# Coping with Pain: The Dialysis Patient's Perspective

Steven A. Iacono, LMSW, FMC Midtown Dialysis, Columbia, South Carolina

The presence of pain among the hemodialysis population and the use of analgesic medication for pain control was investigated. A simple survey was conducted with respondents from a random sample of persons treated with incenter hemodialysis in the state of South Carolina to determine patterns of analgesic use and general satisfaction with pain control. The survey results were descriptive in nature. The majority of respondents reported using analgesic medications and most believed that their physician did enough to control their pain. Possible abuse of these medications was noted and further investigation was recommended. The primary roles of the dialysis social worker in pain management were examined.

## **Background**

Pain is a frequently noted symptom among hemodialysis patients (Merkus et al., 1997; Mittal, Ahern, Flaster, Maesaka, & Fishbane, 2001) though it is not a common focus of research regarding this population. The potential sources for pain are numerous and varied, including such things as diabetic neuropathy, vascular access surgery, and degenerative joint disease associated with age. These sources also range from being chronic to acute conditions. It is known that the presence of chronic pain greatly impacts upon quality of life and can play a major role in the co-morbidity of anxiety and depression (Gureje, Korff, Simon, & Gater, 1998).

As pain assessment techniques and regulations have expanded there has also been a large amount of media coverage regarding the risks of prescribing certain potentially addictive medications (Kleiner, 2001; Spake, 2001). Research regarding the increased medical use of opiate analgesics suggests that though these medications are being widely prescribed, their rate of abuse is relatively stable and small compared to the abuse of illicit substances (Joranson, Ryan, Gilson, & Dahl, 2000). However, it is estimated that 1.6 million Americans used prescription pain medication for nonmedical purposes for the first time in 1998 and this number increased 181% between 1990 and 1998 (Substance Abuse and Mental Health Services Administration (SAMHSA), 2000). In comparison, the rate of first time marijuana use was up by 63% and cocaine by 37% (SAMHSA, 2000).

Patient factors regarding the willingness to talk about pain, concern regarding addiction to medication, and the belief that pain is inevitable have been noted in research pertaining to those being treated for cancer (Ward, Hughes, Donovan, & Serlin, 2000; Paice, Toy, & Shott, 1998). Similar patient factors might be present in other chronically ill populations, including those on dialysis. Awareness regarding the evaluation and treat-

ment of pain has received a large amount of attention over the last few years, especially among physicians. State medical boards have enacted regulations that delineate the proper use of analgesic medication and other treatments. As of March 1, 2000, there were only 12 states that had no physician guidelines or legislation regarding pain management (Federation of State Medical Boards of the United States, 2000).

The purpose of this descriptive study was to examine the presence and level of pain among in-center hemodialysis patients. It also focused on their use of medication for pain control. The questions asked of the participants sought to obtain information regarding how they perceive their pain and its management. This paper should be viewed as a general initial investigation which can lead to further research.

#### **Methods and Results**

A short survey form was developed that asked 13 questions, of which three requested demographic data and one was a five-point scale regarding the intensity of pain. A letter explaining the purpose of the survey was attached. Patients were informed that their participation was voluntary and confidential. Ten copies were mailed to a randomly chosen group of 20 dialysis center social workers in South Carolina. It was requested of these social workers that they provide the survey form to 10 randomly chosen in-center hemodialysis patients. The completed surveys were then returned to the author. Surveys were returned sealed so as to maintain the confidentiality of the responses.

The respondents were mostly female (66%) and African-American (82%). Fifty completed surveys were returned for a response rate of 25%. When asked if they used prescription medication to control their pain, two-thirds (66%) responded yes. The affirmative response to this question by gender was 73% for females and 53%

for males. However, it was noted that the male group was noticeably younger with an average age of 50.5 years as compared to the female average of 62.2 years. It is possible that age-related ailments led to the higher pain responses in the female surveys.

When asked if they believed that their physician did enough to control their pain, 93% responded yes. All of the negative responses received were from males. A further 94% stated that they informed their physician when they are in pain. The average level of pain, rated on a five-point scale with one being very mild and five being extreme, was 3.25, which was moderate pain. The response average by gender was 3.37 (SD = 1.10) for females and 2.75 (SD = .81) for males.

Thirty-six percent of the respondents reported that they had taken more pain medication than their physician had instructed them to use. Two further questions investigated the possible abuse of these medications. When asked if their family or friends had ever told them that they use too much pain control medication, 15% stated yes and 33% reported that they had used their medication for other purposes such as to aid in sleeping.

#### **Discussion**

A large portion of the sample population noted that they use prescription medication for pain control. The average level of pain was in the moderate range. The results of this survey noted a high rate (36%) of respondents who had ever taken more pain medication than their physician had told them to use. This could be viewed at both ends of the spectrum: they are possibly misusing these medications and/or they are being under treated. As for the latter possibility of under treatment, this would somewhat contradict the generally high positive rating regarding whether they believe that their physician does enough to control their pain. The attained data regarding use of these medications for other purposes, and the concerns of friends and family pertaining to their use within this population seem to point to a need for further research regarding substance abuse and patient education. Further research will hopefully lead to a better understanding of pain as an individual experience that might be influenced by intrinsic variables such as age, gender, and race as well as external variables such as staff attitudes toward identifying and treating it.

## **Implications for Social Work**

Pain management through a multidisciplinary approach, which includes social work, can benefit those on dialy-

sis. Since pain is often viewed solely in a medical model there is a potential risk in believing that social work has a minimal role in its treatment. Sieppert (1996) found that a large number of medical social workers believe that the treatment of pain should not be the sole domain of physicians and pharmacists. The Sieppert (1996) study also noted that 90% of medical social workers were interested in further training regarding pain management.

