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This project is developing patient educational materials, both video and written, for lower-income African American and Hispanic women. The materials will be tested in a randomized clinical trial at three sites that serve primarily minority patients. The project began with three studies designed to establish the specific educational needs of women of each ethnic heritage. In the first study, Hispanic and African American women with breast cancer and cancer-related pain and their physicians completed surveys. The results indicated that the majority of the women were receiving analgesics of insufficient strength to manage their pain and that their physicians underestimated pain severity. The second study found that the health care providers of these women demonstrated conservative pain management practices. They reported inadequate pain assessment and patient reluctance to report pain as the top barriers to optimal pain treatment. The structured patient interviews in the third study revealed that minority women feel a need for more information about cancer-related pain, analgesic medications, and side effect management. The Hispanic women reported more concerns about addiction and the efficacy of pain medicine than the African American women. The production of the educational materials will be completed by the end of 1997.

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## INTRODUCTION

Improving pain control for patients with metastatic breast cancer will significantly reduce the morbidity of this disease. It is estimated that 185,700 women are newly diagnosed with breast cancer in the US each year (Parker et al., 1996). Approximately 70% of these women are diagnosed in the early stages of the disease, due mainly to progress in screening and diagnosis. Despite improvements in cancer care for patients with early stage disease, a large number of patients will still develop metastatic disease, and mortality rates for these patients remain relatively constant. Minority women are more likely than white women to have advanced disease at diagnosis, and treatment outcomes are worse for minority women (Freeman & Wasfie, 1989). Improving the quality of life of patients who will die of their disease, especially controlling their pain, should be as much a priority for these patients as improving the therapeutic approaches for their disease.

Women with metastatic breast cancer, especially those from minority populations, are not receiving optimum pain control. While it is estimated that pain could be well controlled in over 90% of patients with cancer (Foley, 1985), data from a recent national study indicate that 43% of women with metastatic breast cancer and pain are not adequately treated by the standards of the World Health Organization (Cleeland et al., 1994). Compared with other patients who have pain due to metastatic disease, women are more likely to be undertreated, and patients from sites treating primarily African American or Hispanic patients are three times as likely to receive inadequate analgesics. Minority patients recognize that they are undertreated; they more frequently report that they need more medication for pain, that they have less pain relief from pain treatment and shorter duration of pain relief from their medications. They also report more pain-related impairment of function.

Poor cancer pain control is a function of many factors, including those related to the inadequate pain management given by health care professionals and those related to barriers created by the health care system in general. Patient concerns, expectations, and behaviors also contribute to poor pain management (Cleeland, 1984; Ward et al., 1993). These patient-related factors include the belief that pain is inevitable, fears of addiction to analgesics, fears of building tolerance to analgesics, and fear of reporting pain to providers.

This project is developing patient educational materials, both video and written, for African American women and women of Hispanic descent. The project began with studies designed to establish the specific educational needs of women of each ethnic heritage. In consultation with medical experts of both African American and Hispanic descent, a video script was written that covered the perceived barriers to good pain control in both groups. This script was reviewed by separate focus groups of women with cancer and pain from each group to determine the best presentation style for the educational material. Specific educational material developed for each group, African American and Hispanic, will be tested in a randomized clinical trial, entering women with breast cancer from each heritage group.

This project is based on the premise that patients who expect pain relief and are able to communicate their distress are liable to promote more responsive pain management from their health care providers. Identifying patient concerns and behaviors that limit effective pain management and providing gender and heritage-specific information and skills training to modify these concerns and

behaviors may present the most effective way, at least in the short term, to reduce the percentages of patients whose functioning is impaired by pain. Training for minority patients will need to be predicated on an assessment of the specific information and skills they will need to manage their pain.

## BODY

The first task in our statement of work was to assess the needs of minority breast cancer outpatients for information and skills needed to manage pain. The second task was to develop multimedia education and training materials that are linguistically and culturally appropriate for low socioeconomic status (SES) Hispanic and African American populations. The final task is to test the effectiveness of these materials in a randomized clinical trial. To accomplish these tasks, we have (a) formed a network of three urban public hospitals that treat these patients, (b) established a multi-disciplinary team to meet project goals, and (c) activated three studies to assess the educational needs of this patient population. We will evaluate the effectiveness of the educational tools in a randomized, controlled clinical trial for low SES African American and Hispanic outpatients with metastatic breast cancer and disease-related pain. If this program is effective, it can easily be introduced by other care centers where these patients are treated.

In September of 1996, the Pain Research Group of the University of Wisconsin Medical School - Madison, the group responsible for the scientific and technical aspects of this project, relocated to the University of Texas M.D. Anderson Cancer Center (UTMDACC) in Houston. Because of Department of Defense policy, the awarded home of the project remains at the University of Wisconsin. Professor David DeMets initially agreed to become project Principal Investigator (PI) but withdrew this offer after several months due to prior commitments. The Pain Research Group had difficulty locating an appropriate replacement PI at the University of Wisconsin Medical School. Recently, Dr. Kurt Hecox, Professor of Neurology, agreed to be the project PI. Dr. Hecox has a long-standing collaborative relationship with the Pain Research Group and currently is the PI on a subcontract from UTMDACC on Dr. Cleeland's NIH-funded study of pain control methods. Dr. Hecox will serve as the administrator of the project subcontracts and will assist in the coordination of site activity.

Dr. Hecox and the University of Wisconsin Medical School have submitted a request to the Department of the Army to name Dr. Hecox as the replacement PI and to subcontract the project work to UTMDACC, with Dr. Cleeland as the subcontract PI. When the grant funds become available again, the Pain Research Group will complete the revised Statement of Work. We have requested an extension of the grant period that will allow us to complete the project. The delays in replacing the project PI and obtaining a subcontract have limited our progress during the period of August 1996 to August 1997. The lack of funding has been particularly difficult for our sites in Los Angeles (Los Angeles County Medical Center) and Miami (Sylvester Comprehensive Cancer Center, University of Miami Hospital and Clinics). The research nurse for the Miami site was transferred to another project and subsequently left the institution. Dr. Richman, the site PI in Miami, is interviewing for a replacement research nurse and plans to resume the project when funds are available. Similarly, the research nurse in Los Angeles has been working on other funded projects but will be available to resume the project work.

Our third site, the Smith Hospital in Fort Worth, radically changed its pattern of service in mid 1996 due to the reassignment of Medicaid and other underserved patients to private hospitals, essentially eliminating the treatment of oncology patients previously seen there. The project subcontract with Smith hospital was terminated in November 1996 because of decreased accrual.

Since re-establishing the project base at the UT MD Anderson Cancer Center (UTMDACC), we have recruited LBJ General Hospital in Houston to serve as the third site for the project, with Vicente Valero, MD, Chief of Medical Oncology at LBJ Hospital as the principal site investigator. Dr. Valero is also on staff at UTMDACC as Assistant Professor of Breast Medical Oncology. Because of the relationship between UTMDACC and LBJ Hospital, no subcontract will be required to have LBJ participate as a project site.

To assess the needs of minority breast cancer patients, two descriptive studies (Study 001 and Study 002) examined the environment in which these patients are treated and the type of treatment typically provided. These studies were completed at the Miami, Los Angeles, and Fort Worth sites. A summary of the findings is included in this progress report. These results provide an estimate of the quality of treatment at each of the sites prior to the introduction of the educational intervention. These studies recently were initiated at LBJ General Hospital in order that these data can be used as a background to estimate the impact of the intervention. The studies at LBJ are not necessary for the development of the intervention and should not delay the progress of the study. The development of the intervention has also been guided by a third study: Structured interviews (Study 004) have been conducted with low SES African American and Hispanic women in Miami, Los Angeles and Fort Worth. A summary of the content analysis of the interviews is presented in the report.

Despite the lack of available funds, the production of the videos is in progress. The script of the video for African American women was reviewed by a focus group of African American women with breast cancer. The results of the focus group are included in Appendix I. The script was subsequently revised after consultation with our focus group experts and other project consultants. The University of Texas Television studio currently is filming the video. Completion of the video is scheduled for the end of October, 1997. The script of the video for Hispanic women is being revised. A focus group of Hispanic women with breast cancer recently was completed, and the results are being analyzed. The printed materials for African American women have been developed after consultation with experts on African American health education and pain management (see Appendix II). The printed materials for the Hispanic women with breast cancer are nearing completion.

Data management for the project has been transferred to the Community Oncology Program, UTMDACC, a program that is under the direction of Rodger Winn, MD. This is the data management center for the MD Anderson NCI-funded CCOP (Community Clinical Oncology Program) research base, and the specific data management for this project will be under the direction of Joanne Bitsura, MPH, who has directed the data management for several NCI-sponsored clinical trials. A data base and a system for quality control of project data for the pilot and clinical trial have been developed. Each site will pilot the study with ten to fifteen minority cancer patients. The video and handbook will be those currently used in an Eastern Cooperative Oncology Group clinical trial (ECOG 3Z93) that also examines patient education for pain control. These materials, designed for majority patients, are not expected to be as effective as the tailored materials produced by this project. However, utilizing them in the pilot study will allow for a run-in of the clinical trial, including patient identification and recruitment and data management and data transfer systems that the trial will employ. This pilot study will allow us to drop the run-in phase of the project with the targeted materials.

## **SUMMARY OF RESEARCH FINDINGS TO DATE:**

### **Study 001 - Outpatient Pain Needs Assessment Survey (Task 1)**

The purpose of this study was to obtain general descriptive data about pain, its severity and treatment, as well as general attitudes toward cancer pain treatment in African American and Hispanic patients with breast cancer and with pain. One aim of this study was to determine if pain relief, treatment, and patient-related barriers to cancer pain might differ between these two ethnic groups. The data included the patients' subjective report of pain and its impact on function, the perception of the treating physician concerning the patients' pain, and the details of the pain treatment these patients are receiving. The survey instruments are based on ones used by Cleeland and the Pain Research Group at the University of Wisconsin (Cleeland, 1986) and in ECOG. Patient and physician questionnaires for this study have been tested within the ECOG system (Cleeland et al., 1994). The patient form is an adaptation of the Brief Pain Inventory (BPI). The physician questionnaire was adapted from a similar survey that was administered to nurses in a previous study.

*Methods:* African American and Hispanic women with previously diagnosed metastatic or recurrent breast cancer were approached by the research nurse during their regularly scheduled clinic visit. The women were asked to complete the BPI. This survey asks patients to rate their pain at its worst, least, and average for the last week, as well as their pain at the time of the study, on a 0 to 10 scale. Each scale is anchored by the words "no pain" at the 0 end and "pain as bad as you can imagine" at the other. Using the same type of scales, patients are also asked to rate how their pain interferes with several quality of life domains that include activity, walking, mood, sleep, work, and relations with others. These scales are anchored by "does not interfere" and "interferes completely". The patients were also asked to estimate the pain relief they were receiving from their pain treatment (in percent), and to answer questions about their perception of pain and attitudes toward taking analgesics. The BPI has been validated in culturally diverse groups and also in different language formats. The Spanish version, developed following a cross-translation method, has been validated in a multi-site study in Mexico and the Dominican Republic as part of a WHO demonstration project (Cleeland, 1989a). The Spanish version has also been successfully used in multi-center studies in the U.S. (Cleeland et al, 1994). The pain and interference scales of the BPI are robust across different language and cultural groups (Cleeland, 1988; Serlin et al., 1995).

Physicians completed the "Physician Pain Assessment" survey form for each scheduled patient within 48 hours of the scheduled patient visit. This survey asked the physician to describe the patient's current pain treatment, to rate the patient's ECOG performance status, and to indicate the causes of the patient's pain. The physician had the patient's record when completing the survey but did not refer to the patient's completed BPI answers, and each physician signed a statement to that effect.

*Accrual:* Part of these data were collected in an ECOG survey of minority patients. These data included 40 Hispanic and 22 African American women with breast cancer and pain. This project collected an additional 15 Hispanic and 8 African American breast cancer patients, for a total sample size of 55 Hispanic and 30 African American breast cancer patients with cancer-related pain.

The reviewers of the revision of our 1996 progress report asked us to explain the discrepancy in reported accrual between the September 1996 progress report and our February 1997 revision. In our progress report of September 1996 we erroneously indicated that 77 patients had been enrolled in the study. The accrual total of 77 included women with other types of cancer and men with metastatic or recurrent cancer. The data on the male patients was collected as part of a NCI-funded study of prostate cancer. We corrected the error in the February 1997 revised report.

Results: The mean ages of the Hispanic (55.3) and African American (51.8) women with breast cancer were not significantly different. Seventy-five per cent of the Hispanic women and 67% of the African American women received an ECOG performance score in the range of 0-2, indicating the ability to function in basic daily activities. There was also no difference between the mean "worst pain" score for Hispanics (6.8 on a 0 to 10 scale) and African Americans (6.3). These data suggest that the groups were comparable in terms of demographics, disease status and pain severity.

Adequacy of treatment was estimated by using the Pain Management Index (Cleeland et al, 1994), a measure of whether or not patients were prescribed analgesics appropriate to the severity of their pain. The Index is based on the World Health Organization's recommendations for cancer pain management, as adopted by the AHCPR Guidelines for Cancer Pain Management (Jacox, et al, 1994). As has been found in other studies, the majority of these minority women were receiving analgesics of insufficient strength to manage their pain, although there was no heritage-based difference, with 64% of Hispanics and 59% of African Americans being under medicated with analgesics.

Previous research has documented that inadequate assessment is a strong predictor of analgesic under medication. We compared the patient's report of pain severity and her physician's estimate of her pain severity. Physicians underestimated pain severity in both groups of patients, 79 percent of the time for Hispanic women and 56 percent of the time for African American women ( $p < 0.05$ ). The physicians also were asked to rate the adequacy of a patient's pain control on a 0-10 scale where 0 equals no pain and 10 indicates always has severe pain. The mean ratings for the Hispanic (3.5) and African American (3.9) women reflects the physicians' belief that their patients' pain is adequately managed.

Several questions were asked about the patients' concerns about pain treatment, their need for additional information about pain management, and their view of the pain treatment that they were receiving. Table 1 demonstrates that several differences were found between the Hispanic and African American women. Hispanic breast cancer patients were significantly more likely to say they needed more information about pain management (71% vs. 46%). A majority of both groups reported that they needed stronger pain medications (60% and 54%), although Hispanic women were more likely to say they needed more of their current analgesic prescription (48% vs. 22%). Even for those with appropriate prescriptions, a majority of Hispanics (57%) and African Americans (57%) took their analgesics two times a day or less, and African Americans were significantly more likely (77%) than Hispanics (47%) to take their analgesics only when necessary. There was no difference between the groups in the number of Hispanics (31%) and African Americans (17%) who worried that they might be taking too many medications. There was a tendency for Hispanics to be more worried (43%) about analgesic side effects than were African Americans (24%).

The results of this initial study documented that the majority of both Hispanic and African American women with breast cancer and pain were under medicated with prescription analgesics,

and that their physicians underestimated the severity of the pain that their patients were experiencing. Hispanic women more frequently reported that they needed information about their pain and more of their current pain medication, and tended to be more concerned about the negative side effects of analgesics. While a majority of both groups were estimated to be incompletely compliant with presumed analgesic instructions (taking analgesics less often than would be typically recommended), African American women were significantly more likely than Hispanic women to report that they took their analgesics only when necessary.

### **Study 002 - Health Professionals' Attitudes Toward Cancer Pain Management (Task 1)**

Surveys of health professionals have identified barriers and provided insight into current pain management practice patterns. Since it has been documented that minority cancer patients are at a greater risk for under management of pain, a survey of health professionals who treat this population should help in designing interventions that target minority cancer patients. We have gathered data on cancer pain management practice from a sample of physicians, nurses, and pharmacists who treat minority cancer patients of low socioeconomic status (SES).

The information from this study was used to (a) identify barriers to pain management which need to be addressed in educational interventions for patients in these minority study sites, (b) document the current status of pain treatment at the three study sites, and c) document the current pain management practice at the three study sites, providing information about health professionals' perception of the barriers to good pain management. The specific objectives of this study were (a) to determine the knowledge of cancer pain and its treatment among physicians, nurses, and pharmacists treating minority patients with cancer of low SES at three sites, (b) to determine the methods of pain control being utilized at these three sites, (c) to determine the staff's perception of barriers to pain management at these three sites, and (d) to compare the knowledge and attitudes of staff at these three sites with the results of cancer pain treatment as reported by patients in the "Outpatient Needs Assessment Survey."

A shortened, booklet form of the Physician Cancer Pain Questionnaire developed by Charles S. Cleeland and the Pain Research Group at the University of Wisconsin was utilized (Cleeland et al., 1986). This questionnaire was the instrument used in a recent study of physicians in the Eastern Cooperative Oncology Group (VonRoenn et al., 1993). The questionnaire was designed to assess physicians' estimates of the magnitude of pain as a specific problem for cancer patients, physicians' attitudes about the adequacy of pain management for cancer pain, and their report of how they manage pain in their own practice setting. As a way of describing more specific pain management practice questions, they provided treatment recommendations for a patient presented in a scenario format. Information was also gathered on the physicians' practice setting, training, and experience with caring for patients with cancer pain. The shortened version of the survey takes about 10 minutes to complete.

**Eligibility:** The eligible participants included all physicians, nurses, and pharmacists serving minority patients of low SES with cancer at the following sites: John Peter Smith Hospital, Fort Worth, TX; University of Miami Hospital and Clinics, Miami, FL; Los Angeles County Hospital, Los Angeles, CA. The study recently was activated at LBJ General Hospital in Houston, TX. No participants were excluded on the basis of sex, age, race, or educational preparation. No

inducements were offered for participation in this study. Receipt of the completed questionnaire was considered informed consent.

Methods: Eligible staff members were identified by the Research Nurse at each site. All nurses, pharmacists, and physicians with some patient care responsibilities for oncology outpatients were approached. The Research Nurse at each site hand-delivered a copy of the survey form, cover letter, and postage-paid addressed return envelope to each eligible staff member. Participants returned completed surveys to the Pain Research Group via a postage-paid envelope. The surveys did not include the name of the respondent, nor were the identification numbers in any way connected with respondents' names in order to insure confidentiality. After three weeks site research nurses redistributed the surveys to the staff member who had not responded. Study data was identified by staff category and by institutional site but not by name of participant to insure anonymity and confidentiality.

Accrual: The second survey distribution for this study was completed at three sites (Miami, Los Angeles, Fort Worth) in April, 1996. This study is now closed at these sites but was recently activated at LBJ General Hospital in Houston. We have received a total of 54 questionnaires from the four sites: 14 from Fort Worth, 21 from Miami, 14 from Los Angeles, and 5 from Houston. The response rates for Fort Worth, Miami, and Los Angeles were 78%, 60%, and 48%, respectively.

Results: A majority of the clinic staff respondents were female (65%) and Caucasian (64%). The remaining ethnic distribution was 16% Asian, 16% African American and 4% others. Nurses were the largest group (47%) followed by physicians (42%) and pharmacists (11%).

Forty-six percent of the health care professionals estimated that 100% of cancer patients experience pain at some point during their illness. Only 2% of the respondents estimated that less than 50% of cancer patients suffer pain at some time. Sixty-three percent of the respondents felt that their settings were doing a good or a very good job in managing pain, with 37% percent reporting only a fair, poor or very poor job. However, 75% said that patients receive adequate pain treatment in their setting. Fifty-nine percent of the health care professionals described themselves as more liberal than their peers concerning the use of analgesic medications for cancer patients. When asked about their professional background, about 50% reported fair or poor training in cancer pain management.

The clinic staff were asked to rank potential barriers to optimal cancer pain management in his or her setting. Table 2 summarizes these results. The four top barriers were inadequate assessment of pain and pain relief (70%), inadequate staff knowledge of pain management (50%), patient reluctance to report pain (51%) and lack of staff time (39%).

To assess clinic staff pain management practice, a hypothetical case scenario was presented: *A 40 year old male cancer patient is hospitalized with severe untreated back pain of more than 1 month duration, attributable to bone metastases without vertebral collapse. He weighs 70 kg., has no cardiovascular or respiratory problems, and has a disease prognosis of more than 24 months. He has no history of medication allergies and is opiate naive. What would be your recommendation for initial pain management for this patient?*

Fifty-five percent chose strong opioids (e.g. morphine, hydromorphone) appropriate for this level of pain, while 28% preferred mild opioids (e.g. codeine, vicodin) as their choice of drug. About 13% recommended NSAID's as the strongest analgesic to be used. Approximately half would administer the drug around the clock while the other half would give it only as needed.



Finally, respondents were asked: At what stage would you recommend maximum tolerated analgesic therapy for treatment of severe pain? Fifty percent of respondents would wait until the patient had less than six months to live before recommending maximum analgesia. However, 82% of the health care professionals felt the most likely explanation for why a terminal cancer patient would request increased doses of pain medication is that the patient is experiencing increased pain.

Fifty-three percent of the professionals correctly stated that constipation is the one side effect of opioid medication that does not decrease after repeated administration of the medication. About 16% of the respondents incorrectly stated that respiratory distress will not decrease, and 14% admitted that they did not know which side effect did not decrease over time.

The responses from staff at these three project institutions can be compared with a previous study of the responses of oncologists from primarily non-minority clinics (VonRoenn, et al, 1993), and also with the recommendations of the Agency for Health Care Policy's Guidelines for the Management of Cancer Pain (Jacox, et al, 1994). In general, fewer of this group would use the more potent opioid analgesics and they would tend to wait until the patient's disease is worse (prognosis of less than 6 months) before using maximum analgesia. Half of the respondents would prescribe analgesics on an as-needed basis rather than around the clock (as recommended by the AHCPR as well as the World Health Organization). As with the large oncologist sample, most saw poor assessment and poor staff knowledge as major barriers to pain management. In contrast to the other group, health professionals in this sample from the three project hospitals felt that lack of time for pain treatment was a major barrier to pain management at their hospitals. Overall, there was a strong suggestion that the approach to the management of cancer pain at the project sites was more conservative than the management of pain received by non-minority patients, suggesting an even more important need for the minority cancer patient to be more assertive in insisting on good pain relief. These data on professional attitudes also are in line with the finding of the first study in this project indicating that minority women with breast cancer are at greater risk for poorly-managed pain.

One purpose of this study was to estimate if there were any potential pain treatment biases at any of the hospitals that could possibly cause differences among the sites prior to the initiation of the intervention. We compared three items previously identified as being associated with pain treatment adequacy. These included the potency of the analgesic selected for the scenario patient, the stage of disease when professionals would use maximum analgesia, and the percentage of health professionals who would schedule analgesics around the clock. There were no differences among the hospitals (Miami, Los Angeles, Fort Worth) on any of these items. It is also interesting to note that approximately half of the clinicians at each of these three sites reported that their clinic was doing a good job or very good job of relieving cancer pain. Minor differences were noted among the sites: For example, Ft. Worth but not the other two sites indicated that lack of equipment or skills was one of the three greatest barriers.

#### **Study 004 - Perceived Pain Management Needs of Minority Outpatients (Task 1)**

We examined African American and Hispanic breast cancer patient attitudes toward pain management and current pain management practice through the use of structured patient interviews. Structured interviews allowed us to probe for previously unidentified barriers to pain management

in these populations. In addition, tape-recorded interviews provided insight into the language style which might be appropriate for the target audience of the educational videos.

The current study is the final part of Phase 1 (needs assessment) in the development of educational materials for low SES African American and Hispanic patients. The information from this study was used to identify barriers to pain management which need to be addressed in educational interventions for patients. Results from the current study were used in conjunction with results from the Outpatient Needs Assessment Survey and the study of Health Professionals' Attitudes Toward Cancer Pain Management, described above, to determine the issues which need to be addressed in patient education materials designed to target African American and Hispanic cancer patients.

The primary objective of this study is to amplify our information about the perceived pain management needs of minority cancer patients of low SES. A second objective is to identify culturally specific language styles in order to ensure that educational materials will appropriately reflect language used by the target populations in discussing cancer pain.

Eligibility: Patients were recruited from the following participating sites: John Peter Smith Hospital, Fort Worth, TX; University of Miami Hospital and Clinics, Miami, FL; Los Angeles County Hospital, Los Angeles, CA. The subjects were outpatients seen in oncology/urology clinics at the participating institutions. All of the patients had received a pathological diagnosis of cancer and had recurrent or metastatic disease. None of the patients had undergone surgery in the past 30 days. All of the patients reported chronic cancer-related pain and a pain worst score on the Brief Pain Inventory (BPI) short form of  $>4$ . In addition, the patients were  $\geq 18$  years of age and a member of one of the following minority group categories: Hispanic, African American. All of the patients had an ECOG Performance Status rating of 0, 1, 2, or 3.

Methods: This study was conducted at the outpatient clinics of the University of Miami, John Peter Smith Hospital and Los Angeles County Hospital. A private room was made available at each site for the structured interviews. Oncology outpatients who met the eligibility requirements were asked to participate in the study. The research nurse or a designated interviewer conducted all interviews. Interviews were conducted in English or Spanish depending on patient preference. Interviews were tape recorded to be transcribed later. In addition, the interviewer took notes summarizing the response to each question. These interview summaries were used in the case of audio or interpretation difficulties during the transcription of the interviews. On-Study Forms, BPI Short Forms, taped interviews and interview summaries were forwarded to the Pain Research Group for tape transcription, data entry, coding, and analysis.

The structured interview was developed by a committee that included members of the Pain Research Group, site investigators, and consultants with extensive clinical experience with patients in each of the target groups. The interview was translated into Spanish and then back-translated by two separate bilingual translators. The interviews took 30 to 60 minutes to complete.

Pain and pain interference were measured with the Brief Pain Inventory (BPI) Short Form. The BPI asks patients to rate their pain for the last 24 hours on 0-10 scales at its "worst", "least", "average", and "now". Each scale is bounded by the words "no pain" at the 0 end and "pain as bad as you can imagine" at the other. Using the same type of scales, patients are also asked to rate how their pain interferes with several quality of life domains including activity, walking, mood, sleep, work, and relations with others. These scales are bounded by "does not interfere" at the 0 end and

“interferes completely” at the other. Issues of the validity and reliability of the BPI have been examined in detail (Daut et al., 1983; Cleeland, 1989b; Serlin et al., 1995). English and Spanish revisions of the BPI have recently been used in a group wide ECOG study of cancer pain and its treatment, following a study of its patient acceptability and its feasibility as a clinical trials tool (Cleeland et al., 1994; Hatfield et al., 1991).

*Accrual:* As of August 1997, 20 female patients with metastatic or recurrent cancer have been registered in the study. The Fort Worth site has registered 1 patient; the Los Angeles site has registered 4 patients, and the Miami site has registered 15 subjects. Sixteen female patients (9 Hispanic, 7 African American) have completed the structured interview. Eleven of the patients have a diagnosis of metastatic breast cancer; the remaining 5 patients have other metastatic or recurrent cancers (lung, colon, lymphoma, myeloma). All of the patients had a pain worst score on the Brief Pain Inventory (BPI) short form greater than 4.

The reviewers of the revision of our 1996 progress report asked us to explain the discrepancy in reported accrual between the September 1996 progress report and our February 1997 revision. In our progress report of September 1996 we erroneously indicated that 32 patients had been enrolled in the study. The accrual total of 32 included men with metastatic or recurrent cancer. The data on the male patients was collected as part of a NCI-funded study of prostate cancer. We corrected the error in the February 1997 revised report.

*Results:* The content analysis compared the responses of the African American and Hispanic women to questions in four general areas relevant to pain management: information and communication about pain, treatment of pain, meaning of pain, and demographic data that might impact pain treatment. The analysis indicated that the responses of the eleven patients with breast cancer are comparable to those of the five patients with other types of metastatic or recurrent cancer. The pain-related concerns of the two subgroups of women do not appear to differ significantly.

