

# The Usefulness of a Daily Pain Management Diary for Outpatients With Cancer-Related Pain

Karen L. Schumacher, RN, PhD, Setsuko Koresawa, RN, MS, Claudia West, RN, MS, Marylin Dodd, RN, PhD, FAAN, Steven M. Paul, PhD, Debu Tripathy, MD, Peter Koo, PharmD, and Christine Miaskowski, RN, PhD, FAAN

**Purpose/Objectives:** To describe the usefulness of daily pain management diaries to outpatients with cancer who participated in a randomized clinical trial of the PRO-SELF<sup>®</sup> Pain Control Program.

**Design:** Randomized clinical trial in which a daily pain management diary was used for data collection in the control group and for data collection and nurse coaching regarding the pain management program in the intervention group.

**Setting:** Seven outpatient oncology settings.

**Sample:** 155 patients with pain from bone metastases and 90 family caregivers.

**Methods:** Content and statistical analysis of audiotaped answers to a semistructured questionnaire.

**Main Research Variables:** Patients' and family caregivers' perceptions of the usefulness of a daily pain management diary; specific ways in which the diary was used.

**Findings:** Patients in both the intervention (75%) and control groups (73%) found the diary useful. The diary was used to heighten awareness of pain, guide pain management behavior, enhance a sense of control, and facilitate communication. Family caregivers in both groups also reported that the diary was useful.

**Conclusions:** The completion of a daily pain management diary is useful to patients and family caregivers and may function as an intervention for self-care.

**Implications for Nursing:** Research-based evidence supports the importance of using a daily pain management diary in clinical practice.

The patient diary is a well-established tool in symptom management research. The subjective and changeable nature of symptoms makes frequent ratings desirable in a wide variety of studies, ranging from descriptions of symptom frequency and severity to randomized clinical trials of intervention protocols. Frequent ratings in a diary minimize recall bias, depict the dynamics of the symptom experience, and produce a dense stream of data for the analysis of symptoms over time (Burman, 1995; Richardson, 1994; Ross, Rideout, & Carson, 1994). Diaries also are useful in clinical practice, particularly in outpatient and homecare settings where direct contact with patients usually is intermittent and nurses must have a valid and reliable way of assessing symptoms between direct patient contacts (Burman; Grant & Rivera, 1995; McCaffery, 1999). In oncology practice, diaries are a central component of pain management (Jacox, Carr,

## Key Points . . .

- ▶ Research evidence suggests that daily recording of pain intensity and analgesic intake is a promising component of an educational intervention to improve cancer pain management.
- ▶ Patients and family caregivers found a daily pain management diary useful in self-care for cancer pain.
- ▶ Patients discovered a variety of uses for the daily pain management diary, but additional education and coaching by healthcare professionals are needed to reap the diary's full potential to improve cancer pain management.

Payne, et al., 1994; McCaffery; McGuire, Yarbrow, & Ferrell, 1995; Steering Committee on Clinical Practice Guidelines for the Care and Treatment of Breast Cancer, 1998). Diaries are advocated for pain assessment, identification of pain patterns, and evaluation of interventions, as well as facilitation of communication between patients and healthcare providers (McGuire, 1995; Spross & Burke, 1995).

Despite their usefulness to researchers and clinicians, little is known about whether patients find symptom diaries useful in their own self-care symptom management. The purpose of this study was to describe the usefulness of a daily pain management diary to outpatients with cancer who participated in a randomized clinical trial of a self-care nursing intervention called the PRO-SELF<sup>®</sup> Pain Control Program, developed by

*Karen L. Schumacher, RN, PhD, is an assistant professor in the School of Nursing at the University of Pennsylvania in Philadelphia; Setsuko Koresawa, RN, MS, is a doctoral student in the School of Nursing, Claudia West, RN, MS, is a clinical professor in the School of Nursing, Marylin Dodd, RN, PhD, FAAN, is a professor in the School of Nursing, Steven M. Paul, PhD, is a senior statistician in the School of Nursing, Debu Tripathy, MD, is an associate clinical professor in the School of Medicine, Peter Koo, PharmD, is a pharmacy specialist in the School of Pharmacy, and Christine Miaskowski, RN, PhD, FAAN, is a professor in the School of Nursing, all at the University of California, San Francisco. This study was supported by a grant (CA 64734) from the National Cancer Institute. Additional support for Miaskowski's program of research was provided through unrestricted grants from Janssen Pharmaceutica and Purdue Pharma L.P. (Submitted September 2001. Accepted for publication January 31, 2002.)*

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faculty at the University of California, San Francisco (Miaskowski et al., 2001; West et al., in press). Data from the diaries were used to evaluate the effectiveness of the intervention and as a source of clinical information in the intervention group. At the conclusion of the study, patients in both groups were asked whether they found the diary useful. Their responses constitute the data for this analysis. Four research questions were addressed: (a) Did patients and family caregivers find the daily pain management diary useful? (b) Did a difference exist in perceived usefulness of the diary between the intervention and control groups? (c) In what ways did patients and family caregivers find the diary useful? and (d) Why was the diary not helpful for some patients and family caregivers?