There are four primary roles in which the social work profession can be instrumental regarding the treatment of pain, and these include being advocates, educators, clinicians, and researchers.

As advocates, we can be intermediaries between patients and physicians. Patients often have more contact with the other professionals in a dialysis center than with physicians and frequently relay their concerns and problems to social workers, nurses, patient care technicians, and dietitians. We can aid them in making their needs known and by advocating that staff not disregard or minimize reports of pain. MacDonald (2000) noted that as advocates dealing with a chronic pain population we can also challenge gender stereotypes. Sieppert (1996) found that medical social workers believe patient advocacy is important in the medical system. Within the role as advocates we can promote systems change through creation of regulations and guidelines that are directed at evaluating and treating pain on a clinic level. Through lobbying we can also influence legislation that might be of benefit to this process.

In the role as educators we can inform patients about other treatment modalities for pain control such as physical therapy, relaxation techniques, and counseling. These non-pharmaceutical methods are of potential benefit to patients who are unable or unwilling to add further medications to their daily regimen. There is evidence that physical therapy is useful in the dialysis population for pain control and management of other symptoms (Pianta, 1999). Education has been noted to be important in removing patient-centered barriers within populations coping with other types of chronic illness (Ward, Hughes, Donovan, & Serlin, 2000). Helping to alleviate a patient's, and his or her family's, concern about addiction or educating them about chronic pain support groups and organizations are matters that can be readily addressed by social workers within the dialysis setting. Social workers can also be vital in educating dialysis clinic staff about the various aspects of pain. This can include topics such as the treatment of chronic versus acute pain, common ailments within the dialysis population, the role of pain in depression, the addictive nature of certain analgesics, and how they can participate in the identification and treatment of pain.

Through the direct clinical role social workers can be essential in the identification and assessment of pain. Many psychometric tools for depression and general functioning contain a pain component. Through these assessments we are able to be an integral part of the treatment process. As social workers we can make pain an issue for treatment within the individualized care plan. This also allows for a more holistic view of the patient as an individual and not merely as a collection of symptoms. By identifying the social, financial, educational, and psychological resources or deficits of each patient we can improve their quality of life. For instance, the cost of analgesic medication might be too high for someone, and so another form of treatment could be recommended. Our ability to provide direct counseling is also of great potential benefit to those in pain within the dialysis population. Social workers are also frequently involved with linking patients to medical equipment and referrals to other services which might be of use outside of the dialysis clinic.

As researchers, we can further investigate better ways to address pain and its management. This not only benefits patients, but also expands the knowledge base of our profession. Research has a secondary impact in that it reinforces the multidisciplinary approach to treatment. The potential variables for further investigation of pain within the dialysis population are broad and can focus on gender differences, hemodialysis patient experiences versus those on peritoneal dialysis, misconceptions among staff and patients, the use of non-pharmaceutical therapies, and many other aspects of the issue.

## **Conclusions**

Pain is a common focus of treatment within the dialysis population and patients are frequently prescribed medication to control it. The findings of the research presented here denote that the majority of patients are pleased with their physician's management of their pain. The average level of pain was found to be in the moderate range. Age and gender differences were noted. Some concern was raised regarding the potential abuse of these substances and further investigation was recommended. The roles of the social worker in a multidisciplinary approach to pain treatment were noted.

## References

Federation of State Medical Boards of the United States. (2000). Position of the Federation of State

- Medical Boards in support of adoption of pain management guidelines. Euless, T.X.: Author.
- Gureje, O., Korff, M., Simon, G., & Gater, R. (1998). Persistent pain and well-being: A World Health Organization study in primary care. *Journal of the American Medical Association*, 280, 147-151.
- Joranson, D., Ryan, K., Gilson, A., & Dahl, J. (2000). Trends in medical use and abuse of opioid analgesics. *Journal of the American Medical Association*, 283, 1710-1714.
- Kleiner, C. (2001, August). A curse and a cure: Is the crackdown on an abused drug causing needless suffering? *U.S. News & World Report*, pp. 42-43.
- MacDonald, J. (2000). A deconstructive turn in chronic pain treatment: A redefined role for social work. *Health & Social Work*, 25(1), 51-58.
- Merkus, M., Jager, K., Dekker, F., Boeschoten, E., Stevens, P., & Krediet, R. (1997). Quality of life in patients on chronic dialysis: Self-assessment 3 months after the start of treatment. *American Journal of Kidney Disease*, 29, 584-592.
- Mittal, S., Ahern, L., Flaster, E., Maeska, J., & Fishbane, S. (2001). Self-assessed physical and mental function of haemodialysis patients. *Nephrology Dialysis & Transplantation*, 16, 1387-1394.
- Paice, J., Toy, C., & Shott, S. (1998). Barriers to cancer pain relief: Fear of tolerance and addiction. *Journal of Pain and Symptom Management*, 16, 1-9.
- Pianta, T. (1999). The role of physical therapy in improving physical functioning in renal patients. *Advances in Renal Replacement Therapy*, 6(2), 149-158.
- Sieppert, J. (1996). Attitudes toward and knowledge of chronic pain: A survey of medical social workers. *Health & Social Work*, 21(2), 122-130.
- Spake, A. (2001, July). Not an appropriate use: Did the makers of OxyContin push too hard? *U.S. News & World Report*, pp. 26.
- Substance Abuse and Mental Health Services Administration (SAMHSA). (2000). Summary of findings from the 1999 national household survey on drug abuse. Rockville, Maryland.
- Ward, S., Hughes, S., Donovan, H., & Serlin, R. (2000, March). *Patient education in pain control*. Paper presented at the Multinational Association of Supportive Care in Cancer (MASCC) Symposium, Washington, D.C.