In the information and communication area, the Hispanic and African American patients reported receiving information about cancer and cancer pain from multiple sources. Fourteen of the sixteen women interviewed reported that their physician is a primary source of information about cancer and cancer pain. A majority of the women also reported their physician as the most trusted source of information about cancer pain for themselves and their families. Eleven of the women reported using booklets as another important source of information. There were no differences between the African American and Hispanic women regarding their reliance on their physicians and written materials. Although several women commented that they would like to watch videos on cancer and cancer pain, they added that none were available to them. The Hispanic women were more likely than the African American women to use family members, friends, and/or other cancer patients as sources of information. Seven of nine Hispanic women mentioned these sources, as compared to three of the seven African American women.

When asked what kind of information received about cancer pain had been helpful, only 2 patients (one African American and one Hispanic) reported receiving helpful information about pain medications. Only one patient reported receiving helpful information about possible side effects of pain medication. A majority of the women in both ethnic groups stated that they have no difficulty talking about having cancer and cancer pain. Six of the seven African American women did report some difficulty talking about physical problems.

All of the patients stated that they talk to their physicians about their pain. Only five patients indicated that they discuss their pain with a nurse. Several patients commented that a nurse is rarely present in their clinic setting. The majority of patients in both ethnic groups feel that their physician understands about their pain. The Hispanic patients also emphasized that their family talks to them about their pain.

In the treatment area, all of the patients reported receiving medications prescribed by their physicians. A majority of the patients in both ethnic groups were receiving opioid medications. Consistent with the results of Study 001, the majority of the patients interviewed were under medicated with prescription analgesics. There were no apparent differences between the African American and Hispanic women in this regard. The Hispanic patients were more likely than the African American patients to report many concerns about becoming addicted to pain medicine. The Hispanic patients also reported that their family members were very concerned about the pain medicine. A majority of the Hispanic but not the African American women were worried about the efficacy of pain medicine. A majority of the patients in both ethnic groups reported concerns about being strong and not leaning on pain medicines. The overall assessment of attitudinal barriers to effective pain management suggested that the Hispanic patients have higher barriers than the African American patients.

The patients in both ethnic groups did not report major difficulty in obtaining their prescribed pain medications from a pharmacy. Cost was not described as a major barrier. Prescriptions were typically filled and taken. Four of the nine Hispanic patients reported taking less of their pain medication than prescribed by their doctor. Only one patient in each ethnic group reported a problem with someone taking their pain medication from them. Gastrointestinal side effects from pain medications were commonly reported by both groups. Only one patient reported calling the cancer clinic about a side effect. Similarly, nearly all of the patients said that they would wait until their pain reached a 9 or 10 (on a 10-point scale) before calling the doctor, nurse, or clinic.

The African American and Hispanic patients described their pain in terms of sensations, associated emotions, and functional effects. The benefits of pain medications were described as feeling better, having a better mood, and being able to participate in work, family, and social activities. The demographic data indicate that the two ethnic groups are similar in terms of education, marital status, job status, and income. Most of the women are not married, have less than a high school education, and at least one child in the home. The average income is less than \$500 per month.

In sum, the results of the content analysis provided important information for the development of the educational materials. The analysis identified the perceived pain management needs of minority women of low SES who have metastatic breast cancer. The identification of these needs was used in the development of the educational materials for the clinical trial. For example, the patients in both ethnic groups appeared to be dependent on their physicians for providing trustworthy information about cancer pain management. Thus, the video script includes physicians talking to their patients about cancer pain and available treatments. As Hispanic patients reported using family members, friends, and other cancer patients as important sources of information about cancer pain, these groups will be included in the video and written materials.

The content analysis suggests that there is a need for helpful information about pain medications, possible side effects (especially gastrointestinal effects), and how to deal with side

effects. The patients also need education about contacting their physician or nurse before their pain level is severe. A majority of patients in both ethnic groups reported noncompliance or incomplete compliance with presumed analgesic instructions. This finding is consistent with the survey results from Study 001. The Hispanic patients and their families are very concerned about addiction to pain medication and demonstrate other attitudinal barriers to effective pain management. The Hispanic women are more concerned about the negative side effects of analgesics than the African American women. Similarly, the results of the structured interviews indicated that the Hispanic patients were more concerned about addiction and the efficacy of pain medicine than the African American patients. The patients in both groups can benefit from learning how to use pain rating scales to discuss their pain with health care providers.

### **Development of Training Materials (Task 2)**

Analyses of the first three studies (outpatient pain needs assessment survey, health professionals attitudes toward cancer pain management and perceived pain management needs of minority outpatients) have guided the development of the video and written materials. As noted above, the videos for African American and Hispanic breast cancer patients will include physicians who are experts on pain management. Both videos will emphasize the importance of communicating with one's physician about pain. In addition, the video will provide an example of how to communicate with a physician in a clinic setting. The patients also will be taught to use a simple pain rating scale. Thus, the videos will include appropriate skills training to accomplish the goal of improved pain management. The women in both ethnic groups will be encouraged to take their medications as prescribed and to contact their physicians for increased pain and/or difficulty with medication side effects. Both videos will include an example of how to contact the physician.

A focus group of African American women with breast cancer and cancer-related pain was held on March 8, 1997. The group was led by Amelie Jean-Francois, M.P.H., Senior Research Associate in the Division of Cancer Control of the University of Miami. Ms. Jean-Francois has extensive experience as a focus group leader and also participates in an outreach program for minority breast cancer patients. The women were asked to review the draft of the script for the African American video and to make recommendations for culturally appropriate revisions. The women also made suggestions for the content and style of the written materials. The transcript of the focus group and the summary analysis are included in Appendix I.

Based on the results of the focus group and the initial studies, the script for the African American women underwent a final revision (see Appendix III). The video currently is being filmed by University of Texas Television, with Jo LaCour as the executive producer. Ms. LaCour has considerable experience with production of educational videotapes and has directed other pain management videos. The video is scheduled to be completed by the end of October 1997. As recommended by the focus group members, the settings for the video include the patient's home as well as the oncology clinic. Family members also are included in the video plan. The focus group women had indicated that hearing from other breast cancer patients is the best way to teach women that they do not have to suffer from pain. Therefore, African American women with breast cancer and cancer-related pain have been interviewed and asked to describe their experiences with pain and

with pain medicine. The video will also include the focus group recommendations for how to talk to a doctor and how to deal with increased pain.

The results of the focus group and the initial studies, as well as consultation with experts on minority patient education, has guided the development of the written materials. A booklet on pain management designed specifically for African American women with breast cancer has been developed (see Appendix II). This booklet is being reviewed by African American women receiving treatment for breast cancer in the oncology clinic at LBJ General Hospital. The booklet address the topics recommended by the focus group and supplements the information provided in the video. The reading level of the booklet has been analyzed as the 5.3 grade level. This level is consistent with the average educational background of our target populations at the three sites. A draft of the booklet for Hispanic women with breast cancer has been developed (see Appendix IV) and will be revised based on the initial studies and the focus group of Hispanic women.

The focus group for Hispanic women with breast cancer was held on August 30, 1997. The group was held in Spanish and was led by Marta Noa Leroy, an educational research coordinator who has extensive experience as a focus group moderator. Although fifteen women had been recruited and confirmed for the group, only three women actually attended. A second focus group has been scheduled to provide additional recommendations. The first focus group reviewed the initial script for the video for Hispanic women and made suggestions for the script and for the written materials. Once the results of both focus groups are analyzed, the script will undergo a final revision. Filming of the video for Hispanic women with breast cancer is scheduled to begin in November 1997. The Spanish and English transcripts, summary analysis, and video script are included in Appendix V.

The consultants to our project recommended that the control group receive an educational video and booklet on a topic unrelated to pain management. These materials will control for the effects of attention and providing credible educational information. Dr. Karen Syrjala, Director of Biobehavioral Services at the Fred Hutchinson Cancer Center, suggested using materials on nutrition similar to ones she employed in a previous study of pain management interventions (Syrjala et al., 1995). The video "Feeling Better with Food - Good Nutrition for People with Cancer Undergoing Treatment" will be shown to the control group. A Spanish version of the video, "Sintiendose Mejor Con Alimentos", recently was completed by University of Texas Television. The transcript for both the English and Spanish versions of the video are included in Appendix VI. The control group will be provided with a booklet on nutrition for cancer patients, "Feeling Good - Nutritional Planning to Improve Your Cancer Therapy". This booklet is published by Mead Johnson and will be provided for our study. A Spanish translation of the booklet was completed by our research staff. The Spanish version is being back translated and will be published by Mead Johnson prior to the start of our clinical trial. The booklet and the Spanish translation are included in Appendix VII.

In sum, the production of our educational materials is near completion. We anticipate completing the pilot phase of the clinical trial in November and December 1997 and initiating the full clinical trial in January 1998 (**Task 3**). Given the interruption in the availability of project funds, we have applied for an extension of the grant period that will allow us to complete the clinical trial, analyze the data, and prepare the final report.

## CONCLUSIONS

This project documents that the majority of Hispanic and African American women are not receiving analgesics of an appropriate strength for their pain, and that physicians underestimated pain severity in these minority breast cancer patients by as much as 77%. Improving patient-health care professional communication about pain should be associated with more appropriate analgesic prescription. Underestimation of pain severity can be due to any of the following: inadequate assessment of pain and pain relief, inadequate staff knowledge of pain management, patient reluctance to report pain and lack of staff time, all of which were reported by the health professionals as major barriers to pain management in our three project sites. Critical goals of the educational materials are to encourage patients to report pain and to give them the skills to report pain and the adequacy of their pain relief. Our educational and video materials address the reluctance of minority breast cancer patients to report pain and encourage them to do so before pain becomes very severe. In addition, the training materials provide information about how to take analgesics and side effect management. Both patient-based studies indicate that both groups of women report that they need more of this information, but few receive it.

Several of the concerns that our Hispanic and African American consultants thought would be important to include in the video and educational materials were not borne out by the assessment phase. For example, the results of the preliminary content analysis do not indicate major difficulties in obtaining prescribed analgesic medications. Also, although the investigators and consultants had speculated that financial, transportation, or other social problems might interfere with obtaining medications, few patients reported these types of barriers. Similarly, availability of the medications in the pharmacy was rarely mentioned. The patients also did not report problems with having analgesic medications stolen or taken away for reasons other than theft. Thus, the patient educational materials do not address these areas.

The studies also indicate that Hispanic and African American breast cancer patients have different educational needs. In addition to the obvious requirement for both English and Spanish versions of the materials, the specific content receives differential emphasis. Hispanics may be more concerned with becoming addicted to medication and worrying about using "too much." They also had more concerns about whether analgesics really relieve pain. The Hispanic materials include a greater emphasis on the family as involved in the pain treatment, with ways of reassuring family about the minimal risk of addiction to opioids used for pain control. African American breast cancer patients may tend to be more isolated in negotiating their pain treatment. Their educational materials include special reinforcement for being their own advocates for pain relief. African Americans are also more likely to take their medications only when needed rather than as prescribed, and the pharmacologic rationale for around-the-clock analgesics receives special emphasis in their educational material.

The results of the three studies indicate that breast cancer patients feel a need for and can benefit from accurate information about analgesic medications and how to adhere to a regular

medication schedule. Patients in both ethnic groups are concerned about possible side effects and will receive education about how to identify and cope with them. Data from all three studies demonstrate the need for patient education regarding patient-health care provider communication. Patients will be encouraged to discuss their pain with their doctors and nurses, to use pain rating scales, and to report major changes in pain level of difficulty with side effects. Patients who learn how to assertively request pain relief should receive effective pain management from their health care providers.

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Table 1. Comparison of Hispanic and African American Breast Cancer Patients on Attitudes Related to Pain Treatment

Item *	Hispanic women	African American women	p values
Need more information	71%	46%	< 0.04
Need more of current analgesic medication	48%	22%	< 0.04
Need stronger analgesic medication	60%	54%	NS
Concerned about using too much med.	31%	17%	NS
Problems with side effects from med.	43%	24%	NS
Taking analgesic med. $\leq$ 2 times/day	57%	57%	NS
Taking analgesic med. on prn basis	47%	77%	< 0.03

\*Percentage of women responding "yes" to the item

Table 2. Barriers to Optimal Cancer Pain Management Reported by Health Care Professionals at Four Study Sites

Barrier	Percentage *
Inadequate pain assessment	70.2
Patient reluctance to report pain	51.0
Inadequate staff knowledge about pain management	50.0
Lack of staff time to attend to patients' pain	39.1
Medical staff reluctance to prescribe opiates	37.8
Patient reluctance to take opiates	32.7
Nursing staff reluctance to administer opiates	20.5
Lack of access to a wide range of analgesics	18.2
Too much paper work	15.8
Lack of access to professionals who practice specialized methods	15.6
Excessive state regulation of prescribing analgesics	15.0
Lack of equipment or skills	14.0
Lack of available neuro destructive procedures	12.5
Patient inability to pay for analgesics	11.6
Lack of psychological support services	11.1

\* Percentage of respondents who selected the item as one of the top four barriers in the survey.

# Appendix I

## MANAGING YOUR PAIN

*Focus Group Analysis (African American Women)*  
*Conducted by the University of Texas*  
*MD Anderson Cancer Center*  
*March 8, 1997*

**Purpose:** The University of Texas MD Anderson Cancer Center wants to make a video tape and booklet about cancer pain for African American women who have breast cancer. The video tape and booklet will be designed to meet the following objectives:

- ◆ To help women receive good management of their pain from their doctors.
- ◆ To teach women how to talk to their doctors about their pain.
- ◆ To teach women that strong pain medicines are safe and not addictive (or habit forming) when taken as directed by their doctor.
- ◆ To make the video and booklet sensitive to the needs and concerns of African American women who have breast cancer.

**Method:** A focus group was conducted with nine African American breast cancer survivors to gain their insight for developing a video and booklet about pain management. The meeting was held in Miami, Florida at the University of Miami School of Medicine, Winn Dixie Hope Lodge. The data obtained during the focus group was transcribed for qualitative analysis.

As part of the group, respondents provided feedback on two materials:

- ◆ Script for the video, "Managing your Pain"
- ◆ Questions about the video and booklet

**Description of participants:** Nine African American participated in the focus group session. Women were selected on the following criteria: having had breast cancer and experienced some types of pain. They were asked to provide demographic characteristics. From previous experience with this group, African American women usually do not like to answer personal information such as income. The table below describes respondents' demographic characteristics. However, a few women did not answer all of them. The age range was 31-65 years old. Most of these women were diagnosed in the 1990's. Their educational level ranged from high school to bachelor degree and half of them are employed.

<i>Participants</i>	<i>Age</i>	<i>Year of diagnosis</i>	<i>Employed</i>	<i>Income range</i>	<i>Occupation</i>	<i>Marital status</i>	<i>Education</i>	<i>Religion</i>
1	41	1990						
2	41				Housewife			
	65	1994	Dade County school		Teacher assistant	widow	AA degree	Weselyn Methodist
3	54	1995	Dade County		Registrar	Widow	B.A. degree	Methodist
5	41	1996	Yes	Small	Housewife	Single	High school	Baptist
6	60	1991	Retired		Nursing, RN	Single	College	
7	31	1995	No	None	Student	Married	College	Baptist
8	40	1995	No	Small	House mother	Single	College Degree	Methodist
9	60	1984	Yes	Small	Rdr/clerk	Single	High school	Baptist

## Findings

### Setting for the Video

The focus group participants liked the script and thought it was well written. They made a few suggestions about the video. They thought setting for the video was important. Several of them believed that different settings, such as doctor's office, home and clinic settings should be used to convey the message. They suggested a family setting, where parents are explaining to the children what is going on with the mother, should be included. They further suggested that a family member should be present when patient is taking to the doctor. One participant wanted to know if real patients or actors would be used in the video.

*The thing about that is if he's going to examine the area that she's complaining about, I would say the doctor's office.*

*Maybe they can use both showing the patient at home, examining herself or maybe reacting to the pain and then the doctor sitting where he is treating her for her complaint.*

*I think you could have the same setting in a clinic...in a waiting room they have a television you watch different pictures-programs while you are waiting to see the doctor. So I feel in the same*

*setting, you are sitting waiting to see the doctor and all of a sudden a pain hit you and you grab your breast. So you see, you have the same motion*

*I don't think people know about the pain as well as it should be with children. The mother or the father explaining to the children what is going on with her.....You are dealing with the family.*

*So bring someone in to help...Like a mother or somebody that is a friend, a real close friend as far as your sister. Someone that can relate to you, that will hold your hand during the time of need.*

### **Music in the Video**

Participants agreed that music should be included in the video. Soothing, soft music, jazz, instrumental music, gospel are some the suggested music. They have further suggested some artists such as Frank Sinatra and Andy Williams.

*Soothing music; something soft*

*Jazz or either like the ocean, like ocean sounds*

*Instrumental, Frank Sinatra type of music*

*Andy Williams type, like Moon River or something like that*

### **Using Videotape at Home**

All participants stated they would use a video about pain at home and would share it with family members.

### **Booklet**

The focus group participants believed that a booklet, identical to the video, should be produced.

*They should reproduce the same thing into a booklet*

### **Religion in the Video**

The focus group participants seemed to be very religious. They stated religious faith should be included in the video because people always get comfort from the Lord. They suggested adding gospel music to the video.

*I believe there is a higher being because I believe in him and I think that's why I am here today. So I think that is very important, you know and as we do have non-believers but I think most in here know we didn't get this far by ourselves.*

*You can have a little gospel because now-a days even jazz has gospel in it*

*Every morning when I get up, that is what I hear (gospel music), to me that's soothing, it's healing*

### **Sources of Information**

Participants were asked "Who would you like to see in the video giving you information about cancer pain and cancer pain management?". They have mentioned people who know about pain, a woman nurse, an African American woman and maybe a family member such as a sister.

*I feel as if someone that knows about pain. Even though the doctors are there, but they don't feel all your pain. They can give you advice to help us out. But someone that needs to know about pain and having been through this already*

*Someone who has dealt with it before.....someone who have had some cancer themselves and my older sister was good in documenting everything down*

*....so maybe it would be better to stick to someone Afro American because our situation is kind of unique. It's a little different from, you know, other people, and so personally I would think that maybe we should stick to our own Afro American people*

*It really doesn't matter but in keeping with the theme, yes that we are concentrating on African American women and I would feel an African American woman would be a better person*

Participants were further asked "Who do you trust the most to give you information about cancer pain and cancer pain management?". They responded an African American woman, a nurse, someone of knowledge, someone who has experienced it and a professional.

*I would want an African American woman who is empowered with the latest knowledge of what is going on*

*Someone of knowledge and somebody who's experienced with it. Got to know more than what I know*

*I would like to have someone who has experienced breast cancer and pain such as and would be also a professional on the topic of breast cancer*

*.....That have the knowledge to know what is pain and who got the knowledge to really give you and teach you how to control your pain because not everybody can do that. It should be like----maybe a nurse can do that*

### **How not to Suffer with Cancer Pain**

They made several suggestions about how to convince people that they do not have to suffer with cancer pain. Providing them with information, talking to them about pain and encouraging them to ask questions, share own experience, counseling and educating them were some of the suggestions.



*Continue to give them information, to talk about it with them and encourage them to ask questions and to talk to someone who has had the experience.*

*Give an example of your own experience, for instance someone you know, their experience and what happened to them and what medications they took and how it turned out the results*

*My way was to educate me, counseling, being in a group (support group) such as this, people who have experienced it that way group therapy*

*I would use myself as an example....and if they see my actions and then I can say to them, well look I've had pain and I would try to convince them to use the same method I have used....because people often say to me " I can't believe you had breast cancer" and I say " I don't dwell on it and keep myself busy"*

*... I share what I went through with and by the time I finish talking to them and I say if I did it you can do it too.....thank my Father... They take a positive attitude about it*

### **Information about Cancer Pain Management**

Participants wanted to know all types of information about cancer pain management including the pain medications, how it works and the side effects.

*All medications is not the same. It has different side effects for different medicine*

*....Some medications have reactions to other medications, so one important question to ask when the doctor give me a prescription to take a medication, you should tell him what you're taking now because the doctors don't always ask you are you taking. They just prescribe a medication and then a week later you feel worse than you did before you took the medication*

*A lot of medications do have side effects. It is really good to become educated about your medication*

### **Encouraging Cancer Patients to Take Pain Medicines**

Few of the participants had suggestions on how to encourage cancer patients to take their medications. Most of them believed that there isn't a way to encourage people to take their medications; they have to make the decision. A few of the respondents expressed paranoia about taking medications, but they stated they would take the medications if the pain is severe enough.

*By talking to someone that's been through it*

*If that pain hurt bad enough, you gonna take that pain medication the way they tell you to take it. You gotta ask nobody*

*You really can't encourage nobody. It's up to you. If you want to suffer that's you. If I am suffering, I'm gonna take the whole thing. I would take it all. You want the pain to go*

*You have to try to manage your body with your activities. Sometimes when I have gone through pain I try to get involved in something else, to divert your pain off of yourself*

### **Worrying about Pain Medications**

Several participants expressed worries about pain medications, such as becoming addicted; doctors don't know about pain and take care of it and medications not working. They did not worry about telling their doctors about their pain or other physical symptoms related to cancer. Many of the participants believed one cannot guarantee anyone assurance that strong pain medications such as narcotics are safe and not addictive. A few respondents stated they would take the medications and worry about them later.

*I am concerned about becoming addicted or relying on medications... but if it is medication that you must take to continue breathing, continue living, those I just grit my teeth and take. But, and don't even think about the other effects knowing that this is what is going to keep you alive*

*I don't worry about them (doctors, nurses), um, worry about me complaining if I tell them that because that's what I think they are there for---to help deal with the pain that we are supposed to be having*

*I start worrying about the pain medicine not working if pain gets worse*

*When I am in pain I really need something and if he (doctor) doesn't, well, give me something stronger---- the doctor gave me marijuana...then I started worrying but I said well, if the marijuana is going to make me sleep, I am going to take it and I did. Cause when I am in pain, should get rid of that pain*

*You really cannot give nobody no assurance about the medicine itself. If it agrees with your body, than that's assurance enough but if you are having problems with the medication, then you have to get it changed*

*Yeah, I would (worry about pain medicine would work or not). And then if that doesn't work. I'll ask for a different kind of medication. Keep asking until he gives me the right one*

### **Talking to Doctors about pain**

Participants expressed they had no problem talking to their doctors about pain medicine. They gave several suggestions on how someone who's afraid of talking to their doctors should approach them.

*I talk to my doctor about everything... You have to develop a trust and a confidence with your doctor and most times people are afraid or think the doctor is so busy....if I have any questions, I make him listen to what I have to say and I want an answer if the answer doesn't suit me, I say 'doctor I don't quite understand you, what do you mean'*

*I don't leave out of there. I take his stethoscope. 'Your heart sound like my heart so you got to pay*

*attention to what I am saying now. I am hurting. You are hurting, I am hurting...So I am telling you about my pain, you'll have to sit here and listen'*

*You have to get their attention....She ( a lady) said she screamed as loud as she could scream and said 'I am hurting----ah...', she just screamed. She said the doctor said 'yeah, you is hurting'. So he stood there and listened*

*So I stopped him and I called him by his name and I said ' Hey, I came here for you to help me and I understand you are so busy doctor', I say, 'but I need to know what's going on with me, right now. Break it down to me in plain English so I can understand'. I said 'because this is why I am her otherwise, I wouldn't even waste your time', I said. 'So right now, I need a little of your time for me. So you, you know, slow down and tell me what I need to know about me'*

*So you have to tell them, hey. If you got to fall out, hollow, scream... the only way they're going to get the help is cry out for help*

### **Making information about pain treatment easier to understand**

Many participants suggested making the information simpler to understand and by reading different pamphlets. They further suggested that the doctors speak in layman terms.

*Reading up on different kind of pamphlets and someone talking to you about it, you know. The doctor, nurse*

*Well, to make the pain medication easier for the patient, they should try to talk to the patient at the patient's level*

*I say educational and then me experience. I'd like for my doctor to break it down to my level*

### **Increase of Pain**

Participants were asked if they would call their doctor if pain increases and how can they encourage women to call their doctor or nurse. All participants, except one, said they would call their doctor if pain increases. Some believed that you can't encourage people to do anything and others have made suggestions, such as involving family members to talk to doctors.

*...When you are in pain you're going to call them. You don't need nobody to encourage you to call*

*I say you have tried and encouraged them and let them know too, that the doctor is there for their well-being and to help them in whatever their needs are and not to be afraid because he's a person that you should confide in, you know. He is supposed to be there for you*

*If your family members are aware of your situation and your problems and what is happening to you, sometimes they may find it easier to talk to a doctor and they can call for you. You have someone like that. A family member*

### **Other Types of Pain Treatment and Chosen Terms**

All participants agreed to include other types of pain treatment beside medications such as relaxation techniques, distraction, meditation. They suggested the following chosen terms: 'taking pain medicine on a regular schedule' rather than 'around the clock', 'constipation' rather than irregularity and 'habit forming' rather than addiction.

*Meditation, the stress tapes that they give us*

*...Sometimes you don't take pain medicine, sometimes it (stress tapes) soothes you*

### Focus Group Summary--Breast Cancer Survivors-African American

<i>Topics</i>	<i>Responses</i>
Setting for the video	Involve several settings ; doctor's office; patient's home examining herself or reacting to pain then at doctor's office; waiting room in clinic; family setting where parents are explaining to children what is going on with mother; have a family member or friend as support when talking to doctor
Music in the video	Soothing music; something soft; jazz; ocean sounds; instrumental; Frank Sinatra type of music; Andy Williams (Moon River)
Using video tape at home	Yes
Booklet	Same thing as in the video
Religion in the video	Include faith and gospel music; emotional, spiritual and financial aspects need to be included in the video because some people deal with all of them
Sources of information	People who know about pain and having been through pain already; a woman nurse; family member such as a sister or a friend; a female; an African American woman empowered with the latest breast cancer knowledge; a professional; someone who knows more than them; someone who can teach them how to control pain
How not to suffer with cancer pain	Give them information; talk about pain with them and encourage them to ask questions; talk to someone who has had the experience; share an example of own experience or someone else' experience; education; counseling; group therapy; use self as an example
Information about cancer pain management	pain medications and the way they work; side effects; become educated about medicine
Encouraging cancer patients to take their pain medicines	Talking to someone that has been through it; can't really encourage no one; it is up to the individual; people would take medicine if pain cancer is severe enough; manage your body with activities; if going through pain get involved in something else

Worrying about pain medications	Becoming addicted; doctors don't know about pain and take care of it; medication not working; difficult to assure someone that strong pain medicine such as narcotics are safe and not addictive; cannot give assurance about medicine itself; having problem with medicine, change it until you get the right one
Talking to doctors about pain	No problem talking to doctor about pain and pain medicine; get doctors' attention by screaming; fall out, hollow and scream to make them listen; be persistent; cry out for help
Making information about pain treatment easier to understand	Read different pamphlets and talking to doctor; ask doctor to speak in layman terms; education
Increase of pain	Call doctor if pain increases; let patients know that doctors are there for their well-being and they can confide in them; ask family member to call for them
Other types of treatments and chosen terms	meditation; stress tapes Chosen terms: 'taking pain medicine on a regular schedule'; 'constipation'; 'habit forming'

**MANAGING YOUR PAIN**  
**TRANSCRIPTION OF FOCUS GROUP SESSION**

**MARCH 8, 1997**

Moderator (Amelie): Introduces group participants and reads script to group.

Moderator (Amelie): Ends the script reading and ask group participants. So what do you think? Who would like to start? Shirley, I see you smiling, what do you think of the script?

Shirley: Who am I comparing it to, me?

Amelie: To anyone who may have had cancer or probably you may have suffered some pain. Would you say that it's a good script and that they should keep it like that or should they make some changes to it, what should they add or subtract?

Shirley: My pain that I suffered was only after surgery. That's what I could speak of. The thing I have had up to now really was from the surgery and I think that was the healing part of it. Since then my pain hasn't been severe as this is (meaning script).

Amelie: Do you think that's a good script. Would you say the way it's written, they could do it just like that?