## Literature Review

In 1980, Verbrugge reviewed studies that had used health diaries for data collection and concluded that a diary was a promising, although underused, tool for research. She found only 19 studies that had used diaries, and these primarily were population-based household surveys to document health, illness, disability, and medical care. Since Verbrugge's review, the use of diaries in health and social science research has increased dramatically. Diaries now are used extensively in symptom management research in a wide variety of clinical conditions, including pre- and perimenstrual syndromes (Blake, Salkovskis, Gath, Day, & Garrod, 1998; Sveinsdóttir, 1998), benign prostatic hyperplasia (Fawzy, Vashi, Chung, Dias, & Gaffney, 1999), asthma (Ayers, Campbell, & Follows, 1996; Janson-Bjerklie & Shnell, 1988), headache (Porter, Leviton, Slack, & Graham, 1981), and diabetes (Clarke et al., 1995), as well as in nonmalignant and cancer-related pain (de Wit et al., 1997, 1999; Lefebvre et al., 1999; Stewart, Lipton, Simon, Liberman, & Von Korff, 1999) and quality of life (Oleske, Heinze, & Otte, 1990). Several reviews supported Verbrugge's conclusions, noting that diaries are useful especially for frequent recordings of day-to-day problems and dynamic experiences (Burman, 1995), thus yielding dense longitudinal data that lend themselves to analytic strategies like time series analysis (Richardson, 1994).

Researchers use diaries primarily for data collection. Diaries have been used to document the incidence and severity of symptoms (Nail, Jones, Greene, Schipper, & Jensen, 1991), delineate patterns of symptoms (Geddes et al., 1990; Mitchell, Woods, & Lentz, 1994; Richardson, Ream, & Wilson-Barnett, 1998; Schwartz, 2000; Woods, 1985), and assess the efficacy of various drug therapies (Milanowski, Qualtrough, & Perrin, 1999; Nathan, Minkwitz, & Bonuccelli, 1999; Silvers et al., 1998).

In addition to symptoms themselves, diaries may include symptom management behaviors. For example, in self-care studies, diaries were used to document patient decisions, help-seeking, and self-care behavior (Avery, March, & Brook, 1980; Dodd, 1984, 1988; Freer, 1980; Hickey, Akiyama, & Rakowski, 1991; Musci & Dodd, 1990; Oleske et al., 1990; Stoller & Forster, 1992; Woods, 1985). Other variables that may be recorded in diaries include activity, medication use, biologic measures, disease-related costs, medical events, and the behavioral consequences of symptoms (Follick, Ahern, & Laser-Wolston, 1984; Moscato et al., 1999).

Diary formats may be more or less structured. Structured formats (e.g., logs, ledgers, diary cards) simply require respondents to rate their symptoms on a scale, such as a visual analogue scale, an ordinal scale with verbal descriptors, or an interval scale with descriptive anchor points (Jensen, Karoly, & Braver, 1986). These data readily lend themselves to quantification. At the other end of the continuum, unstructured formats provide an opportunity for personal exploration through narrative text in the format of a personal journal. Between these extremes are symptom logs with space for notes that serve to contextualize the quantified symptom data. The formats most often used in symptom management research are structured diary cards and semistructured pages consisting of structured scales and space for note-taking (Jensen et al.). Electronic diaries also are available (Honkoop, Sorbi, Godaert, & Spierings, 1999; Lewis, Lewis, & Cumming, 1995). The frequency with which symptoms are recorded varies, typically ranging from hourly to once or twice daily. Occasionally, recording occurs whenever a symptom is experienced, rather than on a prescribed, regular basis.

Symptom diaries have been evaluated extensively for their reliability, validity, feasibility, and sensitivity to change (Geddes et al., 1990; Maunsell, Allard, Dorval, & Labbé, 2000; Oleske et al., 1990; Thys-Jacobs, Alvir, & Fratarcangelo, 1995). The reactive effects of frequent pain assessment also have been evaluated (Cruise, Broderick, Porter, Kaell, & Stone, 1996). Other evaluations have examined the completeness and quality of diary data. In their evaluation of the pain diary used in a randomized clinical trial in which the diary was one component of the intervention, de Wit et al. (1999) found that 85.9% of the diaries were returned at the conclusion of the two-month period of data collection. Patients who returned a diary were in less advanced stages of their disease, prescribed analgesics less frequently, and prescribed weaker analgesics. Of the pain diaries returned, 52% had been filled in completely and 25% were 80%–99% complete. Five of the nine patients who died continued to record in their diaries until zero to five days before death. The researchers concluded that even for seriously ill patients, adherence with diary completion is high.

Patient diaries were used in several studies that tested interventions to improve cancer pain management (de Wit et al., 1997; Du Pen et al., 1999; Ferrell, Ferrell, Ahn, & Tran, 1994). However, although researchers have evaluated the psychometric properties of diaries as data collection instruments, little evaluation has been directed at whether study participants find them useful for their own symptom management. In an early study in which the perceived benefit of a headache diary to patients was evaluated, Porter et al. (1981) found that 38% of the participants reported that the use of the diary was helpful and only 8% thought it was a hindrance.

