis staff.

Key Words: Advance directives, death, chronic dialysis, barriers, staff training

Patient participation in making medical decisions, particularly decisions regarding future medical care, has been promoted recently by passage of the Patient Self-Determination Act of 1990 (1–3). Yet even before the advent of the new Act, 10% or more of patients in the setting of ESRD had already been making decisions regarding withdrawal from chronic dialysis and other life-support treatments (4–6). Recent literature affirms the value of patient input into such decisions, showing that death among ESRD patients can often be reconciled and made acceptable for family members and for staff if future medical care is prospectively addressed (7–9).

When asked about completing AD, ESRD patients generally emphasize the importance of ongoing discussion with dialysis staff who are comfortable in addressing these issues (10,11). It seems that patients want staff input and that staff have substantial influence when it comes to making decisions about AD. Even so, our experience is that many members of the...
**Questionnaire—Part I. Demographic Information**

**Staff Position:**
- Physician ______
- Social Worker ______
- Registered Nurse ______
- Licensed Practical Nurse ______
- Technician ______
- Renal Dietitian ______

**Area of work:**
- Hemodialysis ______
- Peritoneal dialysis ______
- Transplant ______

**Years in Nephrology:** ______
**Age:** ______
**Sex:** M ______ F ______
**Race:** ______

**Have you had a significant event in your life that made you rethink your feelings about death and dying?**

**Have you ever talked with your family or friends about Advance Directives (yours or theirs)?**

**Do you personally have an Advanced Directive?**

**What percentage of your patients do you speak with about Advance Directives? (scale 0–100).**

**Questionnaire—Part II. Attitude and Barrier Questions: Scale 1 (unImportant) to 5 (very important)**

1. I worry that I will upset the patient.
2. My staff role is to give life, not death.
3. I don't want to see my patients cry.
4. Allowing someone to die is a sin.
5. When the time comes for ADs, medical professionals will be best able to determine what is best.
6. I'm afraid I won't have the emotional strength to support the patient through the discussion.
7. If I discuss ADs it will give the impression that I approve of giving up.
8. I don't want to second-guess the Nephrologist.
9. I don't have enough knowledge to make the decisions involved in ADs.
10. If I discuss ADs with the patient the family might blame me if the patient gives up.
11. The patient will think he or she will die soon.
12. If I talk about death they may choose it.
13. Life itself is too precious.
14. Patients base AD decisions on emotions like fear rather than on accurate medical knowledge.
15. I wish I had more training about ADs to answer patients' questions.
16. It is not my business.
17. I don't go into this field to let people die.
18. I don't want to see my patients cry.
19. I don't feel I have enough time to do ADs with patients.
20. I don't have enough training about ADs to answer patients' questions.
21. It is not my business.
22. I didn't go into this field to let people die.
23. It takes lots of interaction and my schedule doesn't allow for it.
24. It will say to patients that they are a burden.
25. I don't have enough training about ADs to answer patients' questions.
26. I don't want to second-guess the Nephrologist.
27. I don't feel I have enough knowledge to make decisions about ADs.
28. This is not an appropriate task for my profession.
29. ADs are in conflict with my religious beliefs.
30. I worry that I will upset the patient.
31. I don't want to second-guess the Nephrologist.
32. It is against my professional training to make patients uncomfortable.
33. I don't want to see my patients cry.
34. I don't want to second-guess the Nephrologist.
35. I don't want to see my patients cry.
36. I don't feel I have enough knowledge to make decisions about ADs.
37. I don't want to second-guess the Nephrologist.
38. I don't want to see my patients cry.
39. I don't feel I have enough knowledge to make decisions about ADs.
40. This is not an appropriate task for my profession.
41. ADs are in conflict with my religious beliefs.
42. I don't want to see my patients cry.
43. I don't feel I have enough knowledge to make decisions about ADs.
44. I don't want to second-guess the Nephrologist.
45. I don't want to see my patients cry.
46. I don't feel I have enough knowledge to make decisions about ADs.
47. I don't want to second-guess the Nephrologist.
48. I don't want to see my patients cry.
49. I don't feel I have enough knowledge to make decisions about ADs.
50. This is not an appropriate task for my profession.
51. ADs are in conflict with my religious beliefs.

