Use of the SF-36 in Dialysis Treatment Planning

Marvin Withers MSEd, LCSW, James B. Harrigan Center for Dialysis, Colorado

This paper describes the use of the SF-36 in the treatment of dialysis patients. Patients in a small dialysis unit were administered the SF-36 at regular intervals. Resulting graphs were generated for each patient to see data for understanding and interpretation. Interventions were developed for problem areas indicated by low scores. These included both nursing and social work interventions as appropriate. The SF-36 was seen as a useful adjunct to more conventional clinical tools and expanded the information available on each patient.

Using the SF-36 (Ware et al., 1993) grew out of the need for the Harrigan Dialysis Center to find an objective tool to assess patients' mood, health status, and quality of life. Many of the Center's patients were elderly and stoic in nature and often minimized their physical and emotional complaints. This situation called for another avenue of assessment that would help provide more complete and accurate understanding of the patients' emotional and physical health status and quality of life. After reviewing several other instruments that have been used to measure overall health status and quality of life the choice was made to use the SF-36.

Nursing acceptance and understanding has been somewhat slow so far. While nurses have not been negative, they have been confused as to how to interpret the results and what they may mean for nursing interventions. Many dialysis orientation programs do not stress the psychological aspects of kidney failure, and nurses are more accustomed to dealing with concrete measures, rather than such relatively "fuzzy" concepts as social functioning and role limitations due to emotional problems. This gap in understanding between what are familiar concepts for a social worker and the issues that nurses are trained to deal with may be at the root of the nurses' hesitancy to embrace this new tool. Fortunately, this situation is improving as nursing staffs become accustomed to the use of this instrument

The nephrologists who refer patients to the Harrigan Dialysis Center have also had mixed reactions to using the SF-36. These nephrologists are from out of town and only see patients two days a month at the Center. Because of this, the time they have to interact with staff members is limited. They have not had time to look closely at the SF-36 results. Yet at the same time they have all been very interested in having the information from the survey related to them in care conferences when appropriate.

The use of the SF-36 has been well documented in many areas of health care, but there seems to be relatively little written on its use in dialysis treatment planning. Most of the studies involving the use of the SF-36 in dialysis seem to focus on results from large populations or on comparing one population to another rather than in treatment planning for individual patients. An Italian study (Mingardi, Cornalba, et al., 1999, p. 1503-1510) reported on the reliability and consistency of the SF-36 with a dialysis population. The authors note, "The SF-36 questionnaire is easy to use with Italian dialysis patients and SF-36 scores are related to important clinical aspects. This approach can help in caring for dialysis patients and can be useful in outcome assessment programs." Another study from the Netherlands (Merkus, Jager, et al., 1999, p. 720-728) compared hemodialysis patients to peritoneal dialysis patients and found that "This prospective study shows that physical quality of life over time in hemodialysis patients is better than in peritoneal dialysis patients." Neither of these studies discusses how this information may be used in treatment planning for individual patients.

A study on the use of Epoetin Alfa therapy with dialysis patients (Levin, Lazarus, et al., 1993, p. 3-12) used the SF-36 as a way of measuring quality of life before and after beginning Epoetin Alfa therapy. The study did say that such therapy had a positive effect on quality of life, especially vitality, but no mention of using the SF-36 for other purposes was noted. On the other hand, this study does give us a demonstration of how the SF-36 is sensitive to the effects of medical interventions. This shows how the SF-36 can reveal the broader effects that various interventions may have on a patient's well being.

Meyer, Espindle, et al. (1994, p. 277) described the use of the SF-36 to monitor patients' health status on a quarterly basis for a three-year period. The authors summarized the value of the SF-36 thus:

When we began this work, we wondered whether we already knew what the SF-36 would tell us about our patients. We did not. Health status surveillance has done more than give quantitative expression to our intuition. The activity reveals new information, and the information it reveals is qualitatively different from the assessments that we otherwise make in the care of our patients.