The only cancer pain study that the current study's researchers are aware of that evaluated the usefulness of a diary to patients was conducted by de Wit et al. (1997, 1999). Patients were asked whether a pain diary had helped them gain insight into their pain. Sixty percent reported that the diary had helped them to do so in part or fully, whereas 37% reported that the diary was of no benefit. No differences in benefit were found for gender, age, education, extent of disease, pain treatment, or pain intensity. However, patients who received district nursing (i.e., home care for the more functionally impaired patients) had a tendency to report less benefit from the diary. In addition to pain scores, patients wrote notes

in their diaries on a variety of topics, including pain treatment, pain location, the illness, and cancer treatment.

In summary, a patient diary is a sound data collection tool and is used extensively in symptom management research. However, the usefulness of diaries from patients' perspectives has received little attention. No studies have explored how patients use their pain diaries, and the usefulness of the diaries to family caregivers is unknown. Therefore, the purpose of this study was to describe patients' and family caregivers' perceptions of the usefulness of a daily pain management diary and the specific ways in which they used their diaries.

## Methods

### Study Design and Settings

Data were collected as part of a large, randomized, clinical trial that tested the effectiveness of the PRO-SELF Pain Control Program compared to standard care in outpatients with cancer who were experiencing pain from bone metastases (Miaskowski et al., 2001; West et al., in press). In brief, the PRO-SELF intervention was delivered over six weeks and included home visits at weeks one, three, and six with follow-up telephone calls during weeks two, four, and five. During the home visits, patients in the intervention group received detailed education about the principles of cancer pain management and individualized coaching about how to manage their own pain. The control group received standard care, including the consumer version of *Management of Cancer Pain: Clinical Practice Guideline* published by the Agency for Health Care Policy and Research (Jacox et al., 1994), as well as home visits and telephone calls with the same frequency as the intervention group.

Patients were recruited from seven outpatient settings in Northern California: one university-based cancer center, two community-based oncology practices, one outpatient radiation therapy center, one health-maintenance organization, one Veterans' Administration facility, and one military hospital. This study was approved by the human subjects committees at the University of California, San Francisco, and at each of the study sites.

At the time of enrollment, patients were stratified according to whether they were participating alone or with a family caregiver and were randomized into the PRO-SELF or standard-care groups. Family caregivers were included in the teaching and coaching sessions because studies have found that family caregivers have different perceptions of patients' pain and can have negative attitudes and lack of knowledge about pain management (Ferrell, Ferrell, Rhiner, & Grant, 1991; Yeager, Miaskowski, Dibble, & Wallhagen, 1995). At the completion of the last home visit, patients and family caregivers in both groups were asked if they had found the pain management diary useful. Responses to this query constitute the data for the present analysis.

### Sample

Participants who were eligible for this study were adult outpatients with cancer and their primary family caregivers. All were older than 18 and able to read, write, and understand English. At the time of enrollment, patients had radiographic evidence of bone metastases, at least an average pain intensity score of 2.5 or greater, and a self-reported Karnofsky Performance Status (KPS) score of 50 or greater (Karnofsky, 1977).

## Instruments

Patients in both the intervention and control groups completed a one-page **pain management diary** once daily at bedtime (see Figure 1). The diary pages were contained in booklets for each week of study participation. The diary asked patients to rate their average, least, and worst amount of pain during the day using a 0–10 numeric rating scale, where 0 indicated no pain and 10 indicated the worst pain imaginable. A daily pain medication diary was located at the bottom of each page of the diary. Patients recorded both routine (i.e., around the clock) and extra (i.e., as needed) analgesic medications and the times they were taken. All of the measures in the pain management diary were valid, reliable, and used in previous studies (Burrows, Dibble, & Miaskowski, 1998; Glover, Dibble, Dodd, & Miaskowski, 1995; Miaskowski & Dibble, 1995; Miaskowski, Zimmer, Barrett, Dibble, & Wallhagen, 1997).

At the last visit, during week six, study nurses conducted the structured **end-of-study interview**. Two end-of-study questions evaluated the usefulness of the pain management diary (i.e., "Tell me about the helpfulness or unhelpfulness of the pain diary," and "Do you have any suggestions about modifying the diary?") Responses were tape-recorded and transcribed verbatim.

### Data Analysis

Content analysis was used for data analysis (Polit & Hungler, 1978). Two members of the research team coded all data independently and then met to compare results and resolve

Date: \_\_\_\_/\_\_\_\_/\_\_\_\_

Please fill out this page before going to bed, keeping in mind how your pain was during the day.

0	1	2	3	4	5	6	7	8	9	10
no pain		mild			moderate			severe		worst pain imaginable

1. Using the scale above, choose a number that best describes

- The average amount of pain you experienced today.
- The least amount of pain you experienced today.
- The worst amount of pain you experienced today.

2. How many hours did you have pain today? \_\_\_\_\_  
(0–24 hours)

*Directions: At the end of each day, please indicate the times you took your routinely scheduled pain medicine and any extra pain medicine you needed.*

	Medicine	Time
Routine		
Extra		

**Figure 1. The PRO-SELF® Pain Management Diary**

*Note.* From *PRO-SELF Pain Management Diary*, by C. Miaskowski, 1995. Copyright 1995 by C. Miaskowski. Reprinted with permission.

differences through consensus. Responses were sorted into clearly positive, clearly negative, or other categories. When patients and family caregivers elaborated on their positive or negative responses, researchers did line-by-line coding and categorization of their narratives to better understand how patients and family caregivers found the diary useful or not useful. Categories and subcategories were allowed to emerge from the data rather than from an investigator-generated, a priori coding scheme. Ethnograph v5.0™ (Qualis Research, Salt Lake City, UT) software was used for data coding and categorization, and CRUNCH4® (Crunch Software Corp., Oakland, CA) was used for statistical analysis. Differences in responses between groups were evaluated using t tests or chi square analyses. Differences were considered significant at the  $p < 0.05$  level.