**Questionnaire—Part III. Open-Ended Questions**

1. Should any specific person on the renal team discuss ADs with patients? Who? When?
2. If you have talked with patients about ADs, what prompted your action?
3. If you believe that it is a good idea to talk with patients about ADs, what kind of support would be helpful to you in having these discussions?
4. Other comments?

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Figure 1. Advance Directives Questionnaire.
METHODS

Questionnaire

A survey instrument was designed to gather information in several areas (Figure 1). The first part of the questionnaire explored demographic information about respondents (professional discipline, age, gender, and years in nephrology work) and the extent to which (percentage of patients with whom) respondents spoke with patients about AD. The second part of this questionnaire explored attitudes or statements that might be barriers to discussing AD with patients. This questionnaire was developed by a multidisciplinary committee from staff at University of Michigan Dialysis Programs, University of Michigan Institute for Social Research, and the Patient Services Committee of the National Kidney Foundation of Michigan. A list of statements or attitudes thought to represent common barriers to addressing AD and life-and-death issues was developed and included the following: (1) such discussion might cause distress to patients; (2) patients lack sufficient knowledge and are incapable of such discussions; (3) such discussion might encourage suicide; (4) having such discussions is not the respondent's role; (5) staff lack sufficient knowledge, materials, or training for such discussions; (6) such discussion conflicts with personal values; (7) such discussion might cause personal distress for staff; (8) such discussion might compromise staff members' professional demeanor; and (9) there is insufficient time for such discussions. Once this list was generated, questions were developed that addressed these attitudes or barriers, asking respondents to rate the importance of each question from 1 (unimportant) to 5 (extremely important). The final questionnaire included 45 such items (Figure 1). A third part of the questionnaire used open-ended questions exploring methods to facilitate discussing death and AD with patients, including which specific team members might best present the issue to patients, additional methods or materials that might facilitate the process, and interdisciplinary difficulties that might affect the discussions.

Respondents

Twelve dialysis facilities in Michigan (see the Acknowledgments section) were selected to include a mix of the following: urban versus rural centers, profit versus nonprofit facilities, hospital versus free-standing facilities, teaching versus community centers, and large versus small facilities. Local coordinators (see the Acknowledgments section) distributed questionnaires to all renal team members at the selected centers, with completed questionnaires returned anonymously by mail. For the purposes of analysis, respondents were grouped into disciplines (e.g., physician, nurse, etc.) that follow the usual composition in dialysis units in the region.

Data Analysis

Data analysis was performed using SPSS (SPSS Inc., Chicago, IL). Statistical analyses included the chi-squared test, one-way analysis of variance, and the Pearson Product-Moment Correlation.

RESULTS

Of the 405 questionnaires distributed, 210 or 52% were completed, a substantial number of completed questionnaires from each of the 12 centers. Table 1 lists the characteristics of respondents, based on direct answers to the first part of the questionnaire. These demographic characteristics were not uniformly distributed among the disciplines. For example, physicians comprised 15% of respondents overall and were predominantly men, whereas registered nurses represented 42% of respondents and were predominantly women. The majority of both of these professional groups were white, of intermediate age, and had relatively extensive experience in nephrology. Licensed practical nurses were few in number, were all women, and represented the oldest group. Dietitians and dialysis technicians were the youngest respondents on average. Overall, the racial distribution was 86% white and 13% black, with a slightly higher representation of nonwhites among the technical staff.