While the study talked about how results related to the experiences of individual patients and acknowledged the value of the information gathered by the SF-36, no mention was made of how this information was used. One clue as to why this should be the case is found in the authors' statement that "Health status assessment makes statements about our patients more general than those we are accustomed to making or acting on in the course of routine clinical work in a general medical environment." They elaborate on this further by saying; "We know what to do about a low Kt/V and what to say to the patient about a high serum phosphorus. By contrast, neither nephrology nor general medical texts teach the differential diagnosis or appropriate evaluation of a declining social function score." As this indicates, most medical personnel are unaccustomed to having this type of information and there are certainly no guidelines on how to incorporate this information into a patient's treatment. This closely parallels the experiences that I mentioned earlier in relation to the Center's nursing staff and their comfort level with relation to the SF-36.

Methods

Participants

The participants are all dialysis patients and therefore have been diagnosed with kidney failure from a variety of causes. The unit is small with only 25 to 30 total patients. All patients are given the opportunity to take the survey but participation is voluntary. Currently there is a database of 66 total survey administrations. Of these, 28 are female patients and 38 are male. This is in keeping with the fact that the unit tends to have more male than female patients. The age range is from 28 years of age to 85 years of age.

Measure

The SF-36 as published by the Medical Outcomes Trust was used for this study. It is scored according to the SF-36 Health Survey Manual and Interpretation Guide (Ware et al. 1993, p. 43). For ease of scoring, an Excel spread sheet was programmed to score the surveys according to the algorithm in the manual. Each survey generates scores on eight scales. These are: physical functioning (PF), role limitations due to physical health (RH), bodily pain (P), general health (H), vitality (V), social functioning (SF), role limitations due to emotional problems (RE), and mental health (MH).

The scales are scored such that higher scores always indicate more positive responses. Thus a score of 75 on the pain scale indicates less actual pain that a score of 25. Similarly, a score of 87 on the physical functioning scale indicates better overall functioning than a score of 56. This helps make interpretation of the scores easier and quicker since the user need only look for the low scores to see what areas need improvement, or the high scores to see where the patient is doing well.

These scales each give information on distinct aspects of patients' quality of life and allow staff to easily determine in what area a patient may be experiencing difficulty. The physical functioning scale helps determine if a patient is having trouble with common daily activities. The role limitation due to physical health scale determines if the patients' usual activities are disrupted due to health problems. The bodily pain scale is self descriptive, measuring how much pain the patient is experiencing on a regular basis. The general health scale rates the patients' overall perceptions of their health status. The ability to engage in social activities is measured by the social functioning scale. Role limitations due to emotional problems indicate how emotional issues may have affected a person's usual activities. The mental health scale provides information about a patients' level of emotional wellness.

In addition to the information provided by each separate scale, the scales can be viewed in combination to give a more complete picture. The first three scales, PF, RH, and P, when viewed together give an overall picture of the patient's physical health. The last three scales, SF, RE, and MH, are related to the patients' emotional or mental functioning. The general health scale and the vitality scale are measures of more general health status and can be combined with either the first or last scales to enhance the understanding of a patient's status. This ability to view the scales either individually or in combination allows the user to take a broad, general view of the subject's health status, or to focus in on specific areas. The user thus has a large amount of flexibility in how the instrument can be used or adapted to suit the purpose at hand.

Procedure

The SF-36 is administered to all patients who are willing to fill out the form. The patients fill out most forms by themselves; for those with poor eyesight the questionnaire is administered orally according to the protocol described in the manual (Ware et al., 1993, p. 188). Results are scored using an Excel spreadsheet programmed according to the scoring algorithm contained in the manual cited above. The results of each administration are entered into a database table from which cumulative averages for the unit are generated. In addition, a graph containing both the patients' scores and the unit averages is generated. An example of this can be seen in Figure 1. These graphs give the patient and staff an easy to understand visual display of the results. Results are then discussed with the patient to determine if the results are consistent with the patients' perceptions and to brainstorm with them on possible ways to improve low scores. The patient's scores are also used during patient care conferences as needed to provide input on the patient's condition beyond what is revealed by the usual lab values and vital signs. Information from the survey and discussions with staff and the patient are used to generate strategies for improving the patient's health and quality of life. Usually the need for such planning is indicated by patient scores that are below our unit averages or are a significant drop from previous scores. Various parts of the multidisciplinary team may be involved in developing strategies as appropriate. Social work may intervene in issues surrounding depressive symptoms or social functioning. Nursing and the nephrologist may work on strategies related to excessive pain. Such plans are then translated into elements of the patient's treatment plan.