## Results

### Sample Characteristics

The sample for the diary analysis consisted of 155 patients and 90 family caregivers who answered the end-of-study questions. Eighty-five (55%) of the patients were in the intervention group. Ninety patients (58%) were participating as dyads with their primary family caregivers, and 65 (42%) were participating as individuals.

Patients were predominantly female (71%) and Caucasian (84%) with a mean age of 59.4 years (SD = 11.9) and an average of 14.8 years of education (SD = 3.1) (see Table 1). Fifty-four percent had breast cancer and another 14% had lung cancer. All of the patients had pain from bone metastases. At the time of enrollment, 46% were receiving chemotherapy, 32% were receiving hormonal therapy, and 16% were receiving radiation therapy. The mean KPS was 70.2 (SD = 12) (see Table 2). The family caregivers were predominantly female (52%) and Caucasian (82%) with a mean age of 54.9 years (SD = 13.7). They were related to the patients as spouses, partners or significant others (69%), friends (10%), adult children (8%), parents (4%), siblings (2%), or other (7%). Seventy-eight (87%) lived with their patients.

**Table 1. Demographic Characteristics of the Sample**

Characteristic	Patients (n = 155)		Family Caregivers (n = 90)	
<b>Age (years)</b>	$\bar{x}$ (SD)		$\bar{x}$ (SD)	
	59.4	(11.9)	54.9	(13.7)
<b>Education (years)</b>	$\bar{x}$ (SD)		$\bar{x}$ (SD)	
	14.8	(3.1)	14.6	(2.6)
Characteristic	n	%	n	%
<b>Gender</b>				
Female	110	71	47	52
Male	45	29	43	48
<b>Ethnicity<sup>a</sup></b>				
Caucasian	130	84	74	82
African American	9	6	6	7
Hispanic	5	3	1	1
Asian	6	4	6	7
Mixed background	3	2	1	1
Other	1	1	2	2

<sup>a</sup> One patient did not provide data on ethnicity.

**Table 2. Disease Characteristics**

Characteristic	n	%
<b>Karnofsky Performance Status score</b>	$\bar{x}$ = 70.2, SD = 12	
<b>Type of tumor<sup>a</sup></b>		
Breast	83	54
Lung	21	14
Prostate	18	12
Other	36	23
<b>Metastases in addition to bone</b>		
Lymph	49	32
Lung	23	15
Liver	18	12
Brain	8	5
Other	19	12
<b>Current treatment<sup>b</sup></b>		
Chemotherapy	71	46
Hormonal	50	32
Radiation	25	16
None	21	14

N = 155

<sup>a</sup> Three patients had more than one type of cancer.

<sup>b</sup> Patients could be receiving more than one type of treatment.

### Usefulness of Pain Management Diaries

One hundred fifteen (74%) patients clearly said that they found the diary useful, and 16 (10%) gave clearly negative responses (see Table 3). Nine others (6%) found no current benefit from the diary, although they could see how it might be useful in the future. Most of the patients in this group were experiencing low levels of pain intensity, which suggests that patients with higher levels of pain may be more motivated to use a pain management diary. Fifteen (10%) of the patients gave no response or an ambiguous response to the question about the diary's usefulness (e.g., "Well, yes and no"). Further analyses were conducted using only responses that were clearly categorized as yes or no (n = 131).

Although family caregivers (n = 90) did not complete a pain management diary themselves, 28 (31%) stated that they found the diary useful and three (3%) stated it was not helpful. Only 42 (48%) of the family caregivers participated in any additional discussion about the usefulness of the pain diary. Two (2%) said that although they did not find it useful at the present time, they could see how it might be useful in the future. Nine (10%) of the caregivers gave unclear responses.

No significant difference was found between the proportion of patients in the PRO-SELF and the control groups who found the diary useful (see Table 4). Of the patients who gave

**Table 3. Usefulness of a Pain Diary as Perceived by Patients and Family Caregivers**

Response	Patients (n = 155)		Caregivers (n = 90)	
	n	%	n	%
Useful	115	74	28	31
Not useful	16	10	3	3
No need now	9	6	2	2
Unclear/no response	15	10	57	63

Note. Because of rounding, not all percentages total 100.

**Table 4. Usefulness of a Pain Diary in the Intervention (PRO-SELF®) and Control Groups**

Response	PRO-SELF Group (n = 70)		Control Group (n = 61)	
	n	%	n	%
Useful	64	91	51	84
Not useful	6	9	10	16

clear “yes” or “no” responses, 64 (91%) in the PRO-SELF group and 51 (84%) in the control group found the diary useful. Of the family caregivers who responded to the question, 15 (63%) in the PRO-SELF group and 13 (72%) in the control group found the diary useful. Because no difference was found in the perceptions of the usefulness of the diary between the intervention and control groups, data were combined for subsequent analyses. Usefulness of the diary was analyzed by gender, age, and years of education, with no significant differences found between those who felt that the diary was useful and those who did not.