Delois: If they are having any type of pain from the time before surgery and before they found out that they had cancer or anything like that and you are going to have severe pain because I did since 1972 when I was going through a lot of pain. But I had a doctor back in 1973 and he told me, he was an older guy, and he said that taking it off of medical records, as my professional, if I was a friend I would tell you back in the older days we did not do that, for you not to have surgery. Because if you could bear the pain as you could, deal with it. Because sometimes young women at your age go through a lot of lymph nodes with milk clogging, and different things like that also could cause pain before you have a baby. So it went on for years until 1990, that's when my pain got severe, very severe. So I call Ladora (Project Coordinator of the Early Detection Program) and explained to her that I was having this pain in my chest. When I finally took a mammogram it was during May of 1990 which they waited so long then before they called me back into the hospital. So I called Ladora and said it's been since May that, you know, I had the mammogram and I haven't heard anything. So here it is November of 1990 and I am still in pain all this time. Still in a lot of pain.

Amelie: Did you tell your doctor you were in pain?

Delois: Yes.

Amelie: And what did he say?

Delois: At the time Tylenol. See, they can't really examine you if they are not in that field. See I was going to like a family doctor. You know, he wasn't really affiliated with what was going on with my body at that particular time. Like uh, she was saying before at one of the meetings (meaning breast cancer support group meeting), that uh, they can tell you, your family doctor can tell you what they think you might be going through, but they really can't explain to you what is really going on. But the pain that I had was very severe. Sometimes she'll (meaning her sister, Deleese) tell you, I'll go down and fall straight to my knees and grab my chest.

Dorothy: He should have recommended you to a specialist.

Delois: That's how bad I was having pain. But see like, you know, you got those family doctors that's not into this kind of a field, you know. And even if he recommends you to a specialist, that's how come Ladora came in at that particular time. And that is when she recommended me to breast cancer (meaning oncology clinic). And then I went for a mammogram again, here it is December, almost before Christmas. I went in the first or the fifth of December, as I remember, because I told her that I didn't want to be in here for Christmas. So they were going to have to give me surgery but by that time the mass had gotten so big that the doctor came and said, "We can't touch her. We can't give her surgery, this mass is too big." So what we are going to do is give her chemotherapy, let her take it to shrink it down, and put her on as much pain medicine that she thinks is comfortable for her. At that time it was Morphine that I did go on.

Amelie: So the doctor just prescribed the Morphine?

Delois: Yeah, he prescribed the Morphine. It got so bad until I went from Morphine back to Demerol, because it was real bad, you know. So they gave me Morphine and he was giving me Demerol and I was wondering why I couldn't stay, you know, woke. The pain wasn't easing up but it got better until the Demerol. While I was sleep I was feeling pain. So, when it was time for chemo, every time I go for chemo, then it (meaning the pain) started which the chemo helped a lot along with the pain medication and the chemo, it started weaning down. What it was doing was shrinking and it was causing the pain to ease up. So Morphine will be good for people at that particular time so the phrase that he gave her in the paragraph is true, you know, to a certain extent. Because some pain is really unbearable that some people cannot take.

Amelie: Does anybody else have something to add about the script?

Mary T.: I didn't have no pain before having surgery. The night before I was going to surgery I was crying out and I felt like an extra mass was there. I have pain now. The doctor says it's a delayed reaction.



Amelie: In the script do you think that would be a good one?

Everybody: Yes. Everybody likes the script.

Amelie: They have a few questions about it and I'm going to ask you. Is the setting important in the doctor's office or in a clinic or in someone's home?

Betty: The thing about that is if he's going to examine the area that she's complaining about, I would say the doctor's office.

Everybody: Yes, yes, because everybody have a different type of medication.

Amelie: So you think that they should use the doctor's office?

Everybody: Yes.

Shirley: Seem like the pain do subsides when you are talking to the doctor.

Mary B: But once you get home there it is again.

Shirley: Yeah.

Betty: Maybe they can use both. Showing the patient at home, finally examining herself or maybe reacting to the pain and then the doctor sitting where he is treating her for her complaint.

Delois: A lot of people don't want the doctor to video them at home. I don't think you need it at home, like you say, the doctor's office is fine. Even though we might have pain when we get home, you know, but you have to also, like even at one of the meetings, like they say, you have children. They might don't be use to that. And remember when she gave us this booklet and told us how we can go by explaining to the kids and telling them how we have cancer and everything else. If the parent didn't tell that child at that particular time what they have and you'll bringing a video in there, that's a scary thing, you know. It's not that, you know, if we want it, you know, but a lot of people don't like things like that in their home.

Betty: Will these be real people or these are actors portraying us?

Amelie: I really don't know. Probably they will be real patients, I don't know.

Dorothy: I think doctor's office. Could have same setting in clinic vs. home setting.

Amelie: Excuse me, I would like for people to speak one at a time because when we are transcribing we need to hear the tape clearly.

Mary T.: You can look at it that you may not want it in your home, I may not want it in my home, but to use the different types of settings would be good. All settings would be helpful.

Mary B: All three.

Amelie: Sophie would you like to add something to that?

Sophie: Having video at home would be better.

Amelie: They are trying to get to know how they want to make their video. They want to produce a video. They want to find out different settings. Do you think they should do it at home, have a shot of the woman in pain, holding on to her breast?

Dorothy: I think you could have the same setting in a clinic because in most clinics they have like a room such as this and in a waiting room they have a television you watch different pictures/programs while you are waiting to see the doctor. So I feel like in the same setting, you are sitting waiting to see the doctor and all of a sudden a pain hit you and you grab your breast. So you see, you have the same motion.

Amelie: Deleese, we haven't heard anything from you.

Deleese: Well, look at like this. If the person is doing the video himself, like if he's a doctor or if people come to you and say that you want to make a video in your home and if you agree with it, fine with you. You can talk to your kids and whatever and let them know that you are having someone to come at this time and if they don't want to be there, send them out. But other than that, you know, if they feel comfortable with it.

Amelie: Should we include music in the video? What type of music should they have in the background?

Everybody: Soothing music. Something soft.

Amelie: Can you give me an example?

Everybody: Jazz, or either like the ocean, like ocean sounds.

Amelie: One person at a time, I'm sorry.

Leona: Well, I think they should have music.

Amelie: Can you give me a name of a person?

Everybody: Instrumental, Frank Sinatra type of music.

Amelie: Alright, Frank Sinatra, alright.

Amelie: What else do you think we should include?

Betty: Andy Williams type, like Moon River or something like that.

Amelie: Benny Williams? Who?

Betty: Andy Williams, the singer. I think in one of his tunes is Moon River. Something soft like that.

Amelie: What else should we include in the video? What else do you think they should include in their video because they are going to make that video? It has not been produced yet so they want to know what you would like to see in the video, so what else do you think? Besides the music, the different settings, what else would you like?

Shirley: I think people who know about the pain as well as it should be with children, the mother or the father explaining to the children what's going on with her.

Amelie: Remember we are talking about pain. The whole target of this video is about pain.

Shirley: With pain, yes. Because the pain could be worser with me. Sometimes you got six children there and they're all saying, la, la, la, la, la, la, la.

Mary B: I got five (meaning children).

Shirley: So it should. I don't know.

Amelie: So you should have the woman explaining to the children about her pain?

Shirley: To show like a family setting.

Betty: Like a family gathering.

Mary B.: Because you're dealing with the family.

Delois: Like with her (meaning her sister), they told me to bring someone in. Don't come by yourself.

Mary B: Right. Like they told me.

Delois: So bring someone in to help. Like she said, like a mother or somebody that's a friend, a real close friend as far as your sister. Someone that can relate to you, that can hold your hand during the

time of need.

Amelie: So, include a family member?

Mary B.: Right or a close friend.

Amelie: While you are talking to the doctor?

Everybody: Yeah.

Amelie: Those are very good.

Amelie: Would you like to take a video tape on cancer pain to your home? Would you like to have that type of video in your home? I think all of you had said yes so far.

Everybody: Yes.

Amelie: Would you use the video tape at home? Would you show it to your family?

Everybody: Yes.

Amelie: Now they also want to do a booklet that's goes along with the video, a pamphlet. What do you think they should include in the pamphlet? Something that goes along with the video. They want to show the video plus a booklet of written material. What else would you like to include in it?

Mary B. & Dorothy: The same thing as in the video.

Leona: It should be something that's pertaining to the video and then in each segment, you know, what's happening right at that moment.

Amelie: So they should just reproduce the same thing into the booklet?

Everybody: Right, a booklet.

Amelie: Should we talk about religious faith in the video? Should we talk about religion in the video and how should we talk about it?

Delois: All of it comes from healing from the Lord Savior.

Amelie: I mean give me a specific example of what you mean to add religion. They say religion but there are different parts, you know, what can they say about it. Deleaze?

Release: ----- (CANNOT DECIPHER WORDS)

Leona: One suggestion is that, I mean you know, if you are a believer, you know, then you gonna put your trust in the higher being and ask him, to uh, you know, help you, to uh, you know, get over this situation, you know. And I do believe there is a higher being because I believe in it and I think that's why I'm here today. So I think that's very important, you know and as we do have non-believers but I think most in here know we didn't get this far by ourselves. We should never forget.

Amelie: So we should include some religion?

Delois: Well, in some homes you go in, they don't have gospel. A lot of people listen to their own music also, you know. Even though it's soothing (meaning gospel) to a lot of people because I hear a lot of gospel. Every morning when I get up, that's what I hear and to me that's soothing, it's healing.

Amelie: So you think they should include some gospel music in the video? No? Yes?

Dorothy: You could have a little gospel because now-a-days even the jazz has gospel in it.

Everybody: That's right. Even jazz. Jazz, b-bop, and everything else.

Delois: --- (CANNOT DECIPHER WORDS) a lot --- (CANNOT DECIPHER WORDS) of that she take from the Blues and add to gospel. Now they got this song called Midnight Train to Heaven instead of Midnight Train to Georgia, if you notice. So it's different and that's a beautiful song, now. I heard that the other day, Midnight Train to Heaven.

Mary T.: I think the emotional aspects, spiritual, and financial aspects have to be included.

Delois: That's true.

Mary T.: Because you deal with all of them.

Delois: Cause a lot of your finances, when you think about your bills that cause a lot of pain.

Everybody: It does.

Shirley: That builds the stress, that build up the pain.

Delois: Those bills, you get so stressed out. You wonder about the rent, the phone bill, and all of that.

Shirley: And the children, too.

Amelie: Alright now. So everybody agreed that it's a good manuscript and you would like it and if they were to make changes you said to make, that's it. OK. I'm going to start with other additional questions they want to know about. Who would you like to see in the video giving you information about cancer pain and cancer pain management? Would you like to hear it from your doctor? From the nurse? From another cancer patient who is having pain? From anyone else? From a man or a woman or does it matter? Or would you like to hear it from an African American?

Delois: I feel if it's someone that knows about pain. Even though the doctors are there, but they don't feel all your pain, they don't just feel your pain. They can give you advice to help us out, you know. But someone that needs to know about pain and having been through this already.

Amelie: Delease, who would you like to hear it from? She said she would like to hear it from somebody who has been through the pain. Who would you like to hear it from?

Delease: Someone who has dealt with it before. Someone who have had cancer themselves. Like my older sister. She was good in documenting everything down.

Shirley: Right, that's how I learned about my pain.

Delease: Before she left, she left like a book itself. She wrote of all the pain she had, certain medicines, she even wrote down. Certain pills they gave her, she said don't take this. They're trying to kill you.

Delois: --- (CANNOT DECIPHER WORDS) die.

Delease: She will write down everything. Everything.

Mary B: Yeah.

Amelie: Remember we are still talking about the video producing that video. So remember that when you are answering the questions. So when I say, who would you like to see in the video giving you information about cancer pain? You said someone who had cancer and who has pain.

Mary B: Maybe a nurse.

Amelie: A nurse.

Amelie: Does it matter if they are man or a woman?

Mary B.: A woman nurse.

Amelie: A woman nurse.

Amelie: Does it matter whether she is African-American or white or it doesn't matter?

Betty: I don't think so. Just a female.

Amelie: Leona would you please speak louder so everybody could hear. I'm sorry.

Leona: Well, I was just saying when this came into being our little group here, it said for Women of Color. So maybe it would be better to stick to someone Afro American because of, you know, our situation, it's kind of unique. It's a little different from, you know, other people, and so I personally I would think that maybe we should stick to, you know, our own I think Afro American people.

Amelie: Because remember it's just for African American women who have had pain.

Everybody: Right.

Betty: It really doesn't matter but in keeping with the theme, yes that we are concentrating on African American women and I would feel an African American woman would be a better person.

Mary B.: Well I feel the same as they feel. African American woman.

Sophie: African American.

Amelie: Who do you trust the most to give you information about cancer pain and cancer pain management?

Mary T.: I would want an African American woman who is empowered with the latest knowledge of what's going on.

Amelie: OK. Dorothy?

Dorothy: I would like to have someone who has experienced breast cancer and pain such as and would be also a professional on the topic of breast cancer, naming Dr. Smith. Somebody like her.

Amelie: OK. Sophie?

Sophie: I need somebody that who are really, you know, that have the knowledge to know what is pain and who got the knowledge to really give you and teach you how to control your pain because not everybody can do that. It should be like, maybe a nurse can do that and give, you know, something.

Amelie: Thank you. OK. Shirley?

Shirley: Same thing here. Someone of knowledge, an African American woman, and somebody who's experienced with it. Got to know more than what I know.

Amelie: OK. Deleaze?

Deleaze: Well, a health professional who knows about it but just like they said, what is pain? Everyone deals with different pains so when you are talking about pain, you got to specific your pain, and her pain, and my pain, they're not all the same. What pain it is?

Amelie: Thank you. Delois?

Delois: A professional.

Amelie: How can we convince people that they do not have to suffer with cancer pain?

Betty: We'll have to continue to give them information, to talk about it with them and encourage them to ask questions, and to talk to someone who has had the experience. That's the best way I think. Just to continue to talk with them, convince them.

Amelie: How do we convince them? How do we do that?

Betty: Well, maybe give an example of your own experience. For instance someone you know, their experience and what happened to them and what medications they took and how it turned out, the results.

Amelie: Alright. Shirley?

Shirley: Question?

Amelie: How can we convince people that they do not have to suffer with cancer pain?

Shirley: My way was to educate me, counseling, being in a group such as this, you know. People who have experienced it, that way.

Amelie: Mary Thompson?

Mary T.: Group therapy.

Amelie: Group therapy.

Dorothy T: I would use myself as an example. That's the best way to know that I, myself, has had cancer and went through the experiences. And if they see my actions and my movements, then I can say to them, "Well, look I've had breast cancer, I've had pain". And I would try to convince them



to use the same methods that brought me this far. Because people often say to me, "I can't believe you had breast cancer." I said, "Well because I don't dwell on it", I say. And just try to keep myself busy.

Amelie: Leona?

Leona: Well, I'm in agreement with what she said. Because I have really come in contact with a lot of people and you know the suffering is right now. So I share with what I went through with and by the time I finish talking to them and I say "If I did it you can do it too. Look at me today, you know. I'm here and I'm fine". And that also brings me back to thanking my Father, you know, for seeing me through this because without him, I wouldn't have been able to do it. But I believed in healing and I believed in the higher power of healing, and I'm here. And I start telling them that and whether or not they believe in who I believe in or not after I finish, the most of them say, "Well, if you can do it then I can too." They take a positive attitude about it.

Amelie: And what types of information about cancer pain management would you like to know?

Delois: What type of?

Amelie: What types of information about cancer pain management would you like to know?

Delois: All types. You know you got to know about everything when it comes down to pain. Mostly all types, you know. But not just for breast cancer because some people be going through a lot of other pain like she said, you know. Because I had breast cancer and it was going in my back, my head, you know. So all types.

Amelie: Would you like to know about the pain medications?

Everybody: Yes.

Amelie: How the pain medicines work?

Everybody: Yes.

Amelie: About the side effects of the pain?

Everybody: Definitely, the side effects.

Amelie: Why do you say the side effects?

Mary B.: Because all medication, you know, is not the same. There are different side effects for different medicine.

Dorothy: I think one of the most important things in taking medication for pain and other types of medication, some medication have reactions to other medications. So one important question to ask when the doctor give you a particular medication, you should tell him what you're taking now because the doctors don't always ask you what are you taking. They just prescribe a medication and then a week later, you find out that you feel worst than you did before you took the medication. And then he would come to his senses and say well, "what are you taking?" and this is a question he should have asked you when he is prescribing you medications, that's important.

Delois: Because I was hospitalized for the same thing, wrong medication and bad side effect. So it's best to know all those things, you know. Because they hospitalized me for what three weeks, and they had to treat me with antibiotics to take an infection away. It caused infection. And that's what will happen to you when you're taking pain medicine that doesn't fit you. Paramedic, he might give us Darvon or Motrins or Morphines and I probably can't take all of those.

Betty: Yeah, the medicine should be compatible. And if you are already taking something, you should make the doctor aware so that you don't mix up something that should not go together and that has happened to a number of people.

Leona: And since a lot of medicines do have side effects, it's really good to become educated about your medications, you know. And right now, that's what they are teaching a lot of people today is to, you know, educate yourself about the medication and that way when you take something, you'll know what it is, why you're taking it, and the side effects from having to take it and that's very good.

Delois: In 1976, Eckerd's took a survey. You know for one while they wouldn't put the side effects on your medications. They just give you your medicine and paper and that's it saying you take Motrins, that's it. But now, they give you the whole history and that's since 1976.

Amelie: And how can we encourage people with cancer to take their pain medicines? How can we encourage people with cancer to take their pain medicines on a regular schedule? How can we encourage them?

Shirley: By talking to someone that's been through it.

Amelie: Talking to someone who's been through it.

Mary B.: If that pain hurt bad enough, you gonna take that pain medication the way they tell you to take it. You gotta ask nobody.

Everybody: Laughter.

Amelie: But they want to know how can you encourage someone?

Mary B.: That's something you really can't encourage nobody. It's up to you. If you want to suffer,

that's you. I know if I'm suffering, I'm gonna take the whole thing.

Betty: It depends on the severity of the pain.

Mary B.: I would take it all. You want the pain to go.

Amelie: Shirley?

Shirley: I'm different because me and fears of medicine, I've got to be hurting. Me, I got to be really hurting, I'm telling you the truth to take a pill or Tylenol. I have a paranoia about medicines.

Mary B.: I have a paranoia about pain.

Amelie: Anybody else has the same fear of taking medicine?

Mary B.: My children be telling me, "Ma, where is your pain pills"?

Shirley: I stick the pain out.

Betty: I try to stick it out, too.

Amelie: Delois?

Delois: I got like that when, like I said, the side effects. That medicine they gave me was the wrong type and it did that. It kinda make you kinda hesitant about going to the next pill, you know. You know even though you're in pain. You know sometimes you say, "Well, if that pain makes this other pain worst, I don't want to take that pill", because that's what happened to me. You know I'm thinking I'm gonna take something to kill one pain and I got another pain. So, ---(**CANNOT DECIPHER WORDS**).

Dorothy: Sometimes medication can be psychological. You can psych yourself to the point where your brain might be telling your body "I feel pain." But you take for instance if you're in a hospital and you cry out, "I have pain," so the nurse will come and give you a shot. She can give you a shot with distilled water. How do you know that's a shot and that's not water. But about 30 minutes later your pain begin to subside. And then the nurse would come in and the nurse would say to you, "How do you feel now?" "Oh, my pain is gone". But the nurse is laughing. I didn't even give her pain medication, I gave her distilled water. So how do you feel? I'm I alright nurse?

Everybody: Laughter.

Amelie: Mary would you like to add something?

Mary T.: I, for myself, try to manage pain and tolerate pain. Once you know the side effects would

occur, you stop this and you toss the other. So then you have to try to manage your body with your activities. Sometimes when I have gone through pain, I try to get involved in something else to divert your pain off of yourself.

Amelie: So there isn't really a way to encourage people to take medications. They have to do it on their own, it's their own will?

Betty: Their own will.

Amelie: OK. What worries about pain medications do you have? For example, do you worry about addiction? About what family members or friends will think about you taking pain medications? About the pain medicine is not working if pain gets worse? About being strong and not leaning on pain medicines? That if you talk about pain the doctor will pay less attention to treating the cancer? Do you worry that taking a strong pain medicine like Morphine means that you are going to die soon? Do you worry that your doctor or nurse will think that you are complaining if you keep telling them about pain? Do you worry about the side effects which a lot of you have mentioned? Pain being worse than the pain? Do you worry about why your doctor doesn't know about pain and take care of it? Do you worry about whether pain medicines will work for you? And would you like me to repeat any of those? OK, so what worries you about pain medications do you have? Getting addicted? Thinking of what people may think about you?

Mary B: I really don't care what nobody think. "If I'm in pain, I'm in pain."

Amelie: OK.

Betty: I'm concerned about becoming addicted or relying on medication. I don't want to be a person who has to every other hour or so, I got to take a pill. That I'm concerned about that. But if it's medication that you must take to continue breathing, continue living, those I just grit my teeth and take. But, and don't even think about the other effects knowing that this is what's going to keep you alive.

Amelie: Leona?

Leona: Well, personally I did not have any problem with taking my medication because I felt like I went step-by-step. If I had pain, I took the medication and then I didn't worry about it at that particular time. I didn't worry about side effects. All I wanted to do was get, you know, get the relief that I needed at that particular time. And then I would deal with, you know, deal with whatever come later so I really didn't have no problems, you know, with the taking of the medication or worrying about the side effects because sometimes I find out my situation was like, she said, psychologically. Sometimes I use to hurt sometimes and then after a while, it would get in my mind "I'm hurting, I need". So you have to really evaluate yourself and find out the difference, you know, because sometimes you may not really have the pain that you think you have.

Amelie: OK. Do you worry that your doctor or nurse will think that you are complaining if you tell them about it? Delois?

Delois: No, I don't worry about them, um, worry about me complaining if I tell them that because that's what I think they are there for; to help deal with the pain that we are suppose to be having. And most of my pain come from meditation from faith because I mediate a lot as far as faith and it keeps me going. And ---**(CANNOT DECIPHER WORDS)** also in my life. So.

Amelie: Do you think, um, what about that statement. Do you worry that taking a strong pain medicine, like Morphine, means that you are going to die soon? Delease?

Delease: No.

Amelie: OK. Do you worry about the pain medicine not working if pain gets worse. Shirley?

Shirley: Then I start worrying.

Everybody: Laughter.

Amelie: And what about that you worry that your doctor doesn't know about pain and take care of it? Sophie? Do you worry about why your doctor doesn't know about pain and take care of it? Like if you go to your doctor, he doesn't talk to you about the pain? Do you worry about that?

Sophie: Yes.

Amelie: Why?

Sophie: Cause you know when I'm in pain I need something to get that pain away. When I'm in pain I really need something and if he does not, well, give me something stronger---because I remember I was having Demerol for my pain, and nothing worked. But doctor give me Marijuana. Then I started worrying but I said well, if the Marijuana is going to make me sleep, I'm going to take it and I did. Cause when I'm in pain, should get rid of that pain.

Amelie: OK. Do you worry about whether pain medicine would work for you or not? Mary?

Mary B.: Yeah, I would. And then if that doesn't work, I'll ask for a different kind of medication. Keep asking until he gives me the right one.

Amelie: OK. How can we convince women that strong pain medicines, such as Narcotics, are safe and not addictive, when taken as directed by their doctors? Delease?

Delease: How can they convince them?

Amelie: um, um.

Delese: Medicine that is safe for them?

Amelie: um, um.

Delese: You really can't. I mean you can't give them no assurance that.

Amelie: I'm sorry.

Delese: You really can't give nobody no assurance about the medicine itself. If it agree with your body, then that's assurance enough but if you are having problems with the medication, then you have to get it changed.

Amelie: Delois?

Delois: You know like she say, sometimes they give you more than one pain medicine. Cause I have been on pills myself and sometimes they'll stop my breathing, you know, and I had to take it back, you know. They would say it's alright, you could take, you could take. I don't know why I was breathing so bad, so I said "I'm not going to take this today." So when I didn't take it, I was alright. When I took it, I say I feel bad. When I went back, uh, you should have told me, you didn't need this. This is too strong for you, this and this and that.

Amelie: Who says that, the doctor?

Delese: Yeah. But at first he carried on this and that, you'll be back on your feet and I was lying in the bed.

Delois: There's no guarantee. That's what she said, there's no guarantee.

Delese: I was ---**(CANNOT DECIPHER WORDS)**.

Amelie: Is it difficult to convince a woman about the safety?

Delois: Like you say, some people doesn't have the pain, so they only take it when they need it. Ok. And sometimes when you need it, may be it will help right then. Then when you take it again for pain, it might not do them any good.

Mary B.: Because you have gotten immune to that medication. You know, you let your doctor know so he can change it.

Amelie: OK. Do you talk to your doctor or nurse about having cancer pain or other physical symptoms related to your cancer? Has any of you talked to your doctor about pain?

Dorothy: I talk to my doctor about everything. That's one thing I'm not afraid of and I know it's very important. You have to develop a trust and a confidence with your doctor and most times people are afraid or think the doctor is so busy. In fact he might make you feel that he's busy because of the way how he turns around and how he tries to rush you out of the room to get to another patient. But I always would make him stop. If I have any questions, make him listen to what I have to say and I want an answer and if the answer does not suit me, I say "Doctor I don't quite understand you, what do you mean"?

Amelie: What happens when you talk to your doctor or nurse about the pain or other symptoms? How do they respond to you? Shirley? If you talk to your doctor, how does your doctor respond to you?

Shirley: He tries to assure me that this is a normal pain cause I've had a real hard pain in my back, and I know by coming to the meetings and talking with other survivors that a lot of people get a pain in their back and inside the clinic that I talk to, you know. They get this pain in their back. He prescribed some medicine, I didn't take it.

Everybody: Laughter.

Shirley: I'm OK, it's gone.

Betty: What is the management because I'm having it right now--pains in my back.

Shirley: I just looked at that prescription, I didn't take it.

Amelie: Delease, same question? What happen when you talk to your doctor about the pain?

Delease: What happen? He give me medicine, different medicine to take.

Amelie: Do you think he paid attention to what you were saying?

Delease: Yes, I make him pay attention to what I'm saying. I don't leave out of there.

Delois: I take his stethoscope. I say, "Listen to your heart. Your heart sound like my heart so you got to pay attention to what I'm fixing to tell you now. I'm hurting. If you're hurting, I'm hurting".

Amelie: That's what you tell them?

Delois: If I have to take the stethoscope from my doctor. I say, "Let me put it in my ear. Let me hear your heart. Yours beating, so listen to mine. Mine's beating too. Yes, so listen. So you're living and I'm living. You can feel, I can feel. You bleed, I bleed. So now I'm telling you about my pain, you'll have to sit here and listen. So when I pinch you, didn't that hurt. Didn't you feel that pain? OK, then".

Amelie: And what did they say?

Delois: He sat there and listen.

Amelie: What would make it easier for you. well since like any of you do not have a problem talking to your doctor about your pain but if you wanted to give another woman some advice. What would make it easier for them to talk to their doctor or nurse about them. Somebody who's afraid to talk to their doctor. how would you tell them to approach their doctor?

Delois: Well, Ladora set me up with a lady before but I forgot her name. But when she had passed, she wouldn't tell her doctor anything. And then her sister, she says, "Well, I'm not going to be the same". So you called me, she found my number. She said when she went into the doctor's office he wouldn't listen to her. She said she screamed as loud as she could scream and said I'm hurting. ah..., she just screamed. So she said the doctor said, yeah you is hurting. So he stood there and listened. You know, sometimes you have to get their attention because like if this guy didn't fall out at the emergency at Jackson, he probably would have died when the other guy did die. So sometimes you have to make them, even the nurses around the desk. You have to make them really pay attention, they'll say oh, you go to ER. They're quick to send you to ER but you'll in a lot of pain. So this young man he was 21 years old, complaining of headaches and look what happened to him. They didn't pay him no attention. Thirty minutes later he was dead. They thought it was sleep. Get up, get up and the lady calling, everybody's flying now.