One common example of this process, as used by social work, has occurred with many newer patients. New patients often score low on the social functioning scale because dialysis is so disruptive to their usual schedule that they feel they will never be able to engage in activities they find enjoyable again. The usual intervention involves educating the patients on how travel all over the United States and most foreign countries is possible while on dialysis. In addition, strategizing on ways to change the dialysis schedule or to find ways to modify activity times can give the patient a renewed sense of being back in control of their life. The result of this type of intervention is usually a much happier patient and a corresponding rise in the social functioning score when the SF-36 is next administered.

On the nursing side we have also experienced several good examples of using the SF-36 to assist in treatment planning. One such instance is of a gentleman who upon starting dialysis had an initial score on the role functioning scale of zero. Since higher scores on all scales mean better functioning, this is the worst possible score. Talking with the patient about the reasons for this score revealed that he was distressed over his inability to work. Nurses and doctors working with the patient were able to adjust his dialysis prescription and schedule as well as his medications so that he was soon able to return to work on a part time basis. The next time the SF-36 was administered, this patient had improved his role functioning score considerably.

Results

As a result of using the SF-36, Center staff members have been able to generate a more complete understanding of a patient's health status and take appropriate action. Initially the results of the survey were reported only as numbers in a table. This was difficult for staff to understand and generated little interest. Currently, graphs are generated which visually display the patient's results from the most recent survey and any past surveys, as well as unit averages for each scale. Again, see Figure 1 for an example of this. The visual representation of the results has made it very easy to see where a patient may be having trouble and need intervention. This can also be used to encourage the patient and staff by showing progress over time as well. The graphic format has also generated more interest in the survey and lead to improved understanding of it by staff and patients.

There are two results of using the SF-36 that have been particularly valuable; the first is that it has been possible on several occasions to intervene sooner due to earlier discovery of a problem. This also gives a much more complete picture of the patient. Understanding problems more completely has lead to more appropriate treatment planning and seems to have lead to improved status for several of our patients. These results have not been quantified but they have been a major factor in demonstrating that the SF-36 is a useful instrument for dialysis patients on this unit.

A third factor that has been useful is that using the SF-36 increases contact with the patient and elicits information that might otherwise be missed. Patients are routinely engaged in casual conversation by the social worker or nursing staff, which leads to inquiries

about their health and emotional status. In spite of this, patients often do not reveal what is really going. Their stoic natures lead them to give perfunctory answers, such as "I'm doing OK," when asked about their health or social functioning. In answering the questions on the SF-36, areas are touched on that are often not considered when patients think about health issues such as role function for example. Follow-up questions on the results often reveal information that would usually be overlooked. Other examples of this are the patient's ability to engage in favorite hobbies, visit friends, travel, and so on. Problems in these areas are often related to health status and can have a profound affect on the patient's quality of life. At other times we have found that problems in areas like these can be related to aspects of the patient's health that we were unaware of, such as decreased energy level, which could indicate perhaps a lowered hematocrit.

Discussion

Probably the overall lesson learned from using the SF-36 so far is that the information gathered must be presented simply in order to be useful. Busy nurses, technicians, dietitians, and doctors do not have time for lengthy explanations of the eight scales, what they mean, how far the scores differ from the mean, and so on. All of the staff members are interested in information that can help them give better treatment to their patients. All of the professionals involved in patient care want facts that are relevant to planning the most effective interventions for those in their care.

By keeping the discussion of scores on the simplest level, patients can understand what the results mean and discuss the reason scores have changed and may be lower or higher than unit averages, or their own last set of scores. Patients' involvement in their own treatment planning is thereby increased and this seems to lead to better compliance in at least some cases, though we again have not currently quantified this.

The result of this is that it is important to distill the information from the questionnaire down to its simplest form and present it in common, non-technical terms. Putting the results in graphic form has been helpful for presenting the results to both staff and patients. Everyone can easily understand the significance of a bar on a graph that is higher or lower than the indicated mean. This often generates questions and gives an opportunity to discuss the results and even do a little

educating about the SF-36 as well. Having a visual representation of results was helpful when introducing a new concept to staff and can help bridge the gap of understanding between the softer concepts surrounding quality of life that a social worker may be comfortable with and a more number-oriented nursing or physician perspective.