Four major categories (see Table 5) emerged from the content analysis of patients’ and family caregivers’ comments about how they found the pain management diary useful: (a) it heightened awareness of the pain experience, (b) it provided a guide to self-care behaviors, (c) it facilitated communication, and (d) it enhanced their sense of control. Illustrative data of these four categories are provided in Figures 2–5. Very few patients and caregivers found the diary to be burdensome.

**Heightened awareness** (see Figure 2) was defined as an increased consciousness of pain or a heightened focus on the pain experience as a result of diary use. Some patients experienced heightened awareness in a general sense, exemplified by the patient who said, “It made me more aware. It helped me better judge my pain. Basically it made me more aware.” Some reported that they “learned a lot out of it” or it was an “eye opener.” Others found it useful to have a visual representation of their pain experiences, using metaphors like “map” or saying that a “graphic image” helped.

Others reported a more analytical awareness of their pain, describing various ways that they used the information contained in the diary to assess specific aspects of their pain experience. Such assessments included evaluating the severity of their pain, keeping track of their pain over time, evaluating the effect of their analgesic(s), and identifying patterns of pain in relation to time of day, activity, and treatment regimen.

Heightened awareness was the most frequently described benefit of using the diary. Fifty-nine percent of the patients and 17% of the family caregivers described heightened awareness as a useful aspect of the diary. No significant differences were found between the PRO-SELF and control groups for either patients or family caregivers in the number of participants who reported heightened awareness. However, more female patients (66%) than male patients (44%) reported greater awareness of their pain as a result of using the diary ( $p = 0.02$ ). Heightened awareness of pain was a negative consequence of using the diary for only four (3%) patients, who said they did not want to think about their pain. All four were in the control group.

The category **guide to pain management** (see Figure 3) refers to the use of the diary as a guide for self-care behaviors. The defining characteristic of this category was that patients

related their use of the diary to action or behavior. Many patients found that recording their medication use in the diary helped them with pain management. Some described how the diary helped them to develop a more structured, disciplined, or organized approach to pain management, whereas others modified their activities or medication regimens as a result of their use of the diary. Thirty-seven (24%) patients and three (3%) family caregivers said that the diary guided their self-care actions. No differences were found between the PRO-SELF and control groups in the number of participants who reported on the use of the diary as a guide to pain management.

**Communication** (see Figure 4) was defined as the use of the diary as a tool to facilitate communication, either with healthcare providers or between patients and their family caregivers. Only two (1%) of the patients mentioned using the diary to facilitate communication, whereas seven (8%) of the family caregivers found communication to be a benefit of using the diary. No difference was found between groups.

**Sense of control** (see Figure 5) refers to a heightened sense of involvement, mastery of pain management, or a perception of “taking charge.” Sense of control took a variety of forms, including feeling more independent and more like a full partner in pain management. Six (4%) patients and two (2%) family caregivers mentioned a greater sense of control in response to the question about how they had found the diary helpful.

Although patients used the daily pain management diary in a variety of ways, they tended not to use the diary to its full potential. Seventy-four (48%) patients mentioned only one of the major coding categories. Twenty-seven (17%) used it for two categories, and only three (2%) used it for three categories. No patients used it for all four purposes. No between-group differences were found. Patients who gave negative responses to the study question found the diary burdensome ( $n = 9$ ; 6%) or did not want to think about pain ( $n = 4$ ; 3%).

## Discussion

In this randomized clinical trial of the PRO-SELF Pain Control Program, the majority of patients in both the intervention and control groups found the daily pain management diary useful for their own self-care purposes. Although diaries have been used in many self-care studies, diary data typically are used to answer research questions rather than as an integral part of patients’ own self-care activities. With the exception of the study by de Wit et al. (1999), no pain study has used diaries as a component of an intervention to improve

**Table 5. Frequency Distribution of the Use of Various Coding Categories<sup>a</sup>**

Category	Patients (n = 155)				Caregivers (n = 90)			
	PRO-SELF®		Control		PRO-SELF®		Control	
	n	%	n	%	n	%	n	%
Awareness	47	55	45	64	8	15	8	19
Guide	18	21	19	27	1	2	2	5
Communication	1	1	1	1	4	9	3	7
Control	4	5	2	3	2	4	-	-
Burden	4	5	5	7	-	-	1	2

<sup>a</sup> Patients could have expressed more than one use for the diary.

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## General Awareness

### PRO-SELF® Group

"I think it was helpful. Otherwise I would never have paid any attention to it."

"For me, where it was helpful was because I'm denying. You know, being superwoman. If you asked me how I was, I said, 'Fine.' So, to be able to look back and realize no, that wasn't quite the case. For me that was helpful."

### Control Group

"Yeah, it brought to light information that I wasn't aware of, or didn't think about, I guess, and I thought that was helpful."