Mary B. & Delois: It's too late.

Mary B: It's too late, he dead's now.

Delois: So you have to tell them, hey. If you got to fall out, hollow, scream, do it.

Mary B.: Ah, they love to call security too.

Delois: The same way they call security, come, come. The same way you can say, I'm in pain, I'm in pain, help, help, you know. Because if they don't help you, you can die. A lot of people have died out to Jackson.

Mary B.: Oh, yeah.

Delois: That's a high risk.

Mary B.: Because they think that your pain is not bad enough for them to, you know, see about you. They're going to look over you and go to someone that has gotten shot and stabbed and all of that. Before they check you out, you feel just as bad as the ones that's cut-up.

Delois: It got so bad that people would call the ambulance, cause they felt like that's the only way



that they can see the doctor right then. Now you go call the ambulance, they have gotten hip (meaning aware). Cause this is what happened to this little 21 year old. He fell out in his mother's yard. So she called the ambulance, we're not going to drive him, so call the ambulance. And then they still called the ambulance. See they have gotten to that now. They're going to say, oh well, they getting the ambulance here so they can get sick right then and there and get out. But it's not the purpose. These people see a serious thing and they need help. And the only way they're going to get the help is they have to cry out for help. Sending them to ---**(CANNOT DECIPHER WORDS)** and waiting till your turn to come up is not going to help you.

Mary B.: Cause people go ahead of you.

Amelie: Leona, would you like to add something?

Leona: Well, I know what you're saying because I had an experience with a GP here, a couple of years ago. When I went to him and I was trying to explain to him why I was there and what my situation was but he was focusing on how many people he had in his waiting room. So I stopped him and I called him by his name and I said, "Hey, I came here for you to help me and I understand you are a busy doctor, I say, but I need to know what's going on with me, right now. So I would appreciate it if you didn't rush through this and use the terminology that you are using that you would use with some other doctor. Break it down to me in plain English so I can understand. I said because this is why I'm here otherwise I wouldn't even waste your time, I said. So right now I need a little of your time for me. So you, you know, slow down and tell me what I need to know about me." And he stopped and he looked at me and then I guess he had a change of mind. Well, this here person here, she's gonna, you know, she's demanding my attention and right now I have to give it, you know. So then he sat down and he explained things to me. But otherwise had I not said anything, she was going to rush me right on out the door with some bills.

Betty: Did you go back to him?

Leona: No, I haven't been back to him.

Betty: OK.

Delois: You have to explain to those doctors the same way I stop you for your help, those patients you feel like you're going to rush out, they need the same attention that you fixin to give me. That's just the way I tell them. So when I leave, you give them the same attention cause I got mine. So you give them the same attention.

Amelie: OK. What would make information about pain treatment easier to understand? How can you make information about pain treatment easier? Delease?

Delease: What was that about?

Amelie: What would make information about pain treatment easier to understand? How can you make the information that you're giving to the person easier to understand?

Delese: Well, you should have booklets and pamphlets to read up on different things that's going on with your body and the doctor talking to them.

Amelie: What would make information about pain treatment easier to understand?

Delese: Like I said before. reading up on different kind of pamphlets and someone talking to you about it, you know. The doctor, nurse.

Amelie: Sophie, would you like to add something to this?

Sophie: Well, to make the pain medication easier for the patient, they should try to talk to the patient on the patient's level. Cause if you're going to try to talk with somebody, like for example, somebody got a breast surgery and got a ---**(CANNOT DECIPHER WORDS)** in the back. But the person might not know what is ---**(CANNOT DECIPHER WORDS)** so you got to try to break it down and explain it to him, why should you get this, then it depend on the patient's level.

Amelie: Shirley, would you like to add something to that?

Shirley: Repeat that question?

Amelie: What would make information about pain treatment easier to understand?

Shirley: I say education and then my experience. I'd like for my doctor to break it down to my level.

Amelie: Do you call your doctor or nurse if your pain increases?

Mary B: Oh, yeah.

Amelie: Dorothy?

Dorothy: Only one time did I take medication for pain since I've had my breast surgery and that's being 33 years old and that was that first week. I still had the tumor and I had such a severe pain I had to call. So he told me to get some, uh, what is the strongest Tylenol?

Everybody: Extra Strength Tylenol.

Dorothy: And I think I took two and then I haven't had any medication since my surgery. I don't take medication, even if I have a headache. I sit and know the reason why I have a headache so I just relax and I have pressure points in just relaxing, give myself therapy. I don't take medication.

Amelie: Have any of you called your doctor if your pain increases? If you are at home or the hospital?

Everybody: Yes, definitely.

Amelie: And how can we encourage women to call their doctor or nurse? Like meaning people again who are afraid to talk to their doctor? How can we encourage them?

Delois: You don't need to call them. When you're in pain you're going to call them. You don't need nobody to encourage you to call.

Mary B.: You're going to call or find the hospital, one.

Leona: I say you have to try and encourage them and let them know too, that the doctor is there for their well-being and to help them in whatever their needs are and not to be afraid because he's a person that you should confide in, you know. He's suppose to be there for you. That's what you're paying him for.

Mary B.: Yeah, he's the one that did it.

Amelie: Help me with that Betty?

Betty: Yes and also if your family members are aware of your situation and your problems and what is happening to you, sometimes they may find it easier to talk to a doctor then the patient and they can call for you. You have someone like that. A family member.

Amelie: OK. Should we include information about other type of pain treatment besides medications such as relaxation techniques, distraction, meditation?

Delois: Meditation. The stress tapes that they give us.

Amelie: So we should include those?

Delois: Yes, include them cause like she say, she meditates. Sometimes you don't have to take pain medicine, sometimes it soothes you.

Amelie: So we should include other type of pain treatments besides medication?

Everybody: Yes.

Amelie: And what types of information about cancer pain from other patients would be helpful to you? I think you have already answered that. What types of information about cancer pain from other patients would be helpful to you. OK. What would be the best way to describe or the best

term to use for around the clock, taking pain medicine on a regular schedule, constipation, regularity, addiction, habit forming. What would be the best way to describe or the best term to use for those terms?

Delois: When you need it because it does cause constipation.

Betty: As needed.

Delois: And a lot of people have problems with constipation and it's bad on them.

Amelie: So it's better to call it constipation or irregularity?

Delois: Only if you need it. When you really need it. Because they give you time to take pain medicine, every four hours, every six hours. Sometimes within those 4-6 hours you might don't need it but then again sometimes it might help some people to keep from bringing the pain on stronger. So anyway it goes but still you have to worry about the constipation and side effects. Sometimes you take too much of medication, it will give cause side effects. But you can be hurting one place and you say, "Hey, I'm getting ready to get headaches from these medicines." You know, like them patches I use. You know automatically they give you headaches. OK. So I can't use them but every so often. So often I don't use them for my heart condition at all.

Amelie: OK. I think they want to know the best term, would you say around the clock or taking pain medicine on a regular schedule. Which one would you like better?

Everybody: Regular schedule.

Amelie: No, I mean of those two terms that I read, which one would you like to use? OK. They said what would be the best way to describe or the best term to use for around the clock or taking pain medicine on a regular schedule? Which one would you like to use better?

Everybody: Regular schedule. On a regular schedule.

Amelie: Constipation or irregularity?

Everybody: Constipation.

Amelie: Addiction or habit forming?

Mary B.: Habit forming.

Amelie: Habit forming. Anybody else?

Everybody: Habit forming. OK.

Amelie: Thank you very much and I made the time for you Delois.

Everybody: Laughter.

# Worries and Facts About Cancer Pain

If you are being treated for cancer pain, you may have some concerns about your pain medicine. Following are some of the most common worries people have and the facts about them.

## Appendix II

# **Worry**

**I can only take medicine or other treatments when I have pain**

# **Fact**

You should not wait until the pain gets bad enough for you to take your pain medicine. It is easier to control your pain when you are having only a little pain rather than when your pain is really bad. You should take your pain medicine as your doctor or nurse tells you. Your doctor may even have you take your pain medicine on a regular schedule and around the clock. Don't forget that you can also use other treatments, such as relaxation and breathing exercises, soft music, hot and cold packs, as often as you want.

# Worry

**I will become “hooked” or “addicted” to pain medicine.**

# Fact

Getting “hooked” or “addicted” to pain medicine is very rare. It is important to take your pain medicine regularly to keep the pain under control.



**Remember: People who abuse drugs take drugs to get high. People with cancer pain take medicine to get relief.**



# Worry

**If I take too much pain medicine, it will stop working.**

## Fact

The pain medicine will not stop working. But sometimes your body will get used to the medicine. This is usually not a problem with cancer pain treatment because your doctor can increase your dose or change your pain medicine and other medicines can be added to relieve your pain.



**Remember: Cancer pain can be relieved, so you don't have to deny yourself pain relief now!**

# Worry

**If I complain too much, I am not being a good patient.**

## Fact

Controlling your pain is a very important part of your cancer care!  
You must tell your doctor and nurses if:

- \* You are having pain
- \* Your pain is getting worse
- \* You are taking your pain medicine and it is not working

They can help you get relief from your pain, but you must tell them:

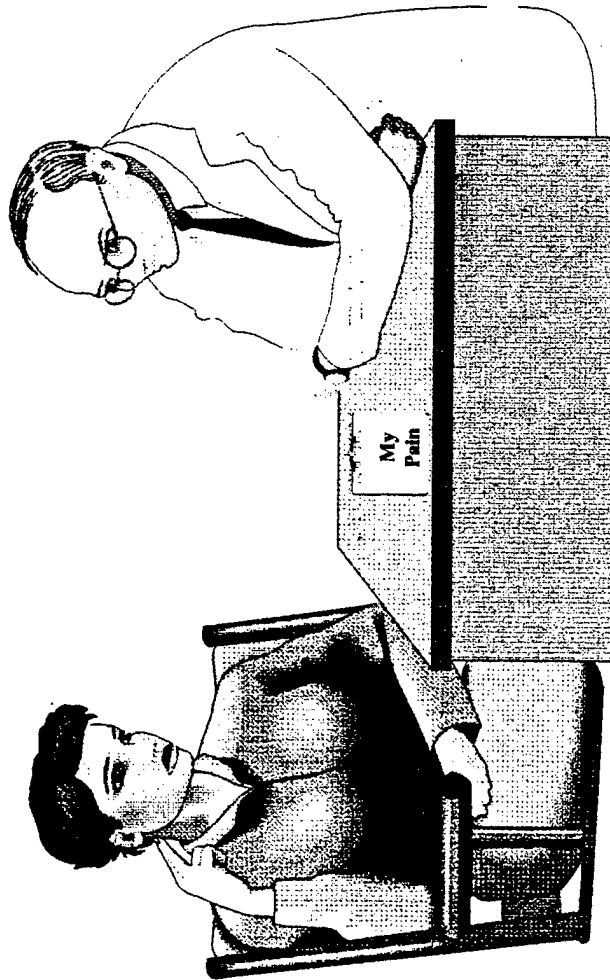
- \* Where you hurt
- \* How bad the pain is
- \* What your pain feels like

You may have other worries about your treatment that were not discussed here.

Remember to always talk to your doctor or nurse about your worries

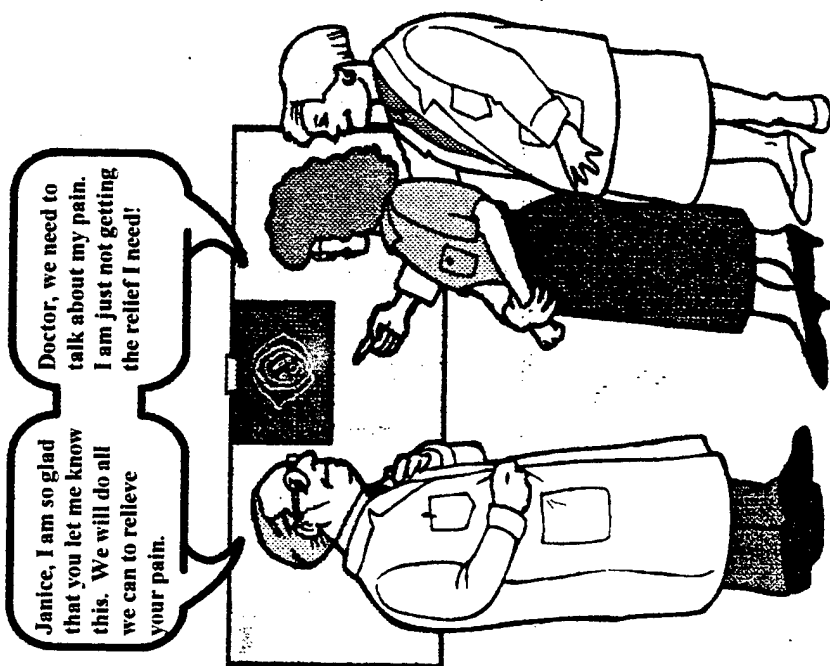


# Talking To Your Doctors And Nurses About Your Pain



Your doctors and nurses can sometimes get so busy that they may forget to ask you about your pain as often as they should. Because your doctor may only be able to spend a little time talking to you at each visit, you must be ready to talk about your pain.

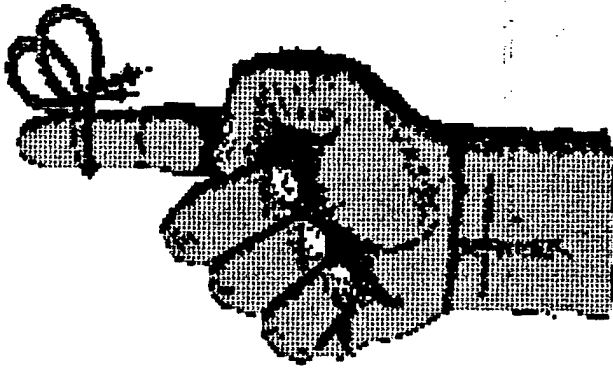
# Get The Doctors And Nurses Attention



If you don't tell them that your pain is not being relieved, they may assume that you are doing fine.

Many people tend to think that their doctors and nurses would know if they were hurting and would be doing whatever they could to relieve the pain. It is both you and your doctors responsibility to talk about your pain.

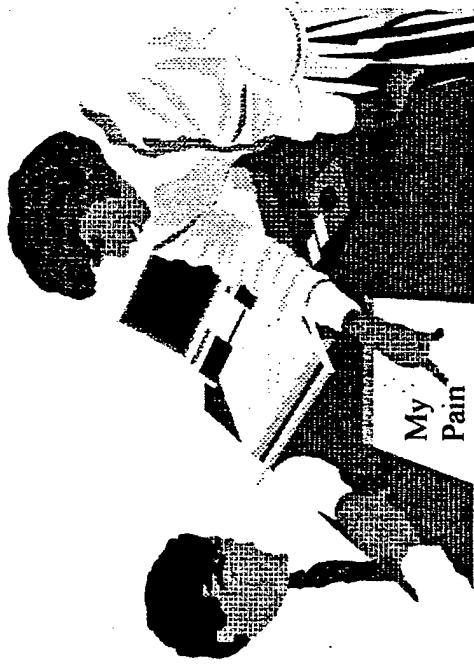
If your doctor or nurse forgets to ask you about your pain control, **PLEASE** remind them, and do it more than once if you have to.



## **REMEMBER!**

**Your doctor is depending on you to let him or her know if you are getting relief from your cancer pain.**

# Things You Need To Tell Your Doctors And Nurses About Your Pain



Once you have your doctors and nurses attention, he or she will ask you try and help them understand how much pain you are having so that they can understand your pain through your eyes.

Also if your doctor has made changes in your pain medicine he or she will need to know if these changes have or have not worked.

## Tell Them:



### How much pain you are having

Some people can rate pain using numbers with zero meaning no pain and 10 meaning that your pain is as bad as it can get. (See pain rating scale below)

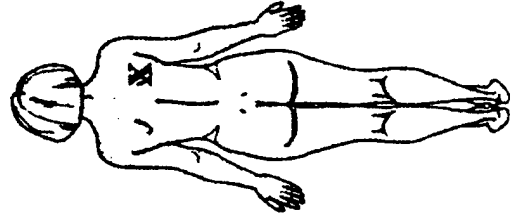
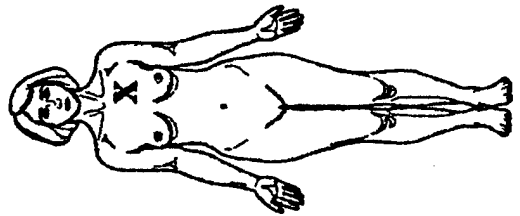
0	1	2	3	4	5	6	7	8	9	10
No Pain			Mild		Moderate		Severe			Pain as bad as can be

Don't worry if you are unable to put a number on your pain, because you and your doctors and nurses will find a way to talk to each other about your pain



## Where you are hurting

As simple as it may sound, your doctor will also ask you where you are hurting. Sometimes where you hurt is quite obvious, like where you had surgery. At other times you may be having some pain that is not as obvious. Therefore it is necessary that you explain where you are hurting. Remember to tell your doctor all of the places that you are having pain. Your doctor may have you mark the places where you are having pain on a picture like the one below.





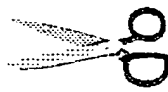


## What type of pain are you having?

There are many different types of pain and the following list are a few of the types of pain. The purpose of listing them is to help you find words to explain your pain to your doctors and nurses.



Burning



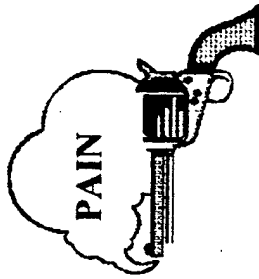
Cutting



Pressure



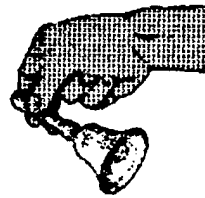
Sharp



Shooting

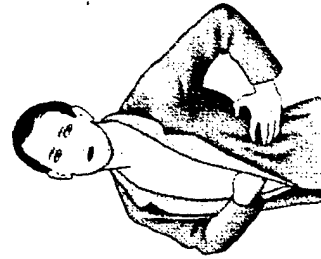


Throbbing



Cramping

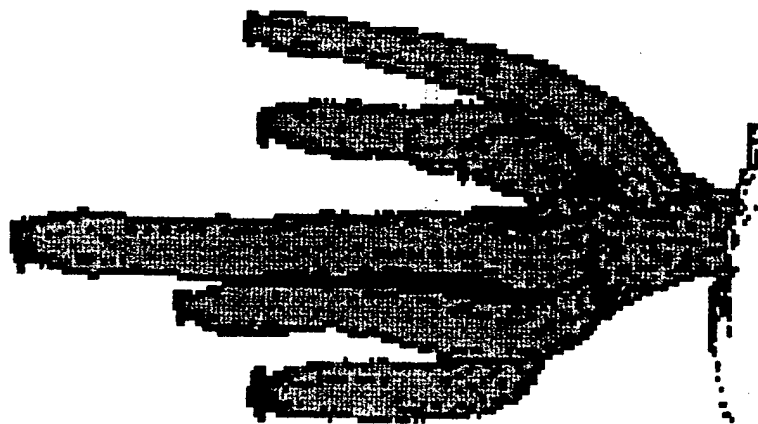
Tingling



Aching

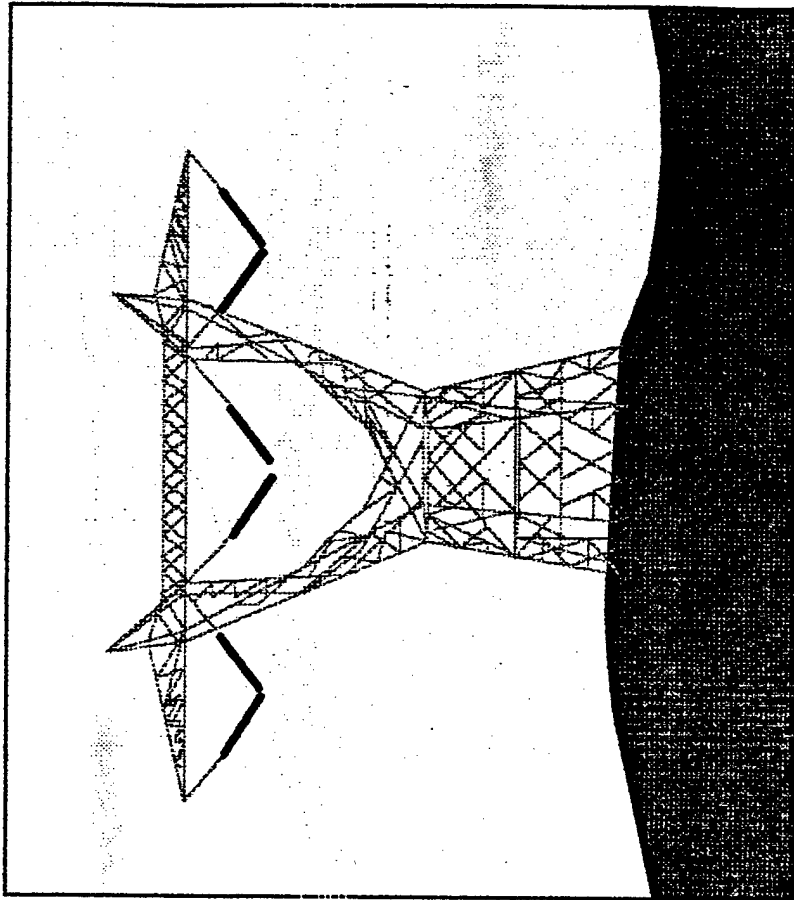
**Other words that might help you  
describe your pain are:**

# Prickly



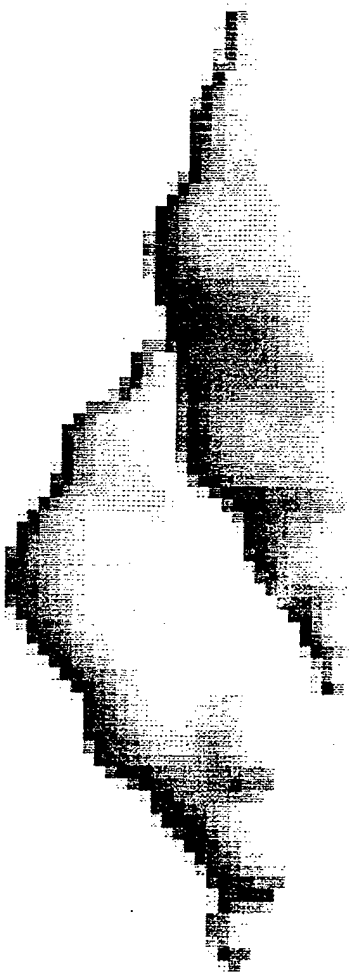
Some pain feels prickly like or even like there are ants crawling all over parts of your body.

# Electrical or Shock-like



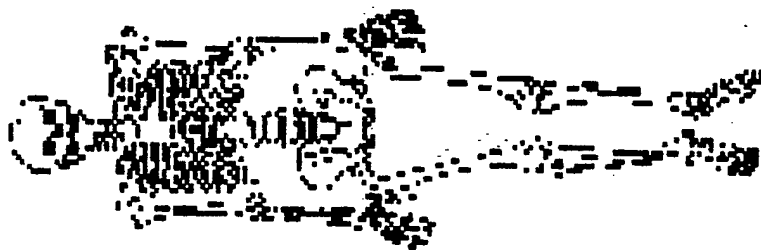
Some pain feels like an electrical shock that travels from one part of your body to another.

# Lightening



Some pain feels like lightening because it moves from place to place. This may also be described as feeling like an electrical shock or jolt as well.

# Bone Pain



Bone pain can be either dull or sharp. Sometimes the skin over bones can get very sore and become extra sensitive to even the slightest touch.

# Burns Like Fire



Some pain feels like you're being burned by a fire but there has not been a flame.

# Feels Like a Horse Kicked Me



Sometimes pain is more dull, like you feel a few days after having been in an accident



## **When is the pain worse?**

- ☐ In the morning
- ☐ During the night
- ☐ With activity
- ☐ I can't predict when it will get worse
- ☐ Before my next dose of medicine

# What things make your pain worse?



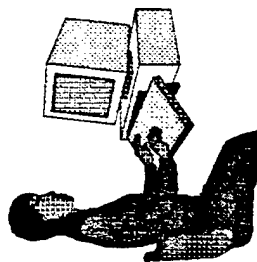
Sitting



Walking



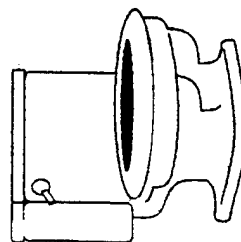
Eating



Working



Being Active

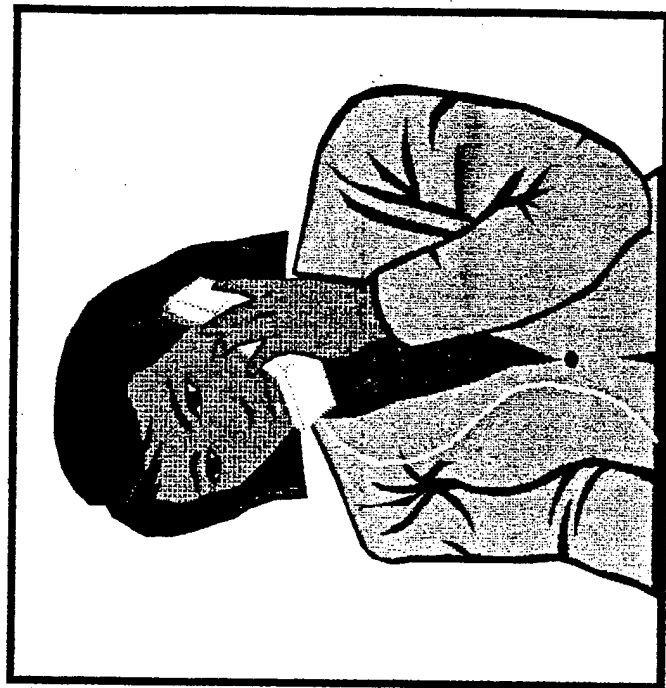


Toilet

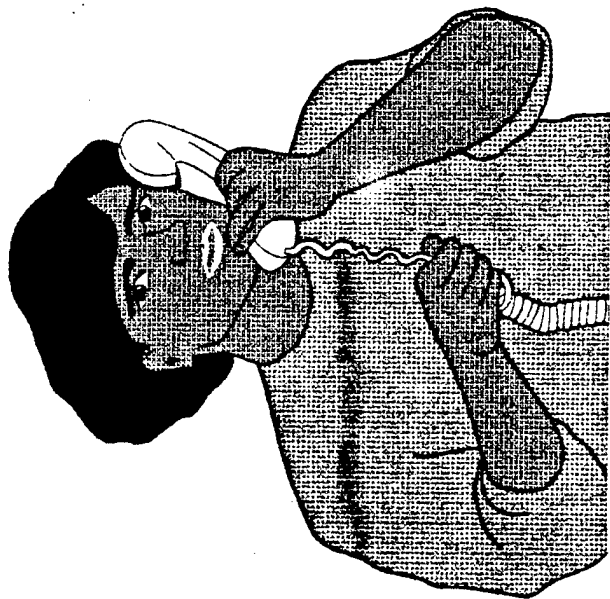


Sleeping

# Talking To Your Doctor And Nurse About Your Pain By Telephone



There may be times when your pain is not being relieved and you are unable to come into the clinic or doctor's office. In times like this your should feel free to call the clinic and let the doctors and nurses know that your pain is not being relieved.



Hi my name is Carol Edwards and I have been having quite a bit of pain for the last 5 days. I am taking Morphine 15 mg every 4 hours but I am not getting very much relief. My pain is located in my left chest wall where I had my breast removed. I would say that my pain is a 9 on a scale of 1 to 10. This pain is keeping me from sleeping and doing my housework. I am also having quite a bit of constipation. Please help me get some relief. I have tried using cold packs and relaxation tapes, but these things have not helped relieve my pain.