The SF-36 algorithm made scoring easy. Without this, the steps required to score the SF-36 are cumbersome and time consuming. Given the case load that most renal social workers have, it is unlikely that they would have time for any extensive use of this tool without some type of automatic scoring. Scoring algorithms and services are available commercially and may be a good option if funds are available and/or facility staff lack the skill to program their own spreadsheet.

One technical limitation to the validity of our method is the lack of any established averages for dialysis patients. Without such a basis for interpreting scores, the decision was made to use the unit averages as the benchmark for deciding if a patient's scores indicated a need for intervention. Lacking established averages based on a larger population, this seemed like the most logical and practical alternative available. The obvious drawback is that averages on our unit may differ significantly from what would be found in a larger sample. If this type of information becomes available, it would no doubt be a more valid way to determine the need for intervention.

One final suggestion is that all staff should be educated in the purpose and value of the SF-36 before it is implemented. We failed to properly do this and this seemed to add to the confusion of nursing staff, technicians, and doctors. Without this initial understanding, the staff at first viewed the SF-36 as the social workers' toy and felt it had no practical use for most of them. As the use of the instrument continued and staff became more familiar with it and understood what it could tell them, their interest increased. As the staff began to be more interested, they came to see how it could relate to their work. It has been noted in this paper that while using the SF-36 has had a positive impact on patients, we have not quantified this impact. It is my hope that others will be able to see a similar impact and possibly measure it. This would help clarify the degree to which use of the SF-36 is really worth the investment of time and money those units and staff must make to implement its use. This use of the SF-36 has also been somewhat

experimental and the technique was developed as time went along. More thoughtful, systematic use, with proper development and staff education should make its use even more effective and valuable.

In summary, the SF-36 seems to be a useful tool for augmenting more customary clinical measures used to measure and evaluate the effectiveness of treatments and the overall health status of the patient, especially in a more global fashion than is customary. When properly implemented, this tool seems to increase the understanding of staff as to the effectiveness of clinical interventions and how they extend to and impact the patient's private life. Thus it may help to generate treatment strategies that are more effective and have a broader impact on the patient's well being.

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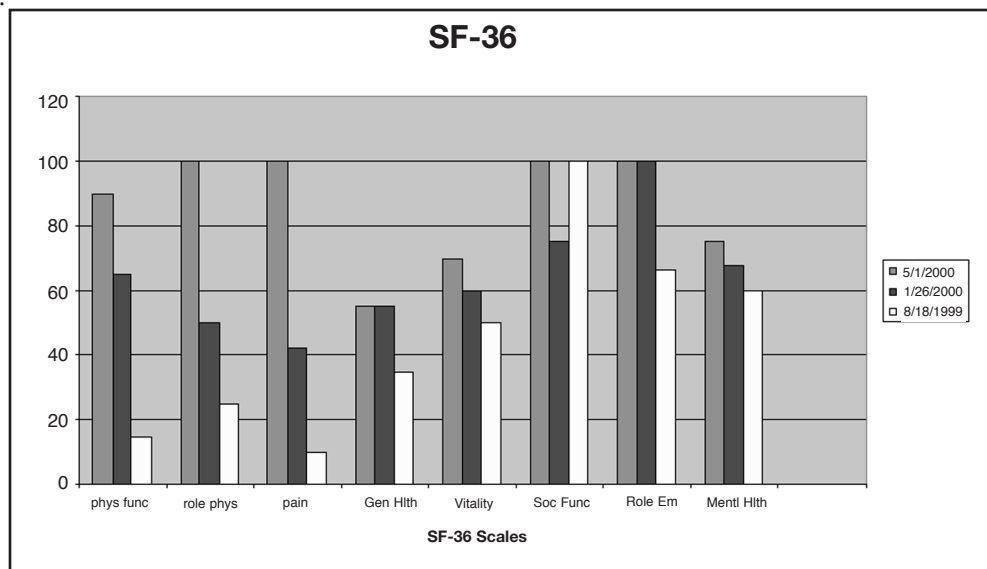

Figure 1. Sample graph showing results from three survey administrations for comparison.