"It helped me to focus on myself. I kind of like to just mentally sort of not—deny is not always the right word because there's connotations, but I kind of like to just deny that I have a problem and just forge on ahead and unless it just stops me cold and I have to wait until I feel better, try picking up the same attitude and just putting it aside as long as I can. So the diary did help me just deal with it a little bit more, increase my awareness instead of just deny it, I guess."

"Very helpful, because it gives me a lot of satisfaction to know that I can see the graphic reference, you know, too."

## Specific Assessments

### PRO-SELF Group

"Well, I think it helped me to evaluate this severity of pain."

"It helped me keep track of the days without. Because I'm very bad about keeping notes. But it helped to keep track of the things that were going on from day to day."

"It's helped me think about what pain I'm having and what levels and how much, and to look at patterns of activities that create the pain."

"Yes. Extremely (helpful). To define the pattern and to see there really was a pattern, cause before I just thought, well, it seems like I'm in an awful lot of pain. Couldn't pinpoint when or why."

### Control Group

"Well, it made me more aware of when I was having the pain, the extent of the pain. Learning to scale it from 1 to 10 and say well today is not too bad, yesterday was worse. I check my book and yesterday was worse. So it made me realize how I can concentrate and kind of find out where was I yesterday as of today and I never had made any comparison, you know, it was just pain was pain."

"I think it's really helpful because (the patient) and I have sometimes different memories of when the pain occurs in relation to the various types of drugs. Like deciding whether the abdominal pains were due to the morphine or due to the infusion or both. Having it down, you can see if there's any relation to when you take the drug and whatever the side effects are. We (family caregiver) don't have to rely on our memories for that. Sometimes we're kind of tired and we forget (the patient)."

"It's kind of strange, but the medication I'm taking will affect, like, the general pain I have, which is what I was taking it for."

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## Figure 2. Pain Diary and Heightened Awareness of Pain Experience

*Note.* Unless otherwise noted, the person quoted is a patient.

cancer pain management. The current study's data support the findings of de Wit et al. (1999) that patients find diaries useful. Further, the current study reports for the first time specific ways in which patients use their pain management diaries. The study also reports for the first time that family caregivers find the pain diaries useful.

Patients used their pain management diaries in a variety of ways. Most often, the diary helped to heighten awareness of pain or to bring the pain experience clearly into consciousness. Some patients also used the diary for more specific self-assessment of their own pain. They kept track of their pain over time, evaluated pain severity, noticed changes in pain as a result of treatment, identified patterns, and made comparisons. Fewer patients found that the diary served as a useful guide for self-care actions or provided them with a sense of control over their situation. Very few reported using it as a communication tool with either healthcare providers or their family caregivers.

The role of the diary in bringing pain into active awareness is intriguing. It seems that being reminded of a noxious symptom like pain would not be necessary. Rather, pain should impose itself into active awareness. However, many participants described how the diary helped them to focus on their pain instead of "denying" it. Others said that it helped them to "remember" their pain, as if they tended to forget it from time to time. These data are congruent with those of de

Wit et al. (1997), who found that 60% of patients stated that they were more aware of their pain problems as a result of using the pain diary. Thus, drawing consistent attention to the pain experience may be a critical aspect of pain management that is facilitated by the use of a diary.

As a guide to self-care behavior, the diary helped patients perform two of the most basic nursing procedures in medication management (i.e., developing an organized system for keeping track of medications and recording the time at which each dose was given and when the next dose was due). These activities are among the most fundamental skills that student nurses learn. However, the patients in this study seemed to have discovered on their own, as opposed to being taught, that organizing and recording medications is useful. Moreover, some of the patients in the control group discovered through the use of the diary that taking their medications on a consistent basis was helpful. (This principle was taught explicitly to patients in the PRO-SELF group.) What is astonishing about this finding is not that patients found organizing, recording, and consistency useful, but rather that they had not received education and coaching on skills for setting up and keeping track of complex medication regimens prior to the study. Possibly, a consistent, systematic approach to medication management is so fundamental to nursing practice that it seems to be a matter of common sense, rather than a behavior learned in the earliest years of professional education. As a result, little attention is given to the

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**PRO-SELF® Group**

"It kind of helped that you can get some kind of guideline on how much to take. I mean, all I did when it got down there—what I did experience. So it kind of helped, I think, both of us as far as that goes."

"I think it was helpful in that it made me more aware of the necessity of taking my medication on a very regular basis. Up until that point I'd been kind of flaky about it but having—I got myself so that I set up the medication once a week and I put out all my medications, not just my pain medications, but my vitamins and all the other medications that the doctors are giving me, including the ones to manage my nerves. And so, I put all that out and it's there and I just look, oh, it's such and such time, yeah, I need to take this. So it's been quite helpful in that sense."

"Helpful to the extent that it helped me keep track of when I gave him things." (family caregiver)

"I actually enjoyed using the (diary). I referred to it constantly. It helped me so much that now that the study is over, I created my own, following the format. I take so much medication now, so many pills at totally different times that the diary itself really helped me chart it well, I felt. And it also, I could go back, week two, I could go back and look at week one to see, had I changed at all, my pain or whatever. So I like the diary."

**Control Group**

"The discipline for one thing. The discipline for one thing but the (inaudible word) I think is reminding me that to be on a schedule. I'm not a very scheduled person, so I just am not one. This has really broken ground on that because it's actually helped me to appreciate (inaudible) when I did something. Very new for me. So now I'm counting hours. And I'm finding that well, that's good in many ways."