When you call the clinic, you should give the following information to the doctor or nurse:

1. Your name.
2. The name of your medicine and the amount you are taking.
3. How long you have been taking the current pain medicine.
4. Where your are hurting.
5. How long you have been hurting without relief.
6. Your average pain rating the last several days using the pain scale on page \_\_\_\_  
(0 = no pain, 10 = most pain possible).
7. Your highest or lowest pain rating in the last 24 hours.
8. Side effects that you may be having as a result of your pain
9. Other things you may be doing to relieve your pain (heat, cold, rest, distraction...)

81.

	<b>ON CAMERA /</b> (comments about her pain) <b>ON CAMERA /</b> (comments about her pain)
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	<b>ON CAMERA NARRATOR</b> The cancer patients you have just seen and heard have all experienced some kind of pain from cancer, either from the disease itself or from side effects from treatments. Some patients believe that having pain is part of having cancer, and that there is nothing that can be done about it. That is not true. Instead of <u>accepting</u> pain as a part of their disease, the patients you have just heard have taken steps to do something about it. They were able to find relief. You can, too.
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<b>TITLE:</b>  <b>Pain from Cancer:</b> <b>You <u>Can</u> Do Something About It</b>	     <b>(music out)</b>
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	<b>ON CAMERA /</b> <b>#1 8:55 :23</b> "I was willing to do whatever it took to help get me out of that pain, to relieve me of that pain and if it meant taking drugs for the rest of my life I was willing to do it, worrying about being addicted to it, I wasn't gonna worry about that, that was my least worry. All I wanted was to be able to get some of my life back."
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	<p><b>ON CAMERA /</b>  <b>#2 14:32 :31</b>  "The doctors explained to me that associated with my type of pain that it's going to be probably ongoing. There is no cure per se for it. I have learned to focus on pain management rather than thinking that it's going to go completely away. I have learned to just manage the pain. You have to stay focused. You have to keep an open mind. You have to keep your spirits up."</p>
	<p><b>ON CAMERA /</b>  (comments about what she did to manage pain)  <b>ON CAMERA /</b>  (comments about what she did to manage pain)</p>
<p><b>CG or Title</b>  You Don't Have To Put Up With Pain</p>	<p><b>ON CAMERA NARRATOR</b>  It's very important for you to know that you don't have to put up with pain. Some 80 to 90% of cancer patients can get <u>good</u> pain relief from <u>medications</u> taken by mouth. The other 10 to 20% can get other pain treatments. Remember, you <u>can</u> get good pain relief. You have a <u>right</u> to it.</p>
	<p><b>INTERVIEW /</b>  <b>(from another video) :19</b>  "What we know is that in patients who are experiencing pain, even severe pain, we can successfully treat it in the vast majority of patients. I'm talking 80 to 90% of patients. By the application of simple principals."</p>

	<b>INTERVIEW /</b> <b>#2 2:28 :16</b> "You do not have to live with cancer pain. There are a lot of things that your doctor can do to help you with pain, but first of all, you need to be able to talk with your physicians and let them know that you are having pain."
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<b>CG of Title</b> Tell you doctor or nurse about your pain	<b>ON CAMERA NARRATOR</b> Good communication is very important. Even if your doctor or nurse doesn't <u>ask</u> about your pain, it's very important for you to <u>tell</u> them about it. If you don't tell the doctor, he won't know how to treat you. Let's look at an example of how you can tell the doctor about your pain.
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### VIGNETTE #1

	<b>VIGNETTE #1</b> <b>Doctor: (looking at chart)</b> "Well, I hope things go well until we see you at your next appointment in about three weeks."
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	<b>Patient:</b> "Um, doctor...there's one other thing I wanted to ask you about. It's about my pain. It's gotten pretty bad. Sometimes I can barely get out of bed, it's so bad."
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	<b>Doctor: (writing in chart)</b> "Uh, huh."
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	<b>Patient:</b> "It's like a sharp stabbing pain in my back that just won't go away. I can't sleep. I don't feel like eating. I got this pamphlet from the nurse the last time that says to give the pain a number, so I tried to think about it like that. And, uh, on a scale of zero to ten I'd say this pain is about a nine."
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	<b>Doctor: (paging through chart)</b> "Let's see...what are you doing for pain now?"
	<b>Patient:</b> "I'm taking Tylenol, and I'm resting as much as possible. The Tylenol helps some of the time. But other times it's not helping at all."
	<b>Doctor:</b> "I'm going to give you something stronger than the Tylenol. And I want you to be sure to take it at the times I've written down for you. We can help you control this pain."
B-roll exam room	<b>ON CAMERA NARRATOR</b> This patient took action to get pain relief. She was able to talk to her doctor about it. Let's look at exactly what she did. First she told the Doctor that she had pain.
	<b>Patient</b> "Um, doctor...there's one other thing I wanted to ask you about. It's about my pain. It's gotten pretty bad. Sometimes I can barely get out of bed, it's so bad."
Show pain scale.	<b>V/O NARRATOR:</b> "Then, by rating the pain on a scale of zero to ten, she made it easier for her doctor to understand that this is not just discomfort. A lot of doctors use a number scale to rate a patient's pain. Zero means no pain at all. 10 means pain as bad as it can get. A pain that is fairly strong might be a 5 or a 6, and a pain that is very hard to put up with might be an 8."

	<b>Patient:</b> "Um, on a scale of zero to ten, I'd say this pain is about a nine."
<b>CG:</b> BE CLEAR (??not sure this title will work here)	<b>V/O NARRATOR</b> She also described her pain clearly, so that the doctor could understand. She didn't just say that she hurt. She described <u>where</u> she was hurting, how the pain felt, and how long the pain was lasting.
	<b>Patient:</b> "It's like a sharp, stabbing pain in my back that just won't go away."
	<b>V/O NARRATOR</b> She also told the doctor that the pain was interfering with her life.
	<b>Patient:</b> "I can't sleep. I don't feel like eating."
	<b>V/O NARRATOR</b> When the doctor asked what she was doing for the pain, she was ready to respond.
	<b>Patient:</b> "I'm taking Tylenol, and I'm resting as much as possible. The Tylenol helps some of the time. But other times it's not helping at all.
	<b>V/O NARRATOR</b> It is important to keep a list of the medications with you. It is also important that you give your doctor an idea about how often you are having to take pain medication. With this information, the doctor can make changes in the medicine to help with your pain.

	<b>Doctor:</b> "I'm going to give you something stronger than the Tylenol. And I want you to be sure to take it at the times that I've written down for you. Taking the medicine on a regular schedule will really help you to control this pain."
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<b>CG:</b> --tell her doctor she was having pain -- <u>where</u> she was having pain --kind of pain -- <u>what</u> she was doing to relieve pain  DON'T LET FEAR OF PAIN MEDICINES KEEP YOU FROM GETTING HELP	<b>V/O NARRATOR</b> By being ready to tell her doctor that she is experiencing pain, this patient was able to get help because she was able to: 1) tell her doctor that she was having pain, 2) tell her doctor <u>where</u> she was having pain, 3) explain the kind of pain she was having, and 4) tell her doctor <u>what</u> she was doing to relieve her pain.  <b>ON CAMERA NARRATOR</b> But some people with cancer don't feel comfortable asking for help to relieve their pain. Patients sometimes let fear keep them from getting help. Let's look at some of the things that keep people from asking for pain relief. One of them is fear of taking medications.
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	<b>ON CAMERA /</b> <b>#1 4:14 :9</b> "I did have fear about taking the medicine, because you know you hear about 'drugs,' 'dope addicts' and 'addiction to medication' and all that kind of stuff..."
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	<b>ON CAMERA /</b> <b>#2 3:48 :24</b> "You should not be worried about becoming addicted to the pain medicines. If you take your pain medicines as your doctor prescribes them, you will get good relief from your pain, and if not you should let them know that you're not 'cause they can adjust it, but you should use your energy to fight your cancer and not, you know, that pain."
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	<b>ON CAMERA /</b> <b>#1 4:38 :20</b> "At that time, all I wanted was something really was to relieve some of that pain, and I was willing to forget about getting addicted to medicine or anything like that ...just to be able to get back to doing some of the things I was used to doing."
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	<b>ON CAMERA / NARRATOR</b> Some patients want to save their pain medicine for times when the pain is severe. They are afraid the medications won't work if they take it at regular times.
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	<b>ON CAMERA / COMMENTS FROM PATIENTS ABOUT SAVING THEIR MEDICATIONS ONLY FOR SEVERE PAIN</b>
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	<p><b>ON CAMERA /</b>  <b>#2 5:46 :29</b>          "You really shouldn't save pain medicines for when your pain is really bad. The reason that your doctor prescribed these pain medicines on a regular basis is so that you can stay on top of your pain to make sure that you take it as directed. It'll keep it under control, because sometimes you can wait and hoard it and then come back and the pain is just out of control, and it's very difficult to get it under control when it's like that."</p>
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	<p><b>ON CAMERA /</b>  <b>(from another video)</b>          "One of the things we have learned over the years about pain is that it is better to control pain and to try to prevent it from building up than to try to treat it after it's built up to a really high level. In fact, we've done lots of studies on this, and we know that you end up taking more medication, and you have poorer pain control if you wait for the pain to build up to as much as you can possibly tolerate, and then try to take medication..."</p>
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	<p><b>ON CAMERA / PATIENT COMMENTS ABOUT LEARNING TO TAKE MEDICATIONS ON A REGULAR BASIS AND NOT WAITING UNTIL THE PAIN GETS REALLY BAD</b></p>
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	<p><b>ON CAMERA / NARRATOR</b>          Some patients are afraid of taking strong medicines because of things they have heard about the drug.</p>
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B-roll shots of over cut	<p><b>ON CAMERA /</b>  <b>#2 30:02 :24</b>          "The fear of being addicted to a pain killer...I think that you should realistically look at that...discuss it with your doctor if you're afraid that your medication is going to become addictive...talk with them about that.. I think that they can tell you if the medication is going to become addictive. They can change it before it does."</p> <p><b>#2 30:25 :11</b>          "I think that in every area, you should be very open, very honest with your doctor. Let him know that you have these fears and they can address them at that time."</p>
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	<p><b>ON CAMERA /</b>  <b>#2 6:38 :19</b>          "Morphine is one of the better medicines that we have for treating pain and that is the reason why it's used so much for pain, such as cancer pain, and it's been shown to be very effective and so it doesn't necessarily mean that you are dying. We just want you to get good pain relief from your pain."</p>
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	<p><b>ON CAMERA /</b>  <b>(from another video) :25</b>          "What we've learned over the past 15, 20 years treating literally thousands of patients who have cancer, is that if you need to use morphine it can be used safely. You don't become addicted. You don't become a crazy person who just wants to take morphine and do nothing else with your life, that you take it just like you take any other medication that a doctor would prescribe."</p>
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	<b>ON CAMERA / PATIENT COMMENTS ABOUT HOW THE MORPHINE WAS EFFECTIVE AND REALLY MADE A DIFFERENCE</b>
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	<b>ON CAMERA NARRATOR</b> Sometimes patients have problems with their pain medicine. Some people experience side effects or find that their pain gets worse after a while. It's very important to call the doctor and ask what you can do to correct these problems.
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## VIGNETTE #2

	<b>VIGNETTE #2 – ON PHONE</b> <b>Patient:</b> "Dr., my pain is getting worse, and I'm having some upset stomach and constipation. It's really keeping me from doing things around the house." <b>Doctor:</b> "O.K., Felicia. I understand. We can certainly give you something for the side effects. And let's try a different dosage of the medication. I'll call the pharmacy and give them a new prescription. I'm glad you let me know."
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Continue shots of phone conversation	<b>V/O NARRATOR</b> This patient is asking for the pain relief she deserves. By taking care of her pain, she can use her energy to fight the cancer, NOT the pain. <b>ON CAMERA NARRATOR</b> Finally, some patients don't get help for their pain, because they think that the doctor is too busy to listen or doesn't want to know about their pain.
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	<p><b>ON CAMERA /</b>  <b>#2 8:11 :17</b>          "I encourage you to please talk to your physician. Your physician is concerned about your pain. He wants you to get good relief, but it is necessary that you talk to your physician to let him know, because you know they really don't know if you are having pain. Only you can give that information to your physician."</p>
	<p><b>ON CAMERA /</b>  <b>#2 20:05 :25</b>          "I think that probably you should sit down at home when you're having your pain, write down what's happening, write down how you're feeling and then when you visit your doctor, pull out your little notepad and say well right now, I may not be hurting, but last week I had this stabbing pain. Talk to them."</p>
	<p><b>ON CAMERA /</b>  <b>#2 8:34 :22</b>          "You just need to get his attention, you know, and just stop him and just say, 'listen, I'm having problems with my pain. It's gotten worse, and I need some help and you need to be able to tell him what type of pain that you're having...where you're hurting and how long you've been hurting...and what you've been doing, you know, to relieve your pain."</p>



	<p><b>ON CAMERA /</b>  <b>(from another video) :28</b>          "Having your pain managed is important, and I would say a critical part of your overall cancer treatments, and so that most doctors or nurses, if they're doing their job, won't feel like you're being a complaining or whining patient when you talk to them about pain. Certainly, many of the patients I see can't even deal with talking about their cancer until their pain gets under control."</p>
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	<p><b>ON CAMERA /</b>  <b>#1 6:24 :13</b>          "it's hard to describe pain. People ask you, well, can you describe your pain? Pain is hard to describe. I mean, you know how you feel and everything, but it's hard trying to tell somebody else, but I would try to the best of my knowledge to try and tell 'em how I feel and everything."</p>
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	<p><b>ON CAMERA ;</b>  <b>#2 20:45 :30</b>          "I've talked with my doctor openly and honestly and said, 'you know, this hurts, and there's nothing that I felt that I couldn't talk to them about. I asked everything, no matter how stupid it sounded to me even. I've asked my doctor...'What's happening to me? What can I expect? What's gonna happen down the road? Are there treatments? Is there anything at home to help me? What can I do?' "</p>
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	<p><b>ON CAMERA /</b></p> <p><b>#1 12:02 :27</b></p> <p>"Don't be afraid. Come on out and ask your questions and talk to him. Talk to him like you would be talking to a friend or a neighbor, and they are willing to listen if you are willing to talk about it...now if you're just going to sit there and not say anything, they don't know how to help you, if you don't talk and that's the only way they gonna...can help you with your problem is by you telling them what's wrong with you."</p>
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<p><b><u>CG LIST over video or background</u></b></p> <p>--You don't have to put up with pain.</p> <p>--Talk to your doctor or nurse</p> <p>--Be clear when describing the pain</p> <p>-- Don't let fear of pain medicines keep you from getting help</p> <p>-- Don't give up</p>	<p><b>ON CAMERA NARRATOR</b></p> <p>The patients we have just heard made sure that they talked to their doctors about their pain. And because of that, their pain got better. Let's review the important things you should do if you feel pain.</p> <p><b>V/O NARRATOR</b></p> <p>One, you should understand that you don't have to put up with pain just because you have cancer. Good pain control has to be part of your cancer treatment.</p> <p>Two, talk to your doctor or nurse about the pain even if your doctor doesn't ask. If you don't tell them, they won't know, and they can't offer the help you need.</p> <p>Three, be as clear as you can about where the pain is, how bad it is, what kind of pain it is, what you are doing to relieve the pain, and how the pain affects your life. Placing the pain on a scale of zero to ten can help the doctor understand how severe your pain is.</p> <p>Four, don't let fears about pain medicine keep you from getting help.</p> <p>Five, and most important, <b>DON'T GIVE UP.</b> If the medicine you are taking doesn't help, keep telling the doctor or nurse about your pain until you get something that helps relieve your pain.</p> <p><b>ON CAMERA NARRATOR</b></p> <p>Remember, instead of accepting pain as part of your disease, you <u>can</u> do something about it.</p>
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	<p><b>ON CAMERA /</b></p> <p><b>#1 12:54 :18</b></p> <p>"I go to work every day. On weekends I do whatever...I go shopping, get up on Sunday and go to church and ready for Monday to go back to work, so I work in my yard. I deal with it. I deal with my pain day by day."</p>
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# Appendix IV

## **Draft of Text for Hispanic Pain Management Booklet**

### **Preocupaciones y explicaciones acerca del dolor por cáncer.**

#### **Preocupación**

**Yo puedo tomar la medicina u otros tratamientos solamente cuando tengo el dolor.**

#### **Explicación**

Usted no debe esperar hasta que el dolor sea lo suficiente intenso o fuerte para tomar su medicina. Es mas fácil controlar su dolor cuando su dolor es poco intenso que cuando su dolor es realmente muy fuerte. Usted debe tomar su medicina como le indicó el doctor y/o la enfermera. Su doctor además querra que Usted tome su medicina con un horario regular y a la misma hora cada día. No se olvide que también puede usar otros tratamientos. Estos tratamientos son: la relajación, los ejercicios respiratorios, música suave, compresas frías o calientes. Además puede usarlos tan seguido como Usted lo quiera.

#### **Preocupación**

**Me volveré dependiente o adicto a la medicina para el dolor.**

#### **Explicación**

Volverse adicto o dependiente a la medicina del dolor es muy raro. Es muy importante tomar la medicina para el dolor regularmente para mantener el dolor bajo control.

**Recuerde: Las personas que abusan de las drogas las toman por sentirse bien, es decir; para cambiar su estado de ánimo. Las personas con dolor por cáncer toman la medicina para aliviarse.**

#### **Preocupación**

**Si tomo mucha medicina para el dolor, esta ya no funcionará.**

#### **Explicación**

La medicina para el dolor no dejará de funcionar. Algunas veces su cuerpo se acostumbrará a la medicina. Esto en general no es un problema para los pacientes con tratamiento para el dolor por cáncer porque su doctor puede hacer algunos cambios. Por ejemplo, puede aumentar la cantidad de la medicina, cambiar de medicina o bien; agregar otras medicinas a la que Usted ya esta tomando para el dolor.

**Recuerde: El dolor por cáncer puede ser aliviado, no se niegue a aliviarse del dolor!**

## **Preocupación**

**Si me quejo mucho, no estoy siendo un buen paciente.**

## **Explicación**

Controlar su dolor es una parte muy importante de su tratamiento del cáncer. Usted debe decirle a su doctor y enfermeras que:

- \*Usted tiene dolor
- \*Su dolor se hace mas fuerte o intenso
- \*Que esta tomando medicina para el dolor y no le esta funcionando

Su doctor y enfermeras pueden ayudarlo a aliviarse de su dolor, pero debe decirles:

- \*Dónde le duele
- \*Que tan fuerte o intenso es el dolor
- \*Que tipo de dolor siente

Usted puede tener algunas otras inquietudes o preocupaciones sobre su tratamiento que no mencionamos aqui. Recuerde hablar siempre con su doctor y enfermeras acerca de sus inquietudes o preocupaciones.

## **Hablando con su doctor y enfermeras acerca de su dolor.**

Su médico y enfermeras algunas veces estan tan apurados que pueden olvidar preguntarle acerca de su dolor. Su doctor solo tiene tiempo muy limitado para hablar con Usted durante las visitas médicas. Por esto; Usted debe estar listo para hablarles sobre su dolor.

## **Llame la atención de los doctores y las enfermeras.**

Si Usted no les dice que su dolor no ha sido aliviado, ellos pensarán que Usted esta bien. Mucha gente piensa o cree que sus doctores y enfermeras sabrán que ellos sienten dolor y que harán todo lo posible por aliviarlos. Es responsabilidad de los dos, de Usted y de su doctor de hablar acerca del dolor que usted siente. Si su doctor o enfermera olvidan preguntarle acerca del control de su dolor, **POR FAVOR** recuérdelos. Hágalo cuantas veces sea necesario.

## **Recuerde!**

**Su doctor depende de usted para saber si usted ha sentido alivio de su dolor por cáncer.**

## **Cosas que Usted necesita decirle a su doctor y enfermeras acerca de su dolor.**

Una vez que Usted llamó la atención de su doctor y enfermeras, ellos le harán preguntas para tratar de entender como es y cuanto dolor tiene. De este modo, ellos podrán entender como es su dolor.

Si su doctor ya ha hecho cambios en las dosis o sea, en la cantidad de su medicina para el dolor, el doctor necesitará saber si estos cambios en la medicina han funcionado o no.

### **Dígales acerca de:**

#### **1) Cuánto dolor siente...**

Algunas personas pueden describir su dolor usando números. Usan el cero para decir que no tienen dolor y el diez para decir que el dolor lo más fuerte o intenso que pueden sentir. No se preocupe si Usted no es capaz de ponerle un número a su dolor pues Usted, su doctor y sus enfermeras encontrarán la manera de comunicarse y hablar de su dolor.

#### **2) Dónde le duele...**

Tan simple como suena, su doctor le preguntará en que parte de su cuerpo le duele. Algunas veces es muy fácil saber donde le duele por ejemplo; en el sitio donde Usted tuvo una operación o cirugía. En otras ocasiones, Usted podrá sentir dolor que no es tan obvio o fácil de reconocer. En estos casos, será necesario que explique en qué parte de su cuerpo siente el dolor. Recuerde decirle al doctor todas las partes de su cuerpo donde siente dolor. Puede que su doctor le pida que marque todas las partes del cuerpo donde siente dolor en un dibujo como el que se muestra en seguida.

#### **3) Que tipo de dolor esta Usted sintiendo..**

Hay muchos tipos diferentes de dolor y en la siguiente lista mencionamos algunos de ellos.

El fin de mencionarlos es para ayudarle a encontrar las palabras para explicarle a su doctor y enfermeras el tipo de dolor que Usted siente.

- \* Quemante (burning)
- \* Cortante (cutting)
- \* Presion (pressure)
- \* Agudo (sharp)
- \* Difuso (shooting)
- \* Palpitante (throbbing)

- \*Cólico (cramping)
- \*Comezón o picante (Tingling)
- \*Continuo (aching)

Otras palabras que le pueden ayudar a describir su dolor son:

- \* como hormigueo o piquetes (prickly) es decir, como si tuviera hormigas sobre su cuerpo
- \* como choque eléctrico o calambres o "toques". Algunos dolores se sienten como un toque o calambre eléctrico que pasa de una a otra parte del cuerpo
- \* como relámpagos que se mueven de una parte a otra del cuerpo
- \* como dolor de huesos. Este dolor puede ser punzante y agudo o bien; sordo y difuso. Algunas veces, la piel que cubre los huesos se siente adolorida y se vuelve muy sensible, aún al mas leve o ligero roce
- \* quema como fuego
- \* como una patada o golpe

#### 4) Cuándo es peor el dolor...

- \*en la mañana
- \*durante la noche
- \*con la actividad o haciendo movimientos
- \*no se puede predecir cuando aumentará o cuando sera peor...
- \*antes de tomar mi dosis de medicamento

#### 5) ¿Qué cosas hacen su dolor peor o mas intenso?

- \*sentarse
- \*caminar
- \*comer
- \*trabajar
- \*estar activo
- \*ir al baño
- \*dormir



### **Hablando con su doctor o enfermera acerca de su dolor por teléfono**

Habrà veces que su dolor no mejore y Usted no se sienta capaz de ir a la clínica o a la oficina del doctor. En momentos así, debe sentirse con libertad de llamar a la clínica y hacerle saber al doctor o enfermeras que su dolor no se alivia o se controla.

Cuando llame a la clínica, deberá dar la siguiente información al doctor o a la enfermera:

- 1) Su nombre
- 2) El nombre de su medicina y la cantidad que esta tomando
- 3) Desde hace cuanto tiempo esta Usted tomando esa medicina
- 4) Dónde le duele
- 5) Desde cuando tiene este dolor sin sentir mejoría
- 6) Su dolor promedio en la escala del dolor durante los últimos días. Recuerde que cero (0) quiere decir que no hay dolor y diez (10) quiere decir el dolor mas fuerte que Usted se puede imaginar
- 7) Su grado de dolor más alto y más bajo desde el día anterior o sea, en las últimas 24 horas
- 8) Efectos colaterales o secundarios que Usted sienta como resultado del dolor
- 9) Otras cosas que haya probado para tratar de aliviar el dolor. Estas cosas son: calor, frio, descansar o distraerse.

# Appendix V

## MANAGING YOUR PAIN

*Summary of Focus Group (Hispanic Women)  
Conducted by the University of Texas  
MD Anderson Cancer Center  
August 30, 1997*

### **Purpose**

The University of Texas MD Anderson Cancer Center wants to make a video tape and booklet about cancer pain for Hispanic women who have breast cancer. The video tape and booklet will be designed to meet the following objectives:

- ◆ To help women receive good management of their pain from their doctors.
- ◆ To teach women how to talk to their doctors about their pain.
- ◆ To teach women that strong pain medicines are safe and not addictive (or habit forming) when taken as directed by their doctor.
- ◆ To make the video and booklet sensitive to the needs and concerns of African American women who have breast cancer.

### **Method**

A focus group was conducted with three Hispanic breast cancer survivors to gain their insight for developing a video and booklet about pain management. The meeting was held in Miami, Florida at the University of Miami School of Medicine, Winn Dixie Hope Lodge. The data obtained during the focus group was transcribed for qualitative analysis.

As part of the group, respondents provided feedback on two materials:

- ◆ Script for the video, "Managing your Pain"
- ◆ Questions about the video and booklet

### **Description of participants**

Twelve Hispanic women agreed to participate in the focus group. However, only three of them attended the session. Women were selected on the following criteria: having had breast cancer and experienced some types of pain. They were asked to provide demographic characteristics. The table below describes respondents' demographic characteristics. They did not answer all the questions. The age range was 34-63 years old. They all were diagnosed in the 1990's. Their educational level ranged from high school to college and one was employed.

Participants	Age	Year of diagnosis	Employed	Income range	Occupation	Marital status	Education	Religion
1	63	1993	No			Married	High School	Catholic
2	53	1995	No			Married	High School	Catholic
3	34	1995	Yes		Cashier	Single	College	Catholic

## Findings

### Setting for the Video

No comments were made about the scripts. Participants stated that any setting can be used including a classroom and the hospital. One of the participants stated that it was up to the producer of the video to choose the setting. One participant suggested that, in addition to the setting, the information included in the video should be as important as well. They further suggested including before and after pictures of women who have been diagnosed with breast cancer, have gone through treatment and are now living normal life. They also suggested including family members and friends in the video because their support is very important.

*I think in my opinion, that any place will be alright and it would be up to those who are going to be working on it to decide where it is more convenient.*

*I think any place would be alright. What I do understand is that it should be sort of like a class so that people are not afraid.*

*It would be in the hospital, because this is the place where the woman is going to be referred to for treatment.*

*They should include picture of women who come at a certain date but later as well. Because this would be predisposed to feel better....not feeling so "down" but feeling that if thousands and thousands have been cured and look so good now, I will then feel better.*

*If they want to participate, because family support is very important. Friends.*

### Music in the Video

Participants agreed that music should be included in the video. The following were suggested: relaxing music, classical music and soft music.

*Relaxing music, classical music and soft music that women would identify the place where she is going to be treated, where she will get many alternatives.*

### Using Videotape at Home

One participant said she would not take a video about pain management at home, another answered maybe. One participant answered yes because she believed that a video can be used to teach prevention. Another participant stated that she did not know if her family members or friends would use the video at home.

*I would, because it is very important. Because you are always meeting people and not only that. It depends on your point of view, because just by showing it to certain people at the right moment, this will help them to prevent too.*

### **Booklet**

Participants suggested including information such as cancer and its origin, addresses, telephone numbers of places where people can go, information about symptoms, procedures and steps to be taken when diagnosed with breast cancer. They emphasized on including pictures such as before and after pictures of breast cancer survivor Hispanic women to show 'there is a tomorrow'.