Table 2 shows the degree to which respondents in each professional discipline claimed to have spoken with patients about AD. Among all disciplines, respondents recalled speaking about AD with 30% of patients on average, and 39% of respondents overall reported never having spoken to patients about AD. Social workers recalled discussing AD with the largest proportion of patients on average (60%), and only 15% of social work respondents report never having such discussions. At the opposite extreme, dietitians recalled having spoken to the smallest average proportion of patients about AD (4%), and 75% of dietitians had never done so. Physicians, who are often the leaders of the treatment team, recalled discussing AD

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TABLE 1. Descriptive characteristics of survey population

<table>
<thead>
<tr>
<th>Professional Discipline</th>
<th>N (%)</th>
<th>Male (%)</th>
<th>White (%)</th>
<th>Mean Age (yr)</th>
<th>Mean Time in Nephrology (yr)</th>
<th>Significant Life Event (%)</th>
<th>Have Own ADa (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physician</td>
<td>31 (15)</td>
<td>81</td>
<td>93</td>
<td>41</td>
<td>10.2</td>
<td>57</td>
<td>23</td>
</tr>
<tr>
<td>Registered Nurse</td>
<td>89 (42)</td>
<td>8</td>
<td>90</td>
<td>41</td>
<td>8.1</td>
<td>70</td>
<td>15</td>
</tr>
<tr>
<td>Licensed Practical Nurse</td>
<td>10 (5)</td>
<td>0</td>
<td>80</td>
<td>45</td>
<td>5.8</td>
<td>64</td>
<td>18</td>
</tr>
<tr>
<td>Dialysis Technician</td>
<td>38 (18)</td>
<td>24</td>
<td>61</td>
<td>36</td>
<td>5.2</td>
<td>67</td>
<td>18</td>
</tr>
<tr>
<td>Dietician</td>
<td>16 (8)</td>
<td>13</td>
<td>94</td>
<td>35</td>
<td>8.4</td>
<td>50</td>
<td>6</td>
</tr>
<tr>
<td>Social Worker</td>
<td>26 (14)</td>
<td>7</td>
<td>81</td>
<td>40</td>
<td>5.6</td>
<td>67</td>
<td>39</td>
</tr>
<tr>
<td>All Respondents</td>
<td>210</td>
<td>21</td>
<td>86</td>
<td>40</td>
<td>7.5</td>
<td>65</td>
<td>19</td>
</tr>
</tbody>
</table>

a AD, advance directive.
with only 38% of patients on average, although only 16% reported never having such discussion.

Across all disciplines, individual staff recalled discussing AD with patients more often when the staff also reported personal life-and-death experiences of their own ($P < 0.02$) or had executed their own AD ($P < 0.002$). There was a trend ($P < 0.07$) for staff with more experience in nephrology to report less frequent discussion of AD with patients, but age itself did not so correlate. Finally, black respondents, when compared with white respondents, claimed to have discussed AD less often with patients ($P < 0.05$) and also tended less often to report personal experience with life-and-death situations ($P < 0.05$), discussion with friends and family about AD ($P < 0.001$), or completion of their own AD ($P < 0.04$). Unfortunately, the survey was not designed to determine the racial mix among staff and patients, even though such differences could have influenced the degree to which discussion of AD took place.

In the second part of the survey, respondents rated on a scale from 1 (unimportant) to 5 (very important) questions (Figure 1) reflecting the list of nine barriers summarized in Table 3. For most questions, the scores averaged less than 3.0, indicating a slightly less than "neutral" importance of each barrier among the survey respondents; thus, the differences between groups reflect the relative importance which respondents attribute to these barriers. The range and mean values show that certain factors, such as the concern that discussing AD might encourage suicidal behavior or that AD conflict with the personal values of respondents, were considered less important overall. Other factors, such as the respondent's perception of their role, knowledge, and preparedness, elicited a wider range and higher degree of concern overall.