"How was it helpful? It made me very aware that I had to change my medication, is what it did. And it also made me aware of the importance of taking the medication before I was in too much pain." (patient) "Just the fact that the change took place as a result of it. It was wonderful, really. It has helped her so much. It made a good difference." (family caregiver)

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**Figure 3. Pain Diary as a Guide to Self-Care Behavior**

Note. Unless otherwise noted, the person quoted is a patient.

learned nature of these skills and patients are not coached specifically in skills for managing multimедication regimens. Be that as it may, patients need education on how to manage complex medication regimens. Such education needs to go beyond instruction about the purpose, dose, timing, and side effects of individual medications to building self-care skills for managing entire medication regimens (Schumacher et al., 2002).

The fact that few patients mentioned using the pain management diary as a communication tool suggests that they are unaware of the usefulness of pain diaries to healthcare professionals. Although textbooks of pain management cite the usefulness of recorded pain data to nurses and physicians (McCaffery, 1999; McGuire et al., 1995), only a few patients mentioned using them in this way. Healthcare providers need to ask patients to bring their diaries with them to office visits so that they can be reviewed jointly with their nurses and physicians.

Similarly, patients seemed unaware of the potential of the pain management diary for communication with family caregivers. Although few family caregivers cited such communication as useful, even fewer patients mentioned it. The caregivers who did say that the diary was useful in this way

said that they did not know that the patients were feeling how they were and that having a more "objective" view of pain intensity helped them to understand what the patients were experiencing. Encouraging communication about patients' subjective experiences of pain may facilitate the involvement and support of family caregivers.

The greater sense of control that resulted from diary use for a few patients was an unexpected finding. Although a perceived lack of control is a known response to the diagnosis of cancer, researchers know little about specific strategies that help patients regain a sense of control. In a study of patients with chronic pain, Jamison and Brown (1991) noted that monitoring pain intensity may provide patients with a greater sense of control over the pain. Similar benefits seem to accrue in patients with cancer through use of a pain management diary.

Although patients found the diary useful, they tended to not employ the full range of possibilities that such a tool offers. For example, they made little use of the diary for communication, either with healthcare providers or family caregivers. Most did not describe using the diary to identify patterns of pain and relatively few described using it to guide

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**PRO-SELF® Group**

"I think it was helpful to me because I kind of looked at what was happening. It helped me when I talked to (the physician) to tell him how much pain I was having."

"I think it's made her more willing to talk about it up front to her oncologist. I think she was always kind of hesitant like. From my point of view, (the patient) seems to believe that admitting that she was in pain is a sign of weakness. I think she feared talking to her oncologist that he would react badly from this. I think it's made her braver than before. More willing to talk about it in a very objective, straightforward manner. I think he was surprised when he looked at the pain log, that she showed him that she was feeling as bad as she was. That's when he gave her that prescription for more." (family caregiver)

"I think it was very helpful. Cause before I really didn't have a handle on day-to-day how much it was different from others. When she was able to verbalize the pain amount in terms of numbers, it was a lot easier for a person (family caregiver) who's not having the pain to understand. When I have some pain and I've not been able to say how much, then she says, okay, now think about it from 1 to 10."

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**Figure 4. Pain Diary as a Communication Tool**

Note. Unless otherwise noted, the person quoted is a patient.

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**PRO-SELF® Group**

"I personally thought it was very helpful. My short-term memory is badly affected by the morphine. It was never very good to start with so (the diary) had a couple of effects. Number one, it helped me to record everything and it helped me to take my pain management more seriously than my previous sort of slap-dash approach. And even though (the caregiver) has been really playing a very active role in my pain management, I had really abdicated too much of that to her and her excellent memory and so forth and so this had an effect on me to really try to be a full partner in managing my pain." (patient) "Yeah, I think in fact you've taken most of your pain (management) back except for me saying, 'What level is your pain?'" (family caregiver)

"The pain log was—I find it, and this is just my quirk, I find it disciplined to journal anyway, but it kind of just let me see how much control I could be of my pain. I think that was the one advantage of it, is I think that cancer patients sometimes just feel that they don't have charge of their life and the log reminds you that you do have charge. It did me. And it encouraged me to take charge."

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**Figure 5. Pain Diary and Enhanced Sense of Control**

Note. Unless otherwise noted, the person quoted is a patient.

behavior or assist in decision making. Perhaps explicit instructions in diary use coupled with examples of the multiple possible uses for a pain management diary would allow patients to tap more fully the potential of the diary in their own self-care. On the other hand, in-depth problem solving based on diary information may require, at least for some patients, review and discussion with a professional pain specialist. Further research is needed in this area.

Of note is the fact that patients were not explicitly instructed in how to use the diary for their own benefit. Rather, they were instructed in how to complete it for study purposes. Thus, any use of the diary for their own benefit was undertaken spontaneously by patients. The lack of a difference found between the PRO-SELF and control groups suggests that reviewing diary content with intervention nurses did not promote a different or more extensive use of the diary. Patients in both groups seemed to discover their own ways to approximately the same extent.