*More than anything else, many pictures. Pictures help very much. Before and after pictures.*

*Of people that are sick, how they are, about cancer, everything, but in pictures.*

*...Yes or no, cancer is or not detected, what should you do from here on and that there is a tomorrow. That after surgery may exist a tomorrow, that after many years well, here are the pictures that demonstrate that you can go on with your life. That it was just a moment. But this allows women to prevent.*

### **Religion in the Video**

They suggested including religion in the video as a form of support for the individual, and it should not focus on any specific religions. Some of the women believed that it is good to have faith, but it is the medicine and treatment that would cure them, not their faith. One participant further stated to have faith that the treatment will cure them.

*Having faith in my religion, I think that the medicines, the treatment, everything will help me more.*

*I know that cancer needs to be treated. You do not need...it is like a support for you, your religion. It is not certainly for the illness because illness is treated with medicines. It is just a support for the person.*

*When you learn about an illness that might kill you, I think two things are broken: the physical and the spiritual. So if you are thinking on lifting the physical one you also have to lift the spiritual one which is very important because you don't know which way to go. Therefore, if you focus on the part... God's way without mentioning each person's type of religious faith, than it is very important because you are taking both hand in hand: the physical and the spiritual. It is very important.*

*You cannot only have trust in your religion and beliefs. You have to do your treatments, do you understand? And to have faith that these treatments are what's going to bring you forward, what's going to fight the illness. But not to think that religion is what is going to cure you.*

Participants made the following suggestions on how religion should be included in the video and booklet. They stated the following sentences.

*To have a lot of faith in life...*

*Never loose hope.*

*Have much faith in life and that everybody go for what he/she wants.*

*To have faith that if you take your medicines with faith the treatment will be positive. Not to get desperate, no....those things.*

### **Sources of Information**

Participants were asked "Who would you like to see in the video giving you information about cancer pain and cancer pain management?". They mentioned a doctor, a nurse, and a cancer patient. One participant stated she preferred a doctor rather than a nurse. Another participant stated even though she would prefer a doctor to provide her with the information, she needed the nurse's support. They believed that nurses are more compassionate than doctors, well trained and use laymen terms. They further stated that a cancer patient can show support, explain what he/she has been through and show encouragement. The gender of the person did not matter; however, they preferred the person to be Hispanic.

*I would prefer the doctor because he is the one with the most knowledge.....and I can ask him for options and solutions, things maybe a nurse would not be able to answer.*

*I think that the nurse also plays a very important role along with that of the doctor. If it is true that I would prefer the doctor to inform me so that he can supply me with all the answers that I need to be satisfied, I need the nurse's support. When you leave the doctor's office, it is the nurse who gives me the last support... I think the nurse's support is very important.*

*They (nurses) are qualified like a doctor. Now days nurses are very well trained.....the doctor gives the explanations, but the nurse explains things to you like a human being and gives that love and support.*

*...This lady went through this or is giving her testimony. It is good. Because a person who has not been through it does not know how it is...*

*I think it should be one in his own language because it is very important...Each one in his own language, we know our habits and everything, you understand better.*

Participants were further asked "Who do you trust the most to give you information about cancer pain and cancer pain management?". They responded anybody that is well informed about the subject such as a cancer social worker, any one who talks the same, same patience, who gives you courage, and a doctor.

*For me, anybody who is well informed.*

*I think that not necessarily a doctor because there are people who are being prepared very much about this subject and who are very knowledgeable as to give me the correct information for me to follow.*

### **How not to Suffer with Cancer Pain**

They suggested talking to them, providing them with breast cancer information and teach them about prevention.

*Think that at the end of the booklet. If you do not want to go through all this sad and painful process, be on guard. Here are addresses, here is how to take care. Here is how you check yourself and then you go to the doctor.*

*Yes, prevention is the only thing that can avoid the pain of cancer.*

### **Information about Cancer Pain Management**

Participants wanted to know all types of information about cancer pain management including the pain medications, side effects, the pain and how it works so people won't become addicted to medications. One participant shared a story about how she learned how to manage pain in her arm after her lymphnodes were removed. One participant suggested sharing information about pain management with other people so they would know about it.

*All the instructions. To know the steps to follow, what to do, what to take, which way to go.*

*Pain, well, to know what type of pain it is. If I have pain what should I do, what should I take.*

*What are they good for, what should you take them for. In order not to abuse them.*

*It is good to know they give you relief and their consequences. Both, that is why it is good to read this information.*

### **Encouraging Cancer Patients to Take Pain Medicines**

Participants suggested showing them role model who have been persistent in taking their medication, using self as an example, showing videos of people taking their medications and living a normal life, talking to them and letting them know that the medicines are good for their well being. One participant believed it is up to the individual to take the medication.

*Seeing people who have overcome it, who are feeling good, who have been persistent in taking their medication, like me. If they see these examples, people will then have faith in their medicines and won't stop taking them.*

*I think that everything enters through the eye...If we want people to remain physically in good conditions, we have to show them many videos....We can show them videos of people who have seen the importance of taking their medications, when they get up, when they go to bed, eating their food, taking their medications and when they look good, they can go to work, even to the gym, you emphasize strongly how important it is not to stop taking your medication.*

*That medicine is everything for your health because if you don't treat the illness you will not see the*

*results. Therefore, I think that putting interest in taking your medicine as directed, the result is going to be good.*

*I think the person herself has to have an interest... I have to do it, I have to think that it is my health.*

*There are many people that decide not to take the medicine, because of a reaction they had. The person has to try and find a way in which the body will assimilate and overcome the reaction of the medicine.*

Participants were asked how to convince women that strong medicines were safe and not addictive, when taken as directed by their doctors. They responded by providing them with information.

*With a lot of information. Lots of information is what help people not to become addicted to anything and to help themselves.*

*....This is like so, this works like this, if you abuse of it, this may happen. But as long as you don't about o f it, everything is going to be fine. It will calm you, it will help you.*

### **Worries About Several Issues Concerning Pain Medications**

Participants were asked if they worry about becoming addicted. They responded no. One participant stated she only takes medicine when she needs it. Another participant stated that becoming addicted depends on the individual. They do not worry about what their family members or friends would think about their taking pain medications, and telling their doctor about their pain or other physical symptoms related to cancer. They worried about the following: the pain medicine not working, about being strong and not depending on pain medicines and the side effects. They believed that the disease has become more advanced if the pain gets worse and the medicines are not working. One participant believed it can be psychological. Participants were asked if they worried about whether or not pain medicines will work for them. They stated yes, but they would go see their doctors and asked him for another medication if it is not working. Some participants believed that taking a strong pain medicine means that you are going to die soon while others did not.

#### Worry about addiction

*I don't believe that. That I may become addicted to a pain medicine. If I take I need it , if not, I will not take it.*

*I don't think I can become addicted to something if I need it. It depends on the person to become addicted to things.*

#### Worry about family members or friends

*I don't understand that this may cause anything with my family or with my friends because I take any medication for cancer.*

*Friends and relatives are there to give support.*



Worry that doctor will think that you are complaining if keep telling them about pain.  
*Well, I don't. If I complain it is because I am in pain.*

*I don't worry in the absolute because who is living the moment is me.*

*I don't think anybody complains just to complain. It must be because he/she is having pain. I don't think that the doctor will think that I am complaining just to complain ....*

Worry about medicines not working if pain gets worse

*Yes, you should be worried because when pain is stronger than the pain killer it is because it has advanced farther. Therefore, you should be worried.*

*Sometimes one worries when the pain killer doesn't work. But sometimes it doesn't work because of how your nerves are. So worries and nerves influence very much in the person.*

Worry about whether medicines will work or not

*Sure. That would worry me if I were taking pain medicines.*

*Well, I would look for an alternative.*

*Yes, I would worry and I would immediately go see my doctor in order to find out what is wrong or why is this happening to me. It may be that these pain killers do not work for me and that he will have to use another type of pain killer.*

*If I am getting the right medicine for my body, pain will definitely stop. If not, I will have to talk to my doctor to change it for another type of medication.*

Worry about being strong and not depending on pain medicines

*....I also agree with depending on how I feel in my spirits, I will worry about depending on medications. Because if my spirits are very low then this will make me take more medicine in order to feel better.*

*....how you are feeling, your nerves, betray you more than the illness. If you are feeling good it will help you to conquer everything much easier.*

Worry about side effects from the pain medicine being worse

*Yes, I do.*

*Yes, there should be enough information about the pain killer in order to avoid side effects because when you have pain later and have an illness, to get something else because of the pain killer, that is very unpleasant.*

Worry if talk about pain, doctor will pay less attention to treating cancer and concentrate on pain  
*I think that it would help me to bear with it and I would look for the cause to see if my pain is mental because sometimes our pain is mental.*

*No, I don't think so. I think both would go together. Yes*

Worry that a strong pain medicine means that you are going to die soon

*No, a long time ago you thought, I believe, that when they gave you morphine it meant that you were about to die. Now days you pretty much know that many types of treatments can put you on strong doses of morphine....it is not because you are about to die.*

*Well, I think that when you are put on those strong medicines it is when your illness status is well advanced.*

### **Talking to Doctors about pain**

Participants expressed they had no problem talking to their doctors about pain medicine. They believed that the doctor has to help them with their pain. Most of them expressed that the experience they have had talking to their doctor or nurse has always been a positive one. One participant, who was experiencing a lot of pain at one time, shared an encounter with a physician who was very kind and nice to her after she told her about her pain. One participant stated she would ask for a second opinion or change doctor if she is not satisfied with her doctor.

*Whenever I've had a problem I have come to the doctor and he has helped me to come out of it and to go through this moment once more. So far I have received his support.*

*What I have. I go and talk, no...no... I go and explain what I have, what's my condition at this moment, you know.*

*I don't doubt that doctors are well trained but if I am in pain and it continues, it is because there is something, and if the doctor tells me that I do not have anything, I will try to be referred to another doctor or get a second opinion because I am the one with the pain, not him....*

### **Making information about pain treatment easier to understand**

Participants did not have much to say about this question. They suggested talking to the doctors and ask them to explain the pain. One participant suggested believing the treatment that one is receiving will help understand the pain.

*That the doctor explained to me why I am having this pain.*

*That you accept it well, that pain will stop. The treatment you are receiving helps the person to understand pain.*

*...Because if the doctor explains to me the cause of the pain and medicine he is giving me will*

*alleviate the pain, it is going to be easier to understand that if I am taking this medication it is because of something specifically...*

### **Increase of Pain**

Participants were asked if they would call their doctor if pain increases and how can they encourage women to call their doctor or nurse. All participants said they would call their doctor if pain increases. Participants suggested doctor and nurses should encourage women to call them by showing support, not rejection. One participant believed that support and care from a physician would give patients confidence.

*I would call him to explain to me why the pain has increased.*

*Yes, definitely. If the pain doesn't stop I have to go to the doctor. It could be that something is wrong and if I don't go to the doctor, it can get worse.*

*The person who could encourage women to consult their doctor are the doctor and the nurse themselves. We should feel that in them we will find support, not rejection.*

*....It had already been 15 days that the doctor had given me her support and gave me her card. Look, you have to call me anytime that something happens to you. This encourages me to feel free to call her whenever I am in pain...this is what gives me confidence to a woman, the patient, to call the doctor whenever needed.... lots of rejection and if you come through emergency, they will kill you.*

### **Other Types of Pain Treatment and Chosen Terms**

All participants agreed to include other types of pain treatment beside medications such as relaxation techniques, distraction, meditation. They suggested the following chosen term: '24 hours'.

*Yes, of course, it is very important. Everything you just said is very important for the relaxation of the body, when one is very tense...*

*...Relaxation techniques, mental techniques, how to breathe, to learn again how to breathe and visualization. There are other alternatives together with medicine that will help you a lot.*

**Summary of Focus group --Breast Cancer Survivors-**

Topics	Responses
Setting for the video	Any setting can be used including a classroom and the hospital; it was up to the producer of the video to choose the setting; information included in the video should be as important as well; before and after pictures of women who have been diagnosed with breast cancer and have gone through treatment and are now living normal life; include family members and friends in the video because their support is very important.
Music in the video	Relaxing music, classical music and soft music
Using video tape at home	No; maybe; yes because a video can be used to teach prevention; did not know if family members or friends would use the video at home.
Booklet	Include information such as cancer and its origin, addresses, telephone numbers of places where people can go, information about symptoms, procedures and steps to be taken when diagnosed with breast cancer; before and after pictures of breast cancer survivor Hispanic women to show 'there is a tomorrow'
Religion in the video	They suggested including religion in the video as a form of support for the individual, and it should not focus on any specific religions; they believed that it is good to have faith, but it is the medicine and treatment that would cure them, not their faith; have faith that the treatment will cure them.
Sources of information	A doctor, a nurse, anybody well informed, cancer social worker, anyone one talks the same, same patience, who gives you courage, and a cancer patient; preferred a doctor rather than a nurse; needed the nurse's support; nurses are more compassionate than doctors, well trained and use laymen terms; a cancer patient can show support, explain what he/she has been through and show encouragement; the gender of the person did not matter; however, they preferred the person to be Hispanic.
How not to suffer with cancer pain	Talk to them, provide them with breast cancer information and teach them about prevention.

Information about cancer pain management	All types of information about cancer pain management including the pain medications, side effects, the pain and how it works so people won't become addicted to medications; sharing information about pain management with other people so they would know about it.
Encouraging cancer patients to take their pain medicines	Show role model who have been persistent in taking their medication, using self as an example, showing videos of people taking their medications and living a normal life, talking to them and letting them know that the medicines are good for their well being; it is up to the individual to take medication.
Worries about several issues concerning pain medications	Did not worry about becoming addicted; one participant stated she only takes medicine when she needs it. Another participant stated that becoming addicted depends on the individual. They did not worry about what their family members or friends would think about their taking pain medications, and telling their doctor about their pain or other physical symptoms related to cancer. They worried about the following: the pain medicine not working, about being strong and not depending on pain medicines and the side effects. They believed that the disease has become more advanced if pain gets worse and the medicines are not working. One participant believed it can be psychological; they worried about whether or not pain medicines will work for them; however, they would go see their doctors and asked him for another medication if necessary; some participants believed that taking a strong pain medicine means that you are going to die soon while others did not.
Talking to doctors about pain	They had no problem talking to their doctors about pain medicine; they believed that the doctor has to help them with their pain; most of them expressed that the experience they have had talking to their doctor or nurse has always been a positive one; one participant stated she would ask for a second opinion or change doctor if she is not satisfied with her doctor.
Making information about pain treatment easier to understand	Suggested talking to their doctor and ask him to explain the pain; one participant stated that the treatment one is receiving will help understand the pain.
Increase of pain	All participants said they would call their doctor if pain increases. Participants suggested doctor and nurses should encourage women to call them by showing support, not rejection. One participant believed that support and care from a physician would give patients confidence.
Other types of treatments and chosen terms	relaxation techniques, distraction, visualization and meditations, and mental techniques; '24 hours'.

## Draft of Script for Hispanic Video

### Manejando Su Dolor

Senor Jones:

Es como un dolor insensible pero que se ha vuelto peor.

Sr. Manley:

Yo no podia sentirme comodo. Solamente me acostaba y esperaba a que se fuera.

Sr. Johnson:

Todo me ponía los nervios de punta. Luego me di cuenta que era porque no me sentia bien.

Sr. Williams:

Yo tenia miedo de tomar medicina. No queria convertirme en drogadicto.

Narrador:

Tods estos pacientes de cancer han experimentado alguna clase de dolor por el cancer. Pero en lugar de aceptar el dolor como parte de su enfermedad, ellos estan haciendo algo al respecto. Ud. tambien puede.

Sr. Jones:

Yo le dije a mi doctora que el dolor era intenso y ella me dio una medicina que me sirvio. Ahora puedo hacer casi todo lo que hacia antes.

Senor Manley:

Cuando no me ayudo la primera medicina que me dio el medico yo se lo dije y el me dio una nueva que si esta funcionando mucho mejor.

Narrador:

Algunos pacientes creen que el dolor forma parte del padecimiento de cancer, pero es muy importante que Uds. sepan que no tienen que soportar el dolor. Ud. tiene derecho de aliviarse del dolor.

Doctor u otro experto:

La gente que padece de cancer no tiene que sufrir. Hay muchas cosas que el medico puede hacer para aliviar el dolor, pero para poder ayudar, el medico o la enfermera necesitan saber que Ud. tiene de dolor.

Narrador:

Aun cuando su medico o la enfermera no se lo pregunten, es muy importante que Ud. se lo informe a ellos. Veamos un ejemplo de como puede Ud. decirle a su medico sobre su dolor.

Doctor (mirando la historia clinica):

Bueno, espero que las cosas vayan bien hasta cuando le veamos en su proxima cita dentro de unas tres semanas.

Paciente:

Ah, doctor, hay otra cosa que quisiera preguntarle. Es acerca del dolor. Se ha empeorado. Es tan fuerte que a veces a duras penas puedo levantarme de la cama.

Dr. (escribiendo en la historia clinica):

Ah, ajah.

Paciente:

Es como un dolor agudo en la espalda que no se me va. La ultima vez, la enfermera me dio este folleto que dice que le ponga un numero al dolor, de modo que trate de pensar asi. Y, ah, en una escala de 0 a 10 yo diria que es como 9. No puedo dormir. No siento deseos de comer.

Dr. (hojeando la historia clinica):

Veamos... que esta haciendo ahora para el dolor?

Paciente:

Estoy tomando Tylenol y descansando. Y el Tylenol ayuda algunas veces. Pero otras no sirve de nada.

Dr.:

Voy a darle algo mas fuerte que el Tylenol. Y quiero que con seguridad se lo tome a la hora en que le he escrito. Podemos ayudarle a controlar este dolor.

Narrador:

Este paciente tomo accion para deshacerse del dolor. Veamos exactamente que hizo. Primero, le dijo al doctor que tenia dolor.

Paciente:

Ah, doctor, hay otra cosa que quisiera preguntarle. Es acerca del dolor. Se ha empeorado. Es tan fuerte que a veces a duras penas puedo levantarme de la cama.

Dr. (escribiendo en la historia clinica):

Ah, ajah.

Paciente:

Es como un dolor agudo en la espalda que no se me va. La ultima vez la enfermera me dio este folleto que dice que le de un numero al dolor, de modo que trate de pensar asi. Y, ah, en una escala de 0 a 10 yo diria que es como 9. No puedo dormir. No siento

deseos de comer.

Dr. (hojeando la historia clinica):  
Veamos... que esta haciendo para el dolor ahora?

Paciente:  
Estoy tomando Tylenol y descansando. Y el Tylenol ayuda algunas veces, pero otras no me sirve de nada.

Dr.:  
Le voy a dar algo mas fuerte que el Tylenol. Y deseo que con seguridad se lo tome a las horas que le he escrito. Podemos ayudarle a controlar este dolor.

Narrador:  
Este paciente tomo accion para aliviar el dolor. Veamos que fue lo que hizo exactamente. Primero, le informo al doctor que tenia dolor.

Paciente:  
Ah, doctor, hay otra cosa que quisiera preguntarle. Es acerca del dolor. 'Se ha empeorado. Es tan fuerte que a veces a duras penas puedo levantarme de la cama.

Narrador:  
Luego, clasificando el dolor en una escala de 0 a 10, hizo que al medico le fuera mas facil comprender que esta no era una incomodidad ordinaria. Cero quiere decir ningun dolor, 10 quiere decir que es lo mas fuerte que puede ser el dolor. Un dolor que es bastante fuerte puede estar entre 5 y 6 y un dolor demasiado fuerte dificil de aguantar puede ser 8.

Paciente:  
Ah, en una escala de cero a 10, yo diria que este dolor es como un 9.

Narrador:  
El tambien describio su dolor en terminos muy claros. No dijo que solamente le dolia. Describio en donde le dolia y como lo sentia.

Paciente:  
Es como un dolor agudo en la espalda que no se me va.

Narrador:  
Tambien le dijo al doctor que el dolor estaba interfiriendo con su vida.

Paciente:  
No puedo dormir. No siento deseos de comer.

Narrador:



Cuando el doctor le pregunto que estaba haciendo para el dolor, el estaba listo.

Paciente:

Estoy tomando Tylenol y descansando. Y el Tylenol ayuda algunas veces pero otras no sirve de nada.

Narrador:

Con esta informacion, el medico puede hacer cambios en la medicina para ayudarle con su dolor.

Doctor:

Le voy a dar algo mas fuerte que el Tylenol. Y quiero que con seguridad se lo tome a las horas que le he escrito. Podemos ayudarle a controlar este dolor.

Narrador:

Estando listo para decirle al medico acerca de su dolor en terminos muy claros, este paciente recibio ayuda.

Pero alguna gente que padece de cancer no se siente bien pidiendo ayuda. A veces los pacientes dejan que el miedo no les permita obtener ayuda. Veamos algunas de las cosas que no permiten que la gente solicite ayuda para aliviar el dolor.

Paciente o persona entrevistada:

Mi doctor me dio morfina, pero tuve miedo de tomarla. Veo a tanta gente tomando estimulantes. No quiero ser como uno de ellos.

Dr. u otro experto:

Mucha gente tiene temor de tomar narcoticos como la morfina para ayudarles con su dolor. Pero hay muchas razones por las cuales Ud. no debe de preocuparse de convertirse en adicto a estas medicinas.

En verdad, tomando estas medicinas para controlar el dolor reduce el riesgo de ser adicto. Tomandolas a las horas regulares que su medico le ha indicado le permitira a Ud. estar al tanto de la situacion, manteniendo el dolor bajo control.

Paciente:

El dolor se puso tan fuerte que yo no podia resistirlo, de modo que decidi ensayar con la morfina. Ayuda bastante. No me siento elevado, solamente que no siento dolor y me permite continuar con lo mio. Hace una gran diferencia. Solo deseo haberme dado cuenta de esto antes.

Narrador:

Algunos pacientes desean guardar sus calmantes para los momentos en que el dolor es

severo. Ellos tienen temor de que la medicina no funcione si la toman a horas regulares.

Paciente o persona entrevistada:

Yo creia que si tomaba medicina para un dolor suave, que no funcionaria igual cuando el dolor empeorara. Yo creia que mi cuerpo se acostumbraria al calmante que mas tarde cuando lo necesitara no me serviria.

Dr. u otro experto:

No se abstenga de los calmantes porque Ud. desea guardarlos para cuando el dolor sea mas severo. Ud. puede y debe de obtener alivio para el dolor que padece ahora. Si mas tarde el dolor se pone mas fuerte, Ud. pude conseguir alivio con mas medicinas u otra clase de medicina. Ud. puede hacer el mejor trabajo de controlar el dolor tomando la medicina a las horas indicadas por su medico.

Paciente o persona entrevistada:

Despues de que empecé a tomar los calmantes mi vida se hizo mas comoda. Si tuve algo de estrenimiento pero el medico me dio algo para ello tambien. Luego, pude volver a hacer las cosas que hacia antes de enfermarme de cancer.

Narrador:

Algunos pacientes tienen temor de tomar medicinas fuertes por lo que han oido sobre la droga.

Paciente o persona entrevistada:

Yo creia que usando la morfina significaba que yo me estaba muriendo. Yo pensaba que solo las personas a punto de morir eran las que les daban la morfina.

Dr. o experto:

La morfina no es solo para pacientes al borde de la muerte. En verdad, la morfina es una de nuestras mejores medicinas para controlar el dolor. Cuidando su dolor Ud. puede utilizar sus energias para combatir el cancer--no la droga.

Paciente o persona entrevistada:

Despues de que empecé a tomar la morfina, pude regresar al trabajo. Yo estaba practicamente casi libre del dolor. Que diferencia!

Narrador:

Finalmente, algunos pacientes no buscan ayuda para su dolor porque creen que el medico esta muy ocupado o no quiere saber nada acerca del dolor.

Paciente o persona entrevistada:

Yo creia que el no deseaba escuchar acerca de mi dolor. El parecia estar muy ocupado y

no deseaba molestarlo.

Dr. o experto:

Los medicos y las enfermeras que tratan gente con cancer necesitan saber acerca de su dolor para asi poder ayudarlo. Los amigos y la familia quiza no deseen hablar acerca del dolor porque se sienten impotentes, pero los medicos no son impotentes. Si una medicina no funciona, ellos encontraran una que si sirva. Si Ud. sufre de efectos secundarios por una medicina, ellos pueden ayudarlo a solucionar el problema. Pero solo pueden ayudarlo si Ud. les dice como se siente.

Paciente o persona entrevistada:

Me alegra haberle mencionado el dolor a mi medico porque el me hizo un cambio en la medicina que en verdad me ayudo. Ahora, en cada visita me pregunta sobre el dolor.

Narrador:

Estos pacientes se aseguraron de hablar con su medico sobre el dolor. Y por eso, su dolor se mejoro. Revisemos las cosas importantes que Ud. debe de hacer cuando sienta dolor.

Uno, Ud. debe de entender que no debe de aguantar el dolor solo porque padece de cancer. Un buen control para el dolor debe de ser parte de su tratamiento para el cancer.

Dos, hable con su medico o enfermera sobre el dolor aunque el medico no se lo pregunte. Si no se los dice, ellos no pueden ofrecerle la ayuda que Ud. necesita.

Tres, sea tan claro como pueda acerca de donde tiene el dolor, que tan fuerte es, que clase de dolor es, y como afecta su vida. Clasificando el dolor en una escala de cero a diez puede ayudarlo al medico a comprender que tan severo es su dolor.

Cuatro. No permita que el temor a los calmantes le impida obtener ayuda.

Cinco y mas importante, NO SE DE POR VENCIDO. Si la medicina que esta tomando no le funciona, continúe diciendole a su medico acerca del dolor hasta cuando obtenga algo que le ayude.

## English Translation of Hispanic Focus Group

### FOCUS GROUP DISCUSSION

#### Theme: Video and Pamphlet About Cancer Pain

I have asked them whether they think that the setting for the video is important. Should we use the doctor's office, a clinic and/or a home setting.

- I think, in my opinion, that any place will be alright and that it would be up to those who are going to be working on it to decide where is more convenient. Any of the three places is good.

What do you think, Ma'm.

- I think, in my opinion, that it should be a little bit more extensive than those shown so far, because what they show now, what I have seen, it is shown very cientifically and crudely. It should be more accessible so that people can understand it. Because when they show it to you, the video, is like a horrible thing with no hope. No. They should show those cases and the advancements made towards people's healing because then the video, for me, what I have seen, frightens you. You feel frightened like any body else feels because they tell you cancer, breast cancer. Especially Hispanics. So I think it should be something more accessible, more....

No. We would like to know more regarding the setting we should choose. If we should, say tape, directly in the doctor's office, a clinic or use somebody's home, a patient's home. If you think this would be a good idea or a bad idea, to use one of these three places. If you have idea of any other place.

- I think any place should be alright. What I do understand is that it should be sort of like a class so that people are not afraid. Its just that today's, those I've seen, is like when they mention cancer, cancer, cancer and then you are like afraid to look at it. No. They should be able to see the good results obtained if you fight for it.

You just mentioned accessible. Accessible. What do you mean by accessible. What do you mean?

- That it be more extensive. That it not be....like what you have seen. For example, on TV they show the video on cancer, the mammogram, watch out for cancer, cancer... but it does not show the good results too so that people are not scared. Because when you see all that, then feeling.... when they tell you that you have cancer you feel something that I cannot explain, you know. So that everybody understands about all those bad moments

you experience but that they also see the good part after the bad moments.

O.K. This drifts us away somewhat from the question. We will be able to discuss about it later.

- I don't mind. I think that any place is good.

Should we include music in the video and what kind of music?

- I think that, in reference to the previous point you were discussing, it would be good to make it in the hospital, right? Because this is the place where the woman is going to be referred to for treatment. So it should identify it, shouldn't it? And with respect to music, relaxing music, classical music, soft music that women would identify the place where she is going to be treated, where she will get many alternatives.

What do you think. Do you agree with her or do you have anything else to say.

- Yes. That is alright.

What else should we include in the video. What do you think.