The last column of Table 3 shows that individual responses for most of the barriers surveyed were strongly correlated with the lower frequency of each individual's reported discussion of AD with patients. For example, the perception that staff themselves lacked sufficient knowledge or training in his area ($P < 0.001$), that discussion of AD might cause distress for the patient ($P < 0.002$) or staff ($P < 0.001$), or that

### TABLE 2. Degree to which respondents discussed ADs with patients

<table>
<thead>
<tr>
<th>Discipline</th>
<th>N</th>
<th>Average Percentage of Patients with Whom AD Discussed</th>
<th>Percentage of Respondents Who Never Discussed AD with Patients$^b$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physician</td>
<td>31</td>
<td>38</td>
<td>16</td>
</tr>
<tr>
<td>Registered Nurse</td>
<td>89</td>
<td>25</td>
<td>35</td>
</tr>
<tr>
<td>Licensed Practical Nurse</td>
<td>10</td>
<td>30</td>
<td>40</td>
</tr>
<tr>
<td>Dialysis Technician</td>
<td>38</td>
<td>20</td>
<td>66</td>
</tr>
<tr>
<td>Dietitian</td>
<td>16</td>
<td>4</td>
<td>75</td>
</tr>
<tr>
<td>Social Worker</td>
<td>26</td>
<td>60</td>
<td>15</td>
</tr>
<tr>
<td>All Respondents</td>
<td>210</td>
<td>30</td>
<td>39</td>
</tr>
</tbody>
</table>

$^a$ Value is percentage of patients with whom respondents reported discussing AD averaged among respondents within each discipline.

$^b$ Value is percentage of respondents within the discipline who reported discussing AD with no patients (0%).
such discussion was not one's role (P < 0.001), correlated strongly with respondents' reported behavior and confirm the role of such barriers in the process of discussing AD with patients.

Table 4 shows the relative impact of the surveyed barriers as judged from the responses of each professional discipline represented in the survey. The numbers in the array of Table 4 show the ranking of the average scores for each barrier comparing the six professional disciplines. Thus, for "Might cause patient distress," dialysis technicians and registered nurses rated this barrier as more important (higher group score) on average than other disciplines, with licensed practical nurses and social workers rating this barrier as less important (lower group score) on average. For each discipline, a profile of rankings among all barriers can be discerned by reading down each column of Table 4, with an overall "average ranking" for each discipline shown in the bottom row.

It is noteworthy that the relative rankings within each discipline were strikingly consistent for the entire list of barriers. Clearly, social workers as a group ranked low consistently in their degree of concern about these barriers, both individually for each barrier and overall for the entire list of barriers. Licensed practical nurses rated slightly higher, physicians intermediate, and registered nurses and dietitians considerably higher; dialysis technicians consistently ranked highest for most barriers and on average. Noteworthy exceptions, which may reflect important distinctions between disciplines, were the concern regarding "insufficient staff time" among social workers and concerns about "patient distress" and related issues (first three rows of Table 4) among physicians.

On further analysis, perceptions regarding the surveyed barriers generally did not correlate with some demographic characteristics such as age or years of nephrology experience, despite the nonuniform distribution of some demographic characteristics across the disciplines. However, there was a significantly higher degree of concern among nonwhite staff for all surveyed barriers (P < 0.05) except the "lack of staff time."

In the third portion of the survey, inherent differences between disciplines in their approach to issues of AD and death were highlighted by responses to open-ended questions. Table 5 shows that, when asked "Who should present AD information to patients?", respondents generally felt that social workers (57% of all respondents) or physicians (51% of all respondents) should do so, and only 11% of all respondents felt that discussion should be a "team" effort. Not only did most other disciplines defer to social workers and physicians, but social workers (81%) and physicians (52%) themselves felt that presenting AD was their own role. Nursing staff generally deferred equally to social workers or physicians, and only 27% felt that registered nurses themselves should present AD information to patients. It was clear from the survey that the responsibility for discussing AD was seldom formally assigned to any particular discipline, although there was an tendency for this responsibility to devolve informally to social workers more often than to any other professional group.

Table 6 shows responses to open-ended questions regarding the reasons that staff undertook discussions about AD with patients. The most common reasons reported were patient inquiry, declining health with complications, or perceived obligations to policies or institutions. Thus, it seems that respondents seldom began discussions of AD prospectively, even though some respondents suggested that AD be presented to patients early in the course of their chronic dialysis before serious complications occur.