The statements by patients in the control group about the effectiveness of the diary in improving their pain management suggest that it served as an unanticipated intervention for this group. Possibly, the significant reduction in pain intensity scores in the PRO-SELF group compared to the control group (Miaskowski et al., 2001) would have been greater without the use of the diary for data collection in the control group.

Only a few patients had unmistakably negative reactions to the diary. Most of these patients found it annoying, too time-consuming, or burdensome. Interestingly, the burden that some patients experienced resulted from not knowing whether they were giving the "right" answers. Perhaps discussing how diary recording is progressing after patients have started using it would provide nurses with an opportunity to reinforce the notion that no "right" or "wrong" answers exist to questions about pain. Some patients may prefer to record qualitative descriptors of their pain, rather than use a numeric rating scale. Fourteen patients voiced difficulty with the numeric rating scales, even though overall they found the diary to be helpful. Some found the level of precision in the diary to be too much, whereas others wanted a more precise way to record their pain. One even suggested hourly recordings. Thus, patients varied tremendously in how often they wanted to record (ranging from wanting to record hourly to finding once a day too burdensome), as well as the extent to which they were able to confidently quantify their pain severity. In clinical practice, nurses may need to tailor the format of the diary to meet patients' needs and self-report styles.

Only four patients said that they did not like the diary because it made them think about their pain; all four were in the control group. The issues about the beneficial or harmful nature of sustained attention to a symptom like pain are complex. On one hand, attention to pain is viewed as harmful in that attention heightens pain perception and leads to increased perceived pain severity. Thus, distraction is a well-known strategy for lessening pain intensity. However, a number of patients in this study found that more sustained attention to their pain overcame a tendency toward "denial." It helped them take their pain "seriously." When and for whom is a heightened awareness of pain beneficial in pain management? In-depth exploration of patients' consciousness of pain was beyond the scope of the current study's data, but the results raise intriguing questions for future research on the role of awareness of pain.

**Study Limitations**

Four aspects of this study limit the generalizability of its findings. First, the end-of-study interview guide did not include specific probes regarding how the diary was used. Thus, patients may have used their diaries in more ways than they articulated. These data contain only patients' spontaneous comments about how they used the diary. An interview guide containing structured probes would increase the validity of the frequencies reported for each coding category. Second, for participants in the PRO-SELF group, the end-of-study interview was administered by the intervention nurses. Therefore, patients' and family caregivers' responses may have been influenced partly by a desire to please the nurses who had worked closely with them. The third limitation is the relative lack of ethnic and cultural diversity in the sample. Although the perception and expression of pain may be influenced by cultural values (Helman, 1994; Juarez, Ferrell, & Borneman, 1998), the data is unclear regarding whether cultural views of pain perception or its expression affect the use of the pain management diary in self-care. Finally, these research results may not be applicable to all types of pain. The patients in this study had pain from bone metastases. Their use of a diary may not be generalizable to patients with other types of pain.

**Clinical Implications and Future Research**

The use of pain diaries is recommended in both patient guidelines and standard texts on pain management (Jacox et al., 1994; McCaffery, 1999; McGuire et al., 1995). This study provides research-based evidence to support the usefulness



of diaries to patients for self-care, as well as for professional assessment of pain and its relief. However, the results indicate that patients may need more explicit education and coaching on how to use a diary to its fullest potential. For example, collaborative evaluation of diary data by nurses, patients, and family caregivers could bolster patients' ability to spot patterns in their own responses and behaviors. Asking patients to take their diaries with them to office or clinic visits would expand its role in patient-provider communication. Similarly, suggesting that patients and family caregivers review the diary together for joint problem solving around pain management, in addition to modeling this behavior for patients and their family members, could enhance this important type of communication. In short, guided use of a pain management diary, as opposed to relying on spontaneous discovery of the usefulness of a diary by patients, may be needed to reap the full range of potential benefits.

Future research is needed on the role of a diary in self-care for pain management. The categories of diary use identified in this study could form the basis for a more structured evaluation in the future of the ways in which a diary is used. Of particular interest is the extent to which diary use changes pain management behavior. In the present analysis, patients appeared to use the diary for awareness of pain to a much greater extent than for behavioral change. However, this finding may be an artifact of data collection, given the fact that specific probes

were not used to explore the connections between awareness and behavior. In the future, researchers will be able to structure data collection to explore this issue explicitly.

Finally, using a pain management diary as an intervention tool rather than for data collection only is a promising strategy for future randomized clinical trials. In a recent review, Allard, Maunsell, Labbé, and Dorval (2001) concluded that progress in pain control would be enhanced by documentation of daily fluctuations in pain levels in a diary and ensuring that diary-documented uncontrolled pain is rapidly brought to the attention of healthcare professionals. The current study's findings support this conclusion but also suggest that the use of a pain management diary enhances patient self-care. Future research will expand healthcare providers' knowledge about the role of a pain management diary in both self-care and patient and professional collaboration.

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**Author Contact:** Christine Miaskowski, RN, PhD, FAAN, can be reached at [chris.miaskowski@nursing.ucsf.edu](mailto:chris.miaskowski@nursing.ucsf.edu), with copy to editor at [rose\\_mary@earthlink.net](mailto:rose_mary@earthlink.net).

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