- I agree with Dolby that they should picture women who come at a certain date but later as well. Because by this you would be predisposed to feel better, wouldn't you? Not feeling so "down" but feeling that if thousands and thousands have been cured and look so good now, I will then feel better. I am going to go through this small process and then I will be feeling fine, correct? I think it should show the present moment, and of course the future of those who have been there before me.

- That they not be so cruel when they tell it to people, as they use to do in this country. You have cancer, just like that, as you put here. That hurts too much. It gives you uncertainty. It is not as if first they would inspire you with courage and then, we will see.

And what do you think should be done?

- I don't know. I think that it should, because at that moment in my own experience, I tell you that you feel very bad. You feel like doing this or that, but you should talk more to the person. Not so rudely, like they do here. When I was informed, it was Dr. Perez who told me. He was wonderful with me and he explained everything and I understood very well. I... what can I tell you, I was mute. Nothing. I just stood there. He told me that everything was going to be alright, I would have no problem. But when I was in pre-op, when I went to have x-rays taken and all that, the doctor told me you have bone cancer. You have bone cancer. I just turned around and left. I left her. I said to myself, well, if I have bone cancer, breast cancer, why should I waste my time. And that was a mistake. I did not have bone cancer. So that makes the person feel bad. Me...because I went back. Not only did my friends give me support but also my family and everybody else, so I kept

on coming. Because if not, at that moment, if I say I am leaving, because if I have bone cancer, breast cancer, what am I going to do now? It is not worth that I take the risk for nothing. So this way, which did not happen in my case because I continued coming and everything, but others don't come back.

Would you like to say something? Do you have an opinion?

- Oh, me? I think it is something very, something very good what you are doing. Because you did my mammogram in the van and that's when I learned that I had cancer and thank God I was able to recover because it was caught on time.

Before that, had you had any information about cancer, for example a video?

- No. I had not seen anything.

You had not seen anything?

- No.

You had no knowledge of this kind of problem, of breast cancer? Or you had never had any information, like this lady says, for example education about cancer?

- Before that, no. Afterwards, yes, but not before. Surely not.

At this moment do you think you would have liked to have such knowledge?

- Of course.

Would you take home a video about cancer pain?

- Maybe.

- I wouldn't.

- I would, because it is very important. Because you are always meeting people. And not only that. It depends on your point of view, right? because just by showing it to certain people at the right moment, this will help them to prevent too. So depending on my point of view, like what she was saying just now that here in the United States people are very rude when they talk to you about cancer. But I do understand how she feels. Unfortunately there is no other alternative. It has to be clear in order for me to make a decision about my life, what am I going to do with my life.

- Yes, I understand that it should be very clear. But when it is sure. As long as things are not sure, because in this case about me it was not sure yet. So what does this do? It draws people away because if you have cancer, then... plus the breast, there is no

alternative. What alternative do you have to be cured? Very little. So what does this do? Does it reject the person? No. You can wait a little and then be sure that you do have this, so this way it is very good to know what you have.

But at this time would you take the tape to your home? The video so that you can see the information? Or if at this moment the doctor tells you look here is this information?

- Yes. Yes. Because I don't.... It didn't happen to me the same as her. I had seen quite a bit. Always. I had many cysts removed, I had a lot of liquid drained. I knew what it was. What I didn't think was that I, being a very conscientious woman, very consistent in checking my breasts, going to the doctor, doing everything, that it would happen to me. I never thought it would happen to me because I am not a negligent person, I am consistent. Do you understand? So I understood that it could not happen to me because I always was watching for this. And it happened to me just it did to her, and others, those who are not watching for this. Because I even went to the Van, they sent me here where they repeated the mammogram, and the doctor here told me that I didn't have anything. It didn't increase, or nothing, because they gave me 6 months which was exactly February 10, 1995 and that same day I came back. But had I been a negligent person, instead of it measuring 3 cm it could have measured 10. O.K.? So I have been.... Currently I check myself (she can tell you), constantly. I never put it off.

And would you, for example, do it now like you just said that you are very careful and Rosa Maria. Would you take this cassette home to listen to the information regarding what Myriam has asked?

- Yes. I would.

Would you use the video at your home?

- Yes. Why not?

- Yes.

Do you think your family or friends would use it at home?

- I wouldn't know. I answer for myself.

- I always would, I don't know if you do it or not, but I am very persistent on cancer and people and I stress very much about it and I insist very much because, I repeat it once again, that I never thought that, being so careful, it would happen to me. Therefore I always tell them that whatever symptom, or anything, they go to the doctor, do not let....

What would you think we should include in the written material (booklet) that will go along with the video?

- I think that pictures of evolution. How it all started. How it evolutioned. How it started and....Exactly. Many pictures.

- More than anything else, many pictures. Pictures help very much. That they you before and after. Many pictures. Not to just read the brochure like a machine, just reading, but no....

- Sure.

- But that you may see it and read at the same time, so that you analyze it yourself.

Pictures of what.

- About cancer.

- Of a person that is ill, of cancer, all of that.

What do you think Rosa Maria? What do you think should be included in the brochure.

What kind of information. Also, there are some pictures that you mention, that you explained about. What kind of pictures did you tell me?

- Of people that are sick, how they are, about cancer, everything. But in pictures.

- The process, the development of....

O.K. Besides this, what kind of information do you think would be useful to be included in the booklet.

- Well.

What information do you think would be good to include.

- I think that the booklet should give addresses and telephone numbers of places where you can go, symptoms a woman begins to feel to detect cancer. When she goes to the doctor and if you have x-rays taken, the process of what is going to happen here. Yes or no, cancer is or not detected, what should you do from here on and that there is a tomorrow. That after surgery may exist a tomorrow, that after many years well, here are the pictures that demonstrate that you can go on with your life. That it was just a moment. But this allows women to prevent. That's the reason for addresses, telephone numbers, what to do. How to mobilize yourself at that moment.

Do you think we should talk about religion in the video as well as in the booklet? And how should we talk about this?



- Yes. Very good.

Why do you think it is good.

- Well, I don't know, because I am a Catholic. I don't know. And I had a lot of faith in everything I was told about medicines, in things, you know. Having faith in my religion, I think that the medicines, the treatment, everything will help me more.

And how should this kind of information be presented, let's say, how should your religion be shown in the video. How do you think it should be included?

- I know that cancer needs to be treated. You do not need.....is like a support for you, your religion. It's not certainly for the illness because illness is treated with medicines. It is just a support for the person.

- Yes, I totally agree with her also but what I do not agree with...because I am a Catholic too.... But naming religion..... because not everybody is from the same religion....

- That's why. That is what I want to tell you.

- Besides, when you learn about an illness that might kill you, I think two things are broken: the physical and the spiritual. So if you are thinking on lifting the physical one you also have to lift the spiritual one which is very important because you don't know which way to go. Therefore if you focus on the part ... God's way without mentioning each person's type of religious faith, then it is very important because you are taking both hand in hand, right? The physical and the spiritual. It is very important.

- That the person have faith but also not to mention religion because not everyone belongs to the same religion. They can support in whichever they want to.

Give me an example of what you think as to how to support this.

- In God. Because God is.... All religions focus to one point. God. Jewish, the... All focus to one point. God. And God knows what to do with your life. God knows when he sent you to this world, how you are going to live, and if you have lived according to His laws, you should not be afraid. There is no problem for you to continue being held by His hand. He will not let anything happen to you.

- You cannot only have trust in your religion and beliefs. You have to do your treatments, do you understand? And to have faith that these treatments are what's going to bring you forward, what's going to fight the illness. But not to think that religion is what is going to cure you.

Give me an indication, an example, as to how to present what you are all saying, in the video.

- Well that... has....

How can this be presented. How can it be represented. Not only in the video but in the written material as well.

- In the booklet, well....
- To have a lot of faith in life and that ....
- Never loose hope.
- Have much faith in life and that everybody go for what he/she wants.
- No. To have faith that if you take your medicines with faith the treatment will be positive. Not to get desperate, no.... those things.
- Sure. In the previous point we were discussing about things that should be written in the booklet. We also agreed that many figures, pictures should be shown. So I think that a way in which this can be incorporated into the booklet is when the person learns about cancer. In other words, what option he/she takes. Because it takes two ways. One, to continuously be going to see the doctor to lean on the physical part, but there is also another way which is religion. To lean in his/her God. If you go supported by both hands you are not going to be afraid. You are going to go forward.

There are some additional questions that we would like to ask you. Who would you like to see in the video giving information about cancer pain and cancer pain treatment? Would you like to hear from a doctor? or from a nurse?

- I would prefer the doctor because he is the one with the most knowledge. A broader knowledge and I can ask him for options and solutions and why, things that maybe, maybe the nurse would not be able to answer. I would prefer the doctor.
- I understand too. It's the doctor who should give all of this. And give you many explanations because I could conquer my problem thanks to a doctor who oriented me a lot and I was able to go through all the process. And for the many things in which he oriented me I was fine and I could overcome it very well.
- Sorry to interrupt for something. I think that the nurse also plays a very important role along with that of the doctor. If it is true that I would prefer the doctor to inform me so that he can supply me with all the answers that I need to be satisfied, I need the nurse's support. When you leave the doctor's office, it's the nurse who gives me the last support. Don't worry because many people come through here, things like that. I think the nurse's support is very important.

- No, and they are qualified. They are qualified like a doctor. Now days nurses are very well trained.

- Yes. But you get mostly love and support from them. And the doctor gives the explanations but the nurse explains things to you like a human being and gives that love and support.

Would you like to hear from a cancer patient who is having pain?

- Yes. If I can give him/her support with my encouragement, with my words. Yes.

- I think that this scene, this moment is very difficult. You are talking about a person who is in pain. It is a very, very difficult moment. I think that I should be well prepared to listen to him/her because both of us are down. If one has fallen down, why both. Therefore not only do I have to be prepared to listen but also to offer my support to that person.

What do you think Rosa Maria?

- Yes. The same.

Would you like to hear from anyone else?

- Well, I am going to tell you. This lady went through this or is giving her testimony. It is good. Because a person who has not been through it does not know how it is, you know.

So it depends on the other person's experience?

- Yes. It is valuable and gives you a lot of support. You notice it when you go to the doctor's office and you see someone who is just beginning. You see all of them very pusillanimous. For example I have a characteristic and I am very strong in that aspect and I try to give a lot of support. Think about me, how well I am, I don't have any problem, I do this. Have reconstruction, there is no problem and all those things. That helps you very much. You find somebody that "oh, that..." then.... because besides the... how can I explain you about the medicines, about what you can do, a sick person's faith that he is going to come through, helps him very much.

- That encourages you.

- Yes. It gives him a lot of support. It helps him very much. That is why it is good to know a lot. That they know a lot of what they have been through. And as she said, that they see that there is a tomorrow.

Would you like to hear from a man or a woman? Does it matter?

- Well, I don't mind who it is as long as it is good information.
- Either a man or a woman is alright with me.
- Yes. Sex does not determine...
- I believe... the same.

Would you like to hear from a Hispanic person?

- Yes. I think that it should be each one in his own tongue because it is very important. It is very important. Because when I was taken to the first class, as I explained earlier, it was an American lady and I could not understand her, so it was so fantastic that I did not feel good. Each one in his own language, we know our habits and everything, you understand better. Everyone in his own language.

What do you think.

- Yes, I think that even if some can speak English, there are others who don't understand.
- Yes, I definitely think that in my own language too because there are some people who speak Spanish but not as well as to be able to understand all the terminology and those things that have to be done in order to get to surgery and all that process. Definitely my own language.

Who do you trust the most to give you good information about cancer pain and cancer pain management?

- No. What is it called.... Who?

Let's say, you always feel more confident getting the information from someone. Who would that someone be for you?

- For me, anybody who is well informed. I think he can.
- I don't understand the question very well. That is why I just stayed like this.
- For example, if the doctor or someone else comes to inform me?

Who do you feel more confident to give you the best information about....

- Look I feel more confident that the person who is going to give me more information about cancer and more security is Dr. Perez. I think he is the best in this specialty and he comforts you and helps you very much to go through this.

- The question specifically was who would be the ideal person, is that right?

Yes.

- The doctor, or the person in the corner, or something like that, is it correct? I think that not necessarily a doctor because there are people who are being prepared very much about this subject and who are very knowledgeable as to give me the correct information for me to follow. Besides the doctor who gave me the diagnostic, there are many other people who are preparing themselves in this subject and they can help me very much.

Who are these people you have had this experience with. In which way.

- Well. Health centers and you, for example, who are getting ready, who are being trained and who are after this subject. Looking, checking. People who are being trained. I am not talking about the person in the corner. I am talking about those who are being trained in group. Who are....

- Look when I had my problem, there was a girl working with them. I don't know, her name is Jackie. To me, she was a nice person. As a counsellor, she was wonderful.

Was she a friend?

- She was what?

Was she a friend of yours or was she a relative?

- No. She was at.... she is with something of cancer.

A social worker.

- A cancer social worker. That for me....

- Yes. I also agree with her but what I understood from the question is like the person that I think is better.... to explain it to you. But what she says anybody from the group who talks the same, same patience, who gives you courage, you accept it. It doesn't have to be a specific person.

How can we convince people that they do not have to suffer with cancer pain?

- I think that at the end of the booklet. If you do not want to go through all this sad and painful process, be on guard. Here are the addresses, here is how to take care. Here is how you check yourself and then you go to your doctor.

- Yes. Prevention is the only thing that can avoid the pain of cancer.

- Yes. And its consequences. It's the only thing.

What kind of information about cancer pain management would you like to know? How to handle it.

- Well. That you get explanation about everything so that you know how to go....
- All the instructions. To know the steps to follow, what to do, what to take, which way to go.
- Yes, exactly. In other words, the question was about pain, correct? how....

What kind of information about pain would you like to know.

- Pain. Well, to know what type of pain it is. If I have this pain what should I do. What should I take. When I have another type of pain what is it. Because there certain types of pain, if you have pain after surgery it is going to be like so... But if it you have another type of pain you have to go to your doctor. But if you have this type of pain, you have no problem. It's part of the surgery, part of the medication, correct?

- For example, look I had.... I had never had pain because after surgery about two and a half months later I went back to work and everything went normal. But some time later, recently I had pain in this arm. It was a very strong pain that I could not even touch it like this. I didn't know and I was very worried. Well, I came to see the doctor on duty and all that and I wondered what do I have in my arm. I couldn't do nothing, not even do this. What happened was that I had been washing by hand. I decided to wash some things by hand every day and it was because of the movement with the lymphatic. But I learned about this later when I came to see the doctor and she explained it to me because I didn't know what was wrong with my arm. You start feeling bad because you think there is something wrong.

So you say that it would be useful to have this information before.

- Sure.

The hospital, what you can avoid.

- Sure.
- Yes, because about her lymphatics was.....
- The lymphatics.
- Exactly. Sure. Because she had her lymphatics removed due to cancer. Therefore the

consequences....

- Therefore the consequences because what they tell you not to let them take your blood pressure, don't hurt yourself, don't get burned. It doesn't tell you anything about exercise like this one, that I decided to wash something by hand every day and.... it was this movement which would not let me touch the arm. For about a week I couldn't touch my arm and this makes you think a lot. If all of this is explained to you, if they put it, like you say, in the brochure or in the video, then you learn about it. And only... it's not that I have all the lymphatics. I only had three removed and I have no major consequences but this happened to me.

What would you like to know about pain medications?

- What are they good for, what should you take them for. In order not to abuse of them.
- In order not to abuse of them because there is always a measure too.

Do you think it would be helpful to know how pain medicines work?

- Yes, it's good to know it. Well. It is good information.
- Very good. Yes. I would like it very much because if I know how something works, I would use it if I have a need for it.
- Yes. The more people who know about it, they can give this information to others. Don't take this or that.
- In a correct measure, the way I can handle it, perfect.

What would you like to know about side effects of pain medications?

- Well, it's good to know about it because....
- It's good to know how they give you relief and their consequences. Both. That's why it is good to read this information.
- Exactly. Because when you know that a certain medication works sometimes you abuse of it. Therefore if you know that this works but that it may or may not have good consequences if you abuse of it, it is good.

How can we encourage people with cancer to take their pain medicines? To take it on a regular schedule?

- Seeing people who have overcome it, who are feeling good, who have been persistent in

taking their medication, like me. I was not given chemotherapy or radiations, but I take Tamoxifen. I have been taking it for about two years without interruption and physically I look good. So if they see these examples, people will then have faith in their medicines and won't stop taking them.

- I think that everything enters through the eye. If publicity sells it is because it's entering through the eye. Therefore, if we want our people to remain physically in good condition, we have to show them many videos. And when they come and we can show them videos of people who have seen the importance of taking their medication, when they get up, when they go to bed, eating their food, taking their medication and then they look good, they can go to work, even to the gym, you emphasize strongly how important it is not to stop taking your medication, right? Because I think that everything enters through the eye. A strong but a visual campaign is very important. Very, very important.

- And especially the medicines which give you a reaction, like Tamoxifen, which is specifically for cancer, you try to work it out. The person herself will look for its own way. I will not take it like this, I will take it later, and works with it, until the reaction is gone. There are many people that decide not to take the medicine, because of a reaction they had. No. The person has to try and find a way in which the body will assimilate and overcome the reaction of the medicine.

- She is asking you.

- Yes. I think it is true. That medicine is everything for your health because if you do not treat the illness you will not see the results. Therefore I think that putting interest in taking your medicine as directed, the result is going to be good.

But for you, how can this be done. She explains how to bring this interest. What do you think would be a good way to put this interest in the person to take the medicine regularly.

- Well, I think the person herself has to have an interest. Because, think about it. I take medicine for my pressure, for the thyroid and I am the one who has to take interest. If not, the neighbor or no one is not going to come and give it to me. I have to do it, I have to think that it is my health.

You don't take medicine for cancer?

- No, I have never taken any.

....because she had radiation. So this is one way and that one is another way.

- And I have never taken any, how do you call it. Treatment for the....there is a hormone treatment and....I have not gotten that. Because it can be that the hormone might develop cancer, some times. Not always is everybody eligible to take hormones.



- Yes, because the problem with hormone treatment and that, has to do with the person who produces hormones as well as with age. There is a different treatment according to age.

What worries you about pain medications? For example, do you worry about addiction?

- I don't believe that. That I may become addicted to a pain medication. I take it if I need it, if not, I will not take it.

- I agree with that. I don't think I can become addicted to something if I need it. It depends on the person to become addicted to things. But information is very necessary.

- Specifically, the question was what to do so that people don't become addicted, is it correct?

As a cancer patient, do you worry that you may become addicted to pain medicines?

- I don't. Absolutely. No, because of the way I am.

And do you worry about what family members or friends may think about your taking pain medicines?

- I don't think that I may have....what do you call it.... that this may cause me any misinformation because of it. I don't think so.

- I don't understand that this may cause anything with my family or with my friends because I take any medication for cancer.

- No. For me neither. To the contrary, that's what friends and relatives are for.

- To give support.

- To give support.

Do you worry about the medicine, pain killers, not working if pain gets worse?

- Well. Yes you should be worried because when pain is stronger than the pain killer it is because it has advanced farther. Therefore you should be worried.

- Yes. Sometimes one worries when the pain killer doesn't work. But sometimes it doesn't work because of how your nerves are. So worries and nerves influence very much in the person.

Do you worry about being strong and not depending on pain medicines?

- Well, I would worry. Because that would mean that I am feeling very .....
- Yes, I also .... agree with her that depending on how I feel in my spirits, I will worry about depending on medications. Because if my spirits are very low then this will make me take more medicine in order to feel better.
- Yes. The same. Like I had said. That how you are feeling, your nerves, betray you more than the illness. If you are feeling good it will help you to conquer everything much easier.
- How you are feeling plays a very important role.

Do you worry that if you talk about pain, the doctor will pay less attention to treating the cancer?

- I think that it would help me to bear with it and I would look for the cause to see if my pain is mental because sometimes our pain is mental.

But I say, if you complain to your doctor that you have strong pain, do you think that he will not try to cure you, to treat the cancer?

- No. I don't think so. I think both would go together.
- Yes. I agree.

Do you worry that taking strong medicines like morphine means that you are going to die soon?

- No. A long time ago you thought, I believe, that when they gave you morphine it meant that you were about to die. That was it. Now days you pretty much know that many types of treatment can put you on strong doses of morphine. When you have surgery, when are having strong pain, and then you will lead a normal life. It is not because you are about to die.

What do you think?

- To tell the truth I have never used any of those drugs but I think that they should help your pain.

No. The question is if the person, or you are taking morphine, which is a very strong medicine, if you think that this would be an indication that you are about to die.

- Well, I think that when you are put on those strong medicines it is when your illness status is well advanced.

- I do not have the information she has but the truth is that if I am put on morphine, I would be worried because morphine is the last medical process. It is the strongest medicine. I may not have the same knowledge, maybe she has a lot more knowledge about cancer medicine. Which of course it is but I in particular, would be very worried.

- No. I do not understand that.... well in this case it's when they would say that it was the last stage. But today with all the advances that exist, these are used for treatment, when you have surgery, that's why they give you strong medicines and nothing happens to you.

- Yes. Yes.

- Yes. They give it and nothing happens. It is another treatment to alleviate the person. Not because you are dying. It is not closeness to death, I think.

Do you worry that your doctor or nurse will think that you are complaining if you keep on telling them about pain?

- Well, I don't. If I complain it is because I am in pain.

- Neither do I.

- No. I don't worry in the absolute because who is living the moment is me.

And you Rosa Maria, what do you think?

- Well, I don't think anybody complains just to complain. It must be because he/she is having pain. I don't think that the doctor will think that I am complaining just to complain but.....

Do you worry about the side effects from pain medicine being worse than the pain?

- Oh yes. I do.

- Yes, there should be enough information about the pain killer in order to avoid side effects because when you have pain later and have an illness, to get something else because of the pain killer, that is very unpleasant.

- Sure. Of course. Definitely.

Do you worry about why your doctor doesn't know about pain and take care of it?

- Well, I think they have the proper knowledge when you tell them about your pain and they prescribe something. It may not work immediately because that's how life is and they change it to another, but I think that they are well trained to take such decision.

What do you think Rosa Maria?

- I don't doubt that doctors are well trained but if I am in pain and it continues, it is because there is something, and if the doctor tells me that I do not have anything, I will try to be referred to another doctor or get a second opinion because I am the one with the pain, not him. And if they have to take x-rays and any necessary lab tests, and he says it's nothing, I will try to get referred to another doctor to see what he thinks, wouldn't you?

Do you worry about whether pain medicines will work for you?

- Sure. That would worry me if I were taking pain medicines.

And what action would you take?

- Well, I would look for an alternative.

- I would be worried if I told the doctor because he is the most capable to give me the one that I need and to look for the causes as to why it is not working. If I may have something that needs a stronger dose or any other type of pain killer.

- Yes, of course I would do the same. I would worry and I would go immediately to see the doctor in order to find out what is wrong or why is this happening to me. It may be that these pain killers do not work for me that he will have to use another type of pain killer.

How can we convince women that strong pain medicines (narcotics) are safe and not addictive, when taken as directed by their doctors?

- With a lot of information. Lots of information is what helps people not to become addicted to anything and to help themselves.

- Yes, exactly. With timely and concise information. That I receive explanation the moment they prescribe something for me. This is like so, this works like this, if you abuse of it, this might happen. But as long as you don't abuse of it, everything is going to be fine. It will calm you, it will help you.

Rosa Maria, do you have an opinion?

- The truth..... the same. Yes.

Do you talk to your doctor or nurse about having cancer pain (or other physical symptom related to your cancer)?

- Yes.

- Yes. I talk to them.

- Even though doctors should detect a little bit more..... Because, for example, almost always, people like us who have no insurance and have to depend on the hospital, every time you come you see a different doctor and he only sees you for 5 minutes. It's not like we are used to in our countries, you have your doctor who continues with your follow-ups. So there are doctors who have an extraordinary patience; others look at you and then leave, therefore it is very helpful if the doctor helps you.

What happens when you talk to your doctor or nurse about pain (or other symptoms)?

- Well, with the explanation given to me by the doctor or the nurse I'll have a better understanding than I have now.

- Whenever I've had a problem I have come to the doctor and he has helped me to come out of it and to go through this moment once more. So far I have received his support.

So the experience you have had by talking to your doctor or nurse has always been positive? About pain.

- Yes, yes. Like I already explained to you, I had that severe pain in my arm because of the ganglions and that. I even came to emergency but since you have to wait so long before seeing the doctor here at Jackson, the doctor explained to me that it was the lymphatics. But I did not wait because they were going to call the oncologist and it was almost the next day's morning, so I went home. I took a pain killer which helped me and I called the Cancer Clinic and made an appointment. It was then that the doctor explained everything to me.... why it had happened and what I was supposed to do next time. She gave me a card with her name and told me to call her. But she explained to me that what I was doing, was moving the arm. That is why I tell you once more that for us information is very favorable.

What would make it easier, how would it be easier for you to talk to your doctor or nurse about pain (or other symptoms)? What would make it easier. Is there anything that would encourage you to talk?

- No, nothing.

- Nothing encourages me. Pain is pain....

- What I have. I go and talk, no... no... I go and explain what I have, what's my condition at this moment, you know.

What would make information about pain treatment easier to understand?

- That you accept it well, that pain will stop. The treatment you are receiving helps the

person to understand pain.

- Sure. If I am getting the right medicine for my body, pain will definitely stop. If not, I will have to talk to my doctor to change it for another type of medication.

- Of treatment.

- Exactly.

Rosa Maria is so quiet, say something.

- I think that if you are in pain you go to the doctor, if you have pain it is necessary to go to the doctor.

But what would it be... What would make it easier for you to understand the information received about pain treatment.

- That it alleviates. If it doesn't....

For example, information on how to treat pain, the medicine or something like that. Which information would be easier for you understand.

There is no other way to put it. How could the information on pain or pain treatment be given. What would make you understand it.

- That the doctor explained to me why I am having this pain. Because certain area is damaged or because....

- It's like I told you that I now understand and I knew it hurt because of the problem with the lymphatics. That's how it was and I understood this. I was very scared and I said, oh my God, what do I have now. And I didn't know it was the movement of the missing lymphatics what brought such strong pain, that's why....

So even written information, the doctor should have this information in order to understand it better?

- Sure. Because if the doctor explains to me the cause of the pain and the medicine he is giving me will alleviate that pain, it is going to be easier to understand that if I am taking this medication it is because of something specifically, isn't that right?

Do call your doctor or nurse if your pain (or other physical symptom) increases?

- Yes.

- Yes. I would call him to explain to me why the pain has increased.

And what do you say?

- Yes, I would also approach them.
- Yes, definitely. If the pain doesn't stop I have to go to the doctor. It could be that something is wrong and if I don't go to the doctor, it can get worse, right?

How can we encourage women to call their doctor or nurse when their pain increases, and before it becomes .... severe?

- The person who could encourage women to consult their doctor are the doctor and the nurse themselves. We should feel that in them we will find support, not rejection. That we may not feel that we are being a nuisance, but that we have support in the doctor and especially the employees who work here and are very cruel. The doctors here are very sweet that the office assistant personnel is very rude when you come looking for help.

So you think that it would be good that they receive training on how to assist people who come looking for help?

- Yes. The doctors are more conscientious than the office personnel. For example, those who are at the desks who collect the fees are very rude with us. The doctors just tell you we don't know and I do not know where you have to go ..... because it has happened to me as I told you when I came here with that pain. To the contrary. It had already been 15 days that the doctor had given me her support and gave me her card. Look, you have to call me anytime that something happens to you. This encourages me to feel free to call her whenever I am in pain. You see? This is what gives confidence to a woman, the patient, to call the doctor whenever needed. .... lots of rejection and if you come through emergency, they will kill you.

Should we include family members in the video?

- If they want to participate, because family support is very necessary. Friends.
- Friends.

Should we include information about other types of pain treatments besides medications? These techniques, distraction, hypnosis, hot or cold pads, etc.