### Table 4. Barriers to discussing AD: Relative ranking in each discipline

<table>
<thead>
<tr>
<th>Barrier or Attitude</th>
<th>Professional Discipline</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M.D.</td>
</tr>
<tr>
<td>Might Cause Patient Distress</td>
<td>4</td>
</tr>
<tr>
<td>Patients Lack Sufficient Knowledge</td>
<td>3</td>
</tr>
<tr>
<td>Might Encourage Suicide</td>
<td>5</td>
</tr>
<tr>
<td>Not Respondent's Role</td>
<td>2</td>
</tr>
<tr>
<td>Staff Lack Knowledge and Training</td>
<td>2</td>
</tr>
<tr>
<td>Conflicts with Personal Values</td>
<td>2</td>
</tr>
<tr>
<td>Causes Staff Distress</td>
<td>3</td>
</tr>
<tr>
<td>Compromise Professional Demeanor</td>
<td>3</td>
</tr>
<tr>
<td>Insufficient Staff Time</td>
<td>2</td>
</tr>
<tr>
<td>Average Ranking</td>
<td>2.9</td>
</tr>
</tbody>
</table>

*The relative rank compares the degree (1 to 6) to which the given attitude or barrier was rated on average between the six disciplines, 1 being the lowest and 6 the highest. Reading across each row compares disciplines scores for each barrier, and reading down each column profiles the specific discipline across all barriers. Thus, for "Might Cause Patient Distress," dialysis technicians and registered nurses rated this barrier as more important (higher group score) on average than other disciplines, with licensed practical nurses and social workers rating this barrier as less important (lower group score) on average.

*The "Average Ranking" is that derived for each discipline among all nine barriers, reading down each column.*
TABLE 5. Who should present AD information to patients?

<table>
<thead>
<tr>
<th></th>
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<th></th>
<th></th>
<th></th>
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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>M.D.</td>
<td>52</td>
<td>51</td>
<td>40</td>
<td>55</td>
<td>50</td>
<td>54</td>
<td>51</td>
</tr>
<tr>
<td>R.N.</td>
<td>13</td>
<td>27</td>
<td>10</td>
<td>42</td>
<td>44</td>
<td>31</td>
<td>29</td>
</tr>
<tr>
<td>L.P.N.</td>
<td>3</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Technician</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>R.D.</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>M.S.W.</td>
<td>39</td>
<td>51</td>
<td>50</td>
<td>55</td>
<td>94</td>
<td>81</td>
<td>57</td>
</tr>
<tr>
<td>&quot;Team&quot;</td>
<td>10</td>
<td>15</td>
<td>10</td>
<td>5</td>
<td>13</td>
<td>12</td>
<td>11</td>
</tr>
</tbody>
</table>

a Respondents could mention more than one discipline, a representative of which they felt should present AD to patients; thus, the "Total" (last column) may not equal the sum of the other columns.

TABLE 6. Reasons for initiating AD discussion with patients

<table>
<thead>
<tr>
<th></th>
<th></th>
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<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Asked</td>
<td>23</td>
<td>31</td>
<td>40</td>
<td>16</td>
<td>25</td>
<td>38</td>
<td>29</td>
</tr>
<tr>
<td>Declining Health</td>
<td>39</td>
<td>24</td>
<td>30</td>
<td>21</td>
<td>13</td>
<td>12</td>
<td>23</td>
</tr>
<tr>
<td>Required by Institution</td>
<td>3</td>
<td>6</td>
<td>10</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Intuition/Judgment</td>
<td>3</td>
<td>7</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>5</td>
</tr>
</tbody>
</table>

a Values represent available responses as a percentage of the total respondents (N) for each discipline.

DISCUSSION

The survey presented here shows that, overall, only a minority of staff report discussing AD with patients. Furthermore, this self-reported reluctance to so is influenced by intrinsic differences in training, by distinct roles and expectations for each professional discipline on the renal team, and by identifiable barriers or attitudes that inhibit such discussion. In spite of these inherent biases against discussing death-related issues with patients, it is clear that personal experience with death or loss favorably influenced respondents toward such discussions. Still, the relatively low rate at which dialysis professionals report addressing AD with patients is disappointing in view of the reported desire of many patients to engage in such discussions (12,14,17,21-23) and in view of the fact that facing death is a common event in the dialysis unit. Among respondents in the present survey, only social workers and staff members who have addressed precisely these issues during their training and who also may be preselected for that training, report having discussed AD with a majority of patients.

The results presented here also suggest that there are definite barriers that inhibit discussion of AD and death with patients. For example, even social workers, who reported the least overall difficulty with the barriers surveyed and felt that such discussion was definitely their role, perceived some discomfort, which they attributed to lack of sufficient time. Physicians, who also might be expected to feel the lack of time, seemed instead to be more concerned that patients would be unable to handle such discussions and reported initiating such discussions only after they perceived declining health, rather than doing so during stable intervals. Thus, physicians are still reluctant to address AD prospectively (12,18), even though doing so might avoid some discomfort and acrimony later (7-9). Registered nurses reported infrequent discussion of AD, expressing their own distress and unpreparedness for this role. It is also possible that nursing staff, because their role in some dialysis units commonly involves executing orders rather than generating orders, may be reluctant to take on the responsibility of addressing AD with patients. Finally, some personnel, such as the dietitians, were the least comfortable with these issues, perhaps reflecting a perception of their own role in the dialysis unit and training, which tends toward matters that are more technical in nature.

The interdisciplinary differences exposed in the present survey highlight a rather complex "ethnology" inherent in the social fabric of the dialysis unit. For example, differences in approach to AD between the physicians and the nursing or social work staff may reflect differences in roles, prior training, or personal characteristics, but these differences may also be confounded further by gender differences. As another
example, staff with longer experience in nephrology tended to report discussing AD less often, consistent with findings that personnel such as dietitians, who do not view discussing AD as their role, have more longevity in dialysis units. This finding might also reflect defense mechanisms such as denial by which some of the more experienced staff cope with frequent deaths in the dialysis unit, the fact that some of the older and more experienced respondents were supervisory staff with less direct patient contact, or the possibility that newer staff with fewer years in nephrology also have been trained more recently in curricula that include exposure to ethical issues.

Additional cultural influences in the dialysis unit ethnology were suggested by the finding that, although nonwhites comprised less than 15% of total respondents, there were significant racial differences in the degree to which staff discussed AD with patients and in the degree to which respondents perceived the barriers surveyed. These findings are not surprising, because there is a growing number of reports describing distinct attitudes toward AD and death among different racial and cultural groups (10, 24-30) and pointing out the impact on discussion of death and dying when staff and patients have different racial origins (25, 27). The report presented here serves to emphasize the importance of recognizing such factors, not only among the patients with whom AD are being discussed, but also among the staff, when planning interventions intended to facilitate addressing AD in the dialysis unit.

It is important to realize that, although the findings of this study have strong implications for the development of teamwork in the dialysis setting, the study represents only a small cross-section of the dialysis community. The completed surveys represented just over 50% of possible responses, and the distribution of respondents was not uniform across race and gender with respect to each discipline. Even so, such outcomes are not unusual for surveys of this type, and survey analytical methods have the power to detect significant and substantial differences between groups with discernible characteristics. In this study, such methodology gives us a new perspective on the impact that important issues such as AD and discussion of life-and-death issues have on the dialysis workplace.

An important example of this impact is the interdisciplin ary friction, cited in responses to open-ended survey questions, that physicians or supervisory nursing personnel do not sufficiently support other dialysis staff in the process of AD discussion. It is not surprising that an emotional issue such as AD stresses the operation of the dialysis unit in a manner that exposes the underlying weaknesses in the social framework of the unit. Obershaw has described the manner in which the “distasteful” issue of death isolates practitioners and interrupts communication between one professional and another (31). Other authors point out that serious ethical dilemmas often lead to conflicts between professional personnel in settings such as the critical care unit (32) or necessitate regular team meetings to address communication breakdowns in team settings such as a bone marrow transplant unit (33). This breakdown within the “team” when uncomfortable situations arise is analogous to the striking increase in divorce rate within marriages when chronic illness or death strikes a child in the family (34).

In the end, it is only by realizing the impact of death-and-dying issues that we will be able to address AD in a meaningful fashion. Thus, some methods must be devised to address the prevalent discomfort with life-and-death issues among dialysis staff. One method might involve formalizing an approach to AD that circumvents some of the specific barriers reported in this study. For example, many nursing staff felt that clear and straightforward written materials would be very helpful. Such prepared materials have been shown to enhance the completion of AD by patients (35, 36), but also might introduce AD in a manner that assists both physicians, who seem to want to avoid upsetting patients, as well as social workers, who seem to need more time to address the complex issues relating to AD. Designating distinct but complementary roles for each discipline could also streamline the process. For example, nursing staff might initiate the process by distributing brochures that discuss the Patient Self-Determination Act and AD in general, letting patients and families know that the social worker will speak to them in more detail at an upcoming visit. The social worker might then include AD as a part of the standard social work assessment, addressing questions in more depth and clarifying some problematic issues for the physician to address at clinic visits or for the team to address during multidisciplinary patient care review.

Another approach might include interactive training focused on talking to chronically ill and dying patients, on role expectations and personal discomfort in this area, and on ethnic and cultural differences regarding life-and-death issues. Such training could potentially reduce personal discomfort, promote team unity in addressing AD, and ultimately help staff deal with death and dying in the dialysis unit. Respondents in this survey felt strongly that any approach required mutual support among the dialysis staff and that medical directors (physicians) and supervisors in dialysis units must not only agree on the value of AD, but also support the roles of other staff in undertaking discussion with patients. The need for such support at all levels, particularly from supervisory personnel, is essential in an organizational structure such as the dialysis unit, which has intrinsic risk differences between personnel (36, 37).

Unfortunately, simply setting up mechanisms to address patient concerns and improve clinical outcomes does not guarantee the personal commitment from staff to make the program work successfully. On the contrary, a recent controlled trial of intervention
Theme is no real substitute for spending time personally with patients, as well as mutual support between participating staff members. By intermediary nursing personnel who made contacts with physicians and families of seriously ill patients failed to alter the ultimate application of intensive therapy at the end of life (38). In fact, the outcome of this intervention was even more disappointing because, despite the effort at intervention, primary physicians still failed to communicate effectively with patients in the majority of cases or to judge accurately the patients’ preferences regarding aggressive resuscitative treatment. In the final analysis, it may be the commitment to the process that is more important than the specific program of intervention.

It is important to realize, before embarking on detailed protocols or complicated algorithms for addressing AD, that the danger inherent in formalizing this process may be loss of the sensitivity that we strive to achieve. In fact, it seems that the ascendancy of dialysis technology has diverted our attention from matters as poignant as life-and-death decisions. The irony is that, by practicing the discussion of AD in our work, we may also be better prepared to face the unknown travails that may occur in our own or our loved ones’ lives.

**CONCLUSION**

The Patient Self-Determination Act (1–3) has focused public attention on patient rights and participation in decisions regarding medical care, and recent reports suggest that there is strong sentiment among patients and staff regarding guaranteed input into future medical decisions for themselves and for others (21–23,39,40). Even so, AD are not always followed during hospital admissions or at chronic-care facilities (41–44). Furthermore, there is the danger that the Patient Self-Determination Act will only result in perfunctory approaches designed to document some minimal compliance but will lack substance in truly addressing important AD and life-and-death issues (3,43,45).

In the ESRD setting, the predictable and relentless attrition from the chronic population exposes patients and staff to death on an ongoing basis. As a result, the necessity of facing death and dying is unavoidable. Dialysis staff have a unique opportunity, based on their long-term relationship with patients, to address, review, and modify long-term plans before crisis ensues. In the end, undertaking such discussions with patients who face difficult chronic illness often can lead to better closure when deaths do occur and foster personal and professional satisfaction (7–9,46). The irony is that, by practicing the discussion of AD in our work, we may also be better prepared to face the unknown travails that may occur in our own or our loved ones’ lives.

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