- Yes. That would be very necessary.
- Yes. That is therapy, isn't it?
- Yes. Of course. It is very important. Everything you have just said is very important for the relaxation of the body. When one is very tense, correct? It is very very important.

What idea would you have to include this type of methods?

- Well, planning, that they inform you, the videos, information, as she said before. That we may be able to come and to be well received whenever you need the service. Because sometimes we do not know where to go or how we are going to be greeted. Therefore, the person feels rejection and does not go anywhere and continues suffering. We need more information so that we know where to go when we have such problems and be aware of the programs available.

What kind of ..... so that we may know which is the technique you are thinking about. What kind of technique would you say would be good?

- Three or four days ago I was watching a TV program which mentioned about many mental techniques that are available along with medicine. Techniques such as those you have just mentioned. Relaxation techniques, mental techniques, how to breathe, to learn again how to breathe and visualization. There are other alternatives together with medicine that will help you a lot.

What types of information about cancer pain from other patients would be helpful to you?

- I didn't understand.

What types of information about cancer pain from other patients would be helpful to you?

- Well, it would be helpful because through other people I would learn how to use it if I had such pain. If I had it I would know from the other patients how to confront it
- Yes. Of course. It would help me very much because if another person has already gone through it she would know which are the symptoms. Therefore, talking with this person she could tell me yes, I feel this. What do you feel. I feel that. Then you go to the doctor.

What would be the best way to describe or the best term to use for "around the clock"--taking pain medicine on a regular schedule.

- Which term?

Which term could we use?

- To indicate that the person should take the medicine around the clock.
- Well, whatever the doctor says but like I told you, it depends on the medicine and how your body will assimilated. For example, Tamoxifen has to be taken twice a day. You have to take it in the morning with meals and I do not assimilated like that. Because you



know that it gives a strong reaction. The nurses were giving it to me like that and I had a strong reaction. Therefore, I trained myself on how to take it correctly.

- Well the question means 'the term', for example, using the term to indicate how to take the medicine.

- Yes. Which term to indicate every 8 hours or 3 times 8 = 24 hours or around the clock. This will be 24 hours.

- I do not know what to tell you, because if they say 'every 8 hours' it is every 8 hours. You can not change the cycle.

- Yes. That they understand that it is around the clock.

- Yes. But the patient has to understand that . Exactly. If you have to take it every 8 hours, you have to take it also during the night, so you will have to set your alarm clock to wake you up on time to take your medicine.

But there is no term that we could use. Like in English you say "around the clock". That indicates.....it's understood.

In Spanish we say the 24 hours. When the doctor tells you 24 hours, you know it is the 24 hours.

Do you think that this term 24 hours would be useful, that it can be used?

- If it is necessary....yes.

- Yes, like a clock, correct? As long as you keep your system like a clock, everything is going to be alright.

## Focus Group Discussion - Spanish Version

### Tema: Video y Folleto Sobre el Dolor a Causa del Cancer

Les he preguntado si creen que el montaje en el video sea algo importante. Si debemos de hacerlo en la oficina del medico, o en la clinica o en algun hogar.

- Yo respecto a mi creo que en cualquier lugar que se haga es util y eso queda a condicion de que los que lo van a montar crean sea donde es mas conveniente. Cualquiera de los tres lugares esta bueno.

Y Ud. que opina, senora.

- Creo que para mi opinion debe de ser un poquitico mas amplio de los que muestran hasta ahora, porque lo que muestran ahora, yo por los que he visto, lo muestran muy cientificamente y muy crudamente. Debe de ser mas accesible a que las personas lo entiendan mas. Porque cuando te lo muestran, el video es como una cosa horrible que no tiene salvacion. No. Que lo muestren mas con los casos y con los adelantos que hay para que la persona se cure, porque entonces ese video para mi, los que he visto hasta ahora, lo que te hacen es dar miedo. Te da el miedo ese que todo el mundo coge porque te dicen cancer, del seno. Sobre todo el hispano. Entonces me parece que debe de ser una cosa mas accesible, mas.....

No. Pues queremos saber mas es sobre el escenario que debiamos escoger. Si debiamos filmar, digamos, en la oficina del medico directamente, o en una clinica, o utilizar el hogar de alguien, de alguna de las pacientes. Si le pareceria buena idea o mala idea que fuera en uno de estos tres lugares. Si tiene alguna idea de otro lugar.

- Cualquier lugar creo que debe de ser bueno. Lo que si entiendo que debe ser como una clase para que la gente no le coja miedo. Sino que los de ahora, que yo he visto, es como una cosa que te dicen cancer, cancer, cancer y entonces te da como un miedo verlo. No. Que vean los resultados de lo bueno que tiene combatirlo.

Ud. dijo ahorita mismo, accesible. Accesible. Que es lo que Ud. dice por accesible. Que es lo que Ud. se refiere.

- Que sea mas amplio. Que no sea asi tan ...como tu ves que lo ponen. En la television te ponen por ejemplo el video del cancer, te ven la mamografia, cuidense del cancer, el cancer ...y no te da los buenos resultados tambien para que la gente no coja miedo. Porque cuando tu ves todo eso entonces el sentirse uno.... cuando le dicen a uno que tiene cancer te da una cosa que no te puedo explicar, tu sabes; entonces para que todo mundo entienda que todos esos malos momentos que pasa pero que vea la parte buena tambien despues de los malos momentos.

Bueno. Esto nos desvia un poquitico de la pregunta. Eso lo podemos discutir ahora mas tarde.

- A mi me da lo mismo. Creo que en cualquier lugar esta bueno.

Cree Ud. que debiamos de colocar musica en el video y que clase de musica.

- Yo pienso que, en cuanto al punto anterior que estaban tratando, seria bueno en el hospital, no? porque es el lugar donde se va a referir a la mujer para ir a tratarse. Entonces que lo identifique, no? Y en cuanto a musica, una musica relajada, una musica clasica, una musica suave que vaya identificando la mujer donde va a llegar que se va a tratar, donde le van a dar muchas alternativas.

Ud. que cree, que opina. Esta de acuerdo con ella o tiene algo mas.

- Si. Eso esta muy bien.

Que otra cosa cree que debiamos incluir en el video. Que se le ocurre.

- Yo pienso igual que Dolby que en el video deberian de poner las mujeres que llegan en una determinada fecha pero tambien tiempo despues. Porque ya con eso te predispone a sentirte mejor, no? Ya no sentirte tan "down" sino a sentirte que ya si miles y miles se salvan y lucen tan bien ahora entonces me voy a sentir mejor yo tambien. Voy a pasar este pequeno proceso y despues me voy a sentir bien, no? Pienso que debe pasar el hoy, claro y el futuro de la gente que ya paso por ese proceso antes que yo.

- Que no sean tan duros cuando le van a decir a las personas que se usa en este pais, no? tiene cancer asi tan tajante que se dice aqui. Eso parte mucho a la persona. Te deslumbra mucho. No es como que te den un aliento primero y despues, vamos a ver

Y como Ud. opina que debe hacerse.

- No se. Me parece, vaya que se le debe, porque en ese momento por mi propia experiencia te digo que uno se siente bien mal. A uno le da por una cosa o lo otro, pero que se le debe hablar mas. No ser tajante asi, como se le dice aqui. Cuando a mi me lo dijeron, a mi me lo dijo el Dr. Perez. Fue muy bien, muy maravilloso conmigo y el me explico muy bien y lo entendí muy bien. Yo me... Como decirte, me encerre. No nada. Me quede ahi. Me dijo todo va a salir bien, no tienes problema. Pero cuando estaba en el pre-operatorio, la doctora, cuando fui a que me hicieran las placas y todas esas cosas, me dijo tu tienes cancer de los huesos. Tienes cancer en los huesos. Yo vire asi la espalda y me fue. La deje. Me dije bueno, si tengo cancer de los huesos, cancer del seno, ya para que voy a perder tiempo. Y era un error. Yo no tenia ningun cancer de los huesos. Y eso hace sentir mal a la persona. Yo porque fui.... Aparte de que me apoyaron mis amistades, mi familia y todos, yo segui viniendo. Pero si no en ese momento yo digo ya

me voy, porque si tengo cancer de los huesos, tengo cancer de mama que voy a hacer ya. No vale la pena que yo me arriesgue a nada. Entonces de ese modo, que en mi caso no sucedio porque yo segui viniendo y todo pero otras personas no vienen mas.

Quiere decir algo, Opina algo.

- Ah, yo. Creo que es algo muy, una cosa muy buena esto que Uds. hacen. Porque por eso que Uds. me hicieron la mamografia en el carrito yo supe que tenia cancer y gracias a Dios por eso me pude restablecer porque a tiempo me lo detectaron.

Antes de eso Ud. no habia visto ninguna informacion sobre el cancer o un video, por ejemplo?

- No. Yo no habia visto nada.

Nunca habia visto nada?

- No.

Nunca estaba enterada de este tipo de problemas, de cancer del seno. O nunca habia tenido informacion, como dice la senora por ejemplo educacion sobre el cancer.

- Antes de eso no. Despues de eso si, pero antes no habia tenido. La verdad que no.

Ud. piensa en este momento que le gustaria haber tenido ese conocimiento?

- Ah, claro!

Se llevaria Ud. para su casa una cinta de video sobre el dolor del cancer, del dolor que produce el cancer?

- A lo mejor.

- Yo no me lo llevaria.

- Eh, yo si, porque es bien importante. Porque como siempre se esta conociendo gente. Y eso no solamente. Depende del punto de vista en que uno lo vea, no? porque el simple hecho tambien de yo mostrarselo en el momento adecuado a determinadas personas hace que estas personas prevengan tambien. Entonces depende del punto de vista en que yo lo vea porque lo que ahorita estaba hablando de que son tajantes aqui en Estados Unidos para hablarte del cancer. Pero es que yo entiendo el sentir de ella. Pero desgraciadamente no hay otra alternativa, tiene que ser claro, para yo decidir de mi vida, que voy a hacer con mi vida

- Si, yo entiendo que tiene que ser bien claro. Pero cuando hay seguridad. Mientras que

las cosas no esten seguras, porque en ese caso en mi no habia seguridad todavia. Yo no lo tenia. Entonces que hace eso? Apartar a la gente, porque si tu tienes cancer, despues, mas lo senos, no tiene alternativa. Que alternativa tiene para curarse? Muy poca. Entonces que eso hace? Rechaza a la persona? No. Si puedes esperar un poquito y entonces darte la seguridad que tienes esto y asi es muy bueno que tu sepas lo que tu tienes.

Pero en este momento se llevaria Ud. un tape para su casa? Una cinta de video para ver la informacion? O si en este momento la doctora le dice a Ud. mire senora aqui esta una informacion..

- Si, si. Porque yo no ....no me paso como ella. Yo si habia visto mucho. Siempre. Me habian operado mucho de nodulitos, me habian extraido liquido. Yo sabia lo que era eso. Lo que nunca pense que yo, que era una persona muy cuidadosa, muy puntual de mirarme mis senos, de ir al medico. de hacer todo que a mi me iba a pasar, yo nunca pense que a mi me iba a pasar porque yo no soy una persona despreocupada, soy constante. Tu me entiendes? Entonces yo entendia que a mi no me podia pasar porque yo estaba muy pendiente de eso. Y me paso igualito que a ella, que a las otras, que a las que le pasa que no estan pendientes de ello. Porque inclusive yo fui al carrito, me mandaron para aca, me la repitieron aqui y aqui el doctor me dijo que yo no tenia nada. Ni me crecio mas ni nada porque me dijeron exactamente los 6 meses justos fue el 10 de febrero del 95 y ese mismo dia yo vine, pero si yo soy una persona abandonada, en vez de medir 3 cms., me hubiera cogido 10. O.K? Entonces yo he sido muy.... Actualmente yo me chequeo (ahi te puede decir ella), constantemente, constantemente yo no me dejo de chequear.

Y Ud., lo haria por ejemplo ahora como Ud. misma dice que es muy cuidadosa, y Rosa Maria. Ud. llevaria este cassette a su casa para escuchar informacion sobre lo que ha preguntado Myriam?

- Si. Yo digo que si.

Utilizaria este video en su casa?

- Si. Por que no?

- Si.

Cree que su familia o sus amistades lo utilizarian en su casa?

- No te se decir, tu sabes? Opino por mi.

- Yo siempre en lo que consiste, no se si Uds. lo haran, pero soy muy persistente en el cancer y en las personas y les machaco mucho en esto e insisto mucho porque como vuelvo y te repito, yo nunca pense que yo que era tan cuidadosa en eso me pasara. Entonces siempre les digo que cualquier sintoma, cualquier cosa, vayan al medico, no se

dejen de ....

Que creen que debiamos de incluir en el material escrito del folleto que iria de acuerdo con el video.

- Pienso que fotografias de evolucion, no? Como empezo todo. Como estuvo evolucionando. Como empezo, y .... Exacto. Muchas fotos.
- Mas que todo, muchas fotos. Las fotos ayudan mucho. Y que te vean antes y te vean despues. Muchas fotos. No que si tu te pones a leer el folleto es como una carreta, estas leyendo, pero no....
- Claro.
- Pero que lo estas viendo y lo estas leyendo, y entonces tu misma vas analizando.

Fotos de que.

- Sobre el cancer.
- De la persona enferma, el cancer, todo eso.

Que opina Rosa Maria? Que cree que debe ser incluido en el folleto?

Que clase de informacion. Ademas, hay unas fotos que dice Ud., que Ud. explico. Fotos de que me dijo?

- De las personas enfermas, de como estan, sobre el cancer, todas las cosas. Pero en fotos.
- El proceso, el desarrollo de....

O.K. Ademas de eso que informacion seria util que tenga el folleto.

- Bueno.

Que informacion Ud. piensa que seria bueno incluirla.

- Yo pienso que el folleto deberia de dar direcciones y telefonos de los lugares donde uno debe acercarse, los sintomas que la mujer empieza a tener para detectar el cancer, cuando llega al medico y si le saca la radiografia, el proceso que va a pasar ahi, y si le detectan el si o el no, que es lo que debe de hacer de ahi para adelante y que existe un manana. Que despues de la operacion puede existir un manana, que despues de varios anos, pues ahi estan las fotografias que si puede seguir adelante continuando con su vida. Que fue un momento nada mas. Pero esto le permite tambien a las demas mujeres

prevenir. Para eso las direcciones, los telefonos, que hacer. Como movilizarse en ese momento.

Cree Ud. que debiamos de hablar sobre religion, o incluir en el video y en el material escrito? Y como deberiamos de hablar sobre ello.

- Si. Muy bueno.

Por que piensa que es bueno.

- Bueno, no se porque yo soy catolica. No se. Y yo tenia mucha fe en lo que me decian en la medicina, en las cosas, tu sabes? Teniendo la fe en la religion mia, creo que las medicinas, el tratamiento, todas las cosas me van a ayudar mas.

Y como se debe presentar ese tipo de informacion, digo, como se debe presentar su religion en el video. De que manera Ud. piensa que se debe de incluir.

- Yo se que el cancer necesita tratamiento. No necesitas..... eso es como un apoyo para uno, la religion de uno. En si no es para la enfermedad, verdad? porque la enfermedad se trata con la medicina. Eso es solamente un apoyo para la persona.

- Si, yo estoy tambien totalmente de acuerdo con ella pero lo que si no estoy de acuerdo..., yo tambien soy catolica. Pero nombrar religion..., porque no todos somos de la misma religion....

- Por eso es. Eso es lo que te quiero decir.

- Ademas, cuando te enteras de alguna enfermedad que te pueda llevar a la muerte yo pienso que se quiebran dos cosas: la fisica y la espiritual. Entonces si estas tratando de levantar la fisica, tambien tienes que levantar la espiritual que es bien importante porque no sabes que camino tomar. Entonces si enfocas la parte... el Camino de Dios sin mencionar el tipo de religion que pueda tener cada persona, entonces es bien importante porque estas llevando de la mano las dos cosas que se llevan, no? La fisica y la espiritual. Es bien, bien importante.

- Que la persona tenga fe pero tambien que no se mencione religion porque todo mundo no pertenece a la misma religion. Que se apoyen en la que quieran ....

Y, deme un ejemplo de lo Ud. piense de como se puede apoyar eso.

- En Dios. Porque Dios es.... Todas las religiones apuntan a un solo punto: Dios. Los judios, los.... Todos. Apuntan a un solo punto: Dios. Y Dios sabe lo que hace con tu vida. Dios sabe cuando es que te mando a esta tierra, como vas a vivir, y si tu viviste de acuerdo a las leyes de El, no tengas miedo. No hay ningun problema que tu continuas de la mano de El. El no te va a dejar que nada te dane.

- Tu no puedes confiar solamente en tu religion y en la creencia . Si no tienes que hacerte los tratamientos. Tu comprendes? Y tener fe que esos tratamientos son los que te van a sacar adelante, que te van a combatir el mal. Pero no creer que la religion te va a sanar.

Deme una indicacion, un ejemplo, como se puede presentar eso que Uds. estan diciendo, en el video.

- Bueno eso... tiene ....

Como se debe presentar. Como se debe representar.... No solamente en el video sino en el material escrito del folleto.

- En el folleto, bueno....

- Pues que tengan mucha fe en la vida y que ...

- Nunca perder la esperanza.

- Tener mucha fe en la vida y que cada cual se vaya a lo que desea.

- No. Que tengan fe si en que si hacen las medicinas con fe le va a resultar el tratamiento. Tu sabes. No desesperarse, no .... esas cosas.

- Claro. Se hablaba en el punto anterior del folleto se hablaba de las cosas que debia ir escrito. Y tambien se acordo que debian de ver muchas figuras, muchas fotografias. Entonces pienso yo de la forma en que se puede incorporar en el folleto es cuando esta persona se entera del cancer. O sea, que opcion toma, no? Porque toma dos caminos. Toma, continuamente esta yendo a su medico, para apoyarse en la parte fisica, pero tambien hay otro camino que es la religion, no? Apoyarse en su Dios. Si va apoyado de las dos manos no va a tener miedo. Va a seguir adelante.

Hay otras preguntas adicionales que quisieramos hacerles. Quien desearia Ud. que le diera la informacion sobre el dolor respecto al cancer y su manejo. Desearia escuchar esto de su doctor o de la enfermera?

- Yo prefiero del doctor porque es el que tiene mayor conocimiento, un conocimiento mucho mas amplio y le puedo pedir opciones y soluciones y por que, cosas que quizas, quizas no me pueda responder la enfermera. Prefiero que lo haga el doctor.

Yo tambien entiendo. El doctor es el que debe dar todo eso. Y darte muchas explicaciones porque yo me supere mucho mi problema gracias a un doctor que me oriento mucho y pude hacer todo mi proceso. Y por muchas cosas que me oriento lo pase bastante bien y lo supere bastante bien.



- Perdon que interrumpa una cosita. Yo pienso que la enfermera tambien juega un papel bien importante a la obra del doctor. Si bien es cierto que yo preferiria que me lo diga sea el doctor para que me pueda dar las respuestas que yo necesito para satisfacerme, necesito el apoyo de la enfermera. Cuando uno sale del consultorio, es la enfermera la que termina de darme el apoyo. No te preocupes que por aqui pasa mucha gente, cosas asi. Me parece importante el apoyo de la enfermera.

- No, y ellas estan capacitadas. Ellas estan capacitadas como un doctor. Hoy por hoy las enfermeras estan muy preparadas.

- Si. Pero en ellas se recibe mas el amor y el apoyo. Y en el doctor es que te explique, pero en ella es que te explique como ser humano que te brinde ese amor, ese apoyo.

Desearia Ud. escuchar sobre el cancer de una persona que esta sufriendo de dolor?

- Si. Pues si la puedo ayudar aunque sea con mi aliento, con mis palabras. Si.

- Yo pienso esa escena, ese momento es bien dificil. Ud. esta hablando acerca de una persona que esta sufriendo de dolor. Es un momento bien, bien dificil. Creo que tendria que estar lo suficientemente yo preparada para escucharlo porque dos caidas.... Si una esta caida, para que dos. Entonces tengo que estar yo preparada para no solamente escucharla sino para brindarle mi ayuda a esa persona. No?

Que opina Ud. Rosa Maria.

- Si. Yo igual.

Desearia que otra persona le diera esa informacion?

- Bueno, te voy a decir. Esta senora sufrio eso, o esta dando su testimonio es muy bueno. Porque el que no ha pasado no sabe como es, tambien. Tu sabes.

Entonces depende de la experiencia de la otra persona?

- Si. Vale mucho, si, y te da mucho apoyo. Tu lo notas cuando tu vas a la consulta y tu ves a una persona que esta comenzando. Tu las ves todas apagadas. Por ejemplo yo tengo una caracteristica y en ese aspecto soy bastante fuerte y siempre trato de darle mucho apoyo. Y piensa en mi, ue bien yo estoy, no tengo problema, yo hago esto. Hazte la reconstruccion, no tienes problema, y todas esas cosas. Eso te ayuda mucho. Se encuentra una persona que 'ay, que '.... entonces.... porque aparte de... como explicarte de la medicina, de lo que puedan hacer Uds. la fe que tenga el enfermo en que va a salir adelante, lo ayuda mucho.

Eso le da animo.

- Si. Le da mucho apoyo. Eso te ayuda muchísimo. Por eso es bueno que sepan mucho. Que sepan mucho de lo que han pasado. Y como dijo ella, que vean que hay un mañana.

Desearía escuchar esta información de un hombre, o de una mujer, o le importa quien sea?

- Bueno, en sí no me importa quien sea siempre siendo una información buena.
- Para mí lo mismo me da un hombre que una mujer.
- Si. El sexo no determina.
- Yo creo ... eso mismo.

Desearía escuchar esta información de parte de una persona hispana?

- Si. Yo opino que debe ser cada cual en su lengua porque es muy importante. Es muy importante. Porque cuando a mí me llevaron a la primera clase, como te explique ahorita, era una americana y yo no le entendía, entonces yo lo veía tan fantástico que me puso muy mal. Sino que cada uno en su idioma, sabemos nuestras costumbres y todo eso, lo comprende más. Cada uno en su idioma.

Ud. que opina.

- Si yo creo que aunque algunas hablen el inglés, otras no comprenden.
- Si yo también creo definitivamente en mi idioma porque hay gente que habla español pero no lo suficiente como para poder entender todos los términos y las cosas que hay que hacer para poder llegar hasta la operación y todo ese proceso, no? Definitivamente en mi idioma.

En quien confía Ud. más para que le de buena información sobre el dolor que produce el cáncer y su manejo.

- No. Como se llama.... Quien.

Digamos, Ud. siempre tiene más confianza recibiendo la información de parte de alguien. Quien sería ese alguien, para Ud.

- Para mí, yo creo que cualquiera que esté bien informado. Yo creo que puede serlo.
- Yo no te entiendo bien la pregunta. Por eso me quede así.
- Por ejemplo si viene el doctor a decírmelo u otro?

Quien confía más que le va a dar la mejor información sobre ....

- Mire yo confio mas que me va a dar la mayor informacion sobre el problema del cancer y la mayor seguridad el Dr. Perez. Para mi creo que es lo maximo en esta especialidad y te conforta tanto y te ayuda tanto que te ayuda mucho a pasarlo.

- La pregunta especifica era para mi quien seria la persona ideal, no?

Si.

- El medico, o la persona de la esquina, o algo asi, no. Yo pienso que no necesariamente seria un medico porque hay gente que se esta preparando muchisimo acerca de este tema y esta muy empapada como para darme la informacion correcta a yo seguir. Despues que el medico que me dio el diagnostico, hay muchisima gente que se esta preparando muchisimo en este tema y que me puede ayudar mucho.

Quienes son estas personas que Ud. ha tenido esta experiencia. En que forma.

- Bueno. En los centros medicos y Uds. por ejemplo, que se estan preparando, se estan capacitando y estan detras de este tema. Viendo, chequeando. Gente que se esta preparando. No hablo de la persona de la esquina. Hablo de la gente que se esta capacitando en grupo. Que se esta .....

- Mire cuando yo tuve mi problema, una muchacha que trabajaba alli con esta gente, yo no se, que se llama Jackie ella, para mi fue muy buena persona. Como consejera una maravilla.

Era una amiga?

- Era que?

Era una amiga suya o era un familiar?

- No. Solamente que pertenecia a.... ella pertenece a lo del cancer.

- Una trabajadora social.

- Una trabajadora social del cancer. Eso para mi....

- Si. Yo tambien estoy de acuerdo con ella pero yo entendi la pregunta como que la persona que yo entiendo que sea mas..., para exponerte la cosa, pero lo que ella dice cualquiera del grupo que tenga la misma forma de hablar, la misma paciencia, que te de el mismo animo, tu lo aceptas. No tiene que ser una especifica persona.

Como podriamos convencer a la gente de que no tiene que sufrir el dolor del cancer.

- Supongo que al final del folleto. Si Uds. no quieren pasar por todo este proceso lastimoso y doloroso, prevenganse. Aqui estan las direcciones, aqui esta la forma de cuidado. Aqui esta la forma manual de uno chequearse y luego ir a su medico.

- Si. La prevencion es lo unico que puede evitar los dolores del cancer.

- Si. Y su consecuencia. Eso es lo unico.

Que clase de informacion desearia Ud. conocer respecto al dolor que produce el cancer y su manejo. La forma de manejarlo.

- Bueno. Que le expliquen a uno todas las cosas para uno saber como seguir....

- Todas las instrucciones. Saber los pasos a seguir, que debe hacer, lo que debe tomar, que camino tomar.

- Si exacto. O sea la pregunta era del dolor, no? como....

Que clase de informacion quisiera Ud. saber sobre el dolor.

- El dolor. Bueno, saber que tipo de dolor es. Cuando yo sienta este dolor que cosa es lo que debo hacer. Que es lo que debo de tomar. Cuando siento otro tipo de dolor que cosa es. Porque hay determinados tipos de dolor que te dice si te va a doler despues de la operacion es asi. Pero si te duele de otra forma tu tienes que acudir a tu medico. Pero si tienes este tipo de dolor, no hay problema. Es parte de la operacion, parte de la medicina, no?

- Por ejemplo, mira yo tuve... Nunca me habia dolido porque yo despues que me opere, enseguida a los 2 meses y medio yo empecé a trabajar y todo fue normal. Pero despues, hace poco yo tuve en este brazo un dolor muy fuerte que no me podia ni tocar asi. Yo no sabia y me tenia muy preocupada. Bueno, estuve aqui donde el medico de guardia, y todas esas cosas y yo decia que tengo en el brazo. No me podia.... nada, ni hacer asi. Resulta que era que yo me habia puesto a lavar a mano. Me dio por lavar todos los dias a mano y fue el movimiento que hice con el linfatico, pero todo eso lo supe despues que vine a consulta que la doctora me explico porque yo no sabia que tenia en el brazo. Ya te vuelves a sentir mal porque tu vuelves a pensar que tienes algo.

Entonces Ud. dice que esa informacion seria util saberla antes.

- Claro.

Del hospital, que cosa puede evitar.

- Claro.

- Si, porque lo de los linfaticos de ella fue...
- De los linfaticos.
- Exacto. Claro. Porque le quitaron los linfaticos, debido al cancer. Entonces las consecuencias...
- Entonces las consecuencias que pueden traer porque lo que ellos te dicen no te dejes tomar presion, no te pinches, no te quemes. No te dice nada de ni ningun tipo de ejercicio como este que yo, me dio por lavar a mano todos los dias una cosa y era ..., entonces el movimiento ese me dio que no podia ni tocarme el brazo. Estuve como una semana que no me podia tocar el brazo, entonces esto te da muchos pensamientos. Si toda esa informacion te la explican, te la ponen, como tu dices, en el folleto o en el video, ya tu lo sabes. Y solamente... no es que yo tenga todos los linfaticos. A mi nada mas me quitaron tres. Y no tengo gran consecuencia pero me ocasiono eso.

Que desearia Ud. saber respecto a los calmantes.

- Para que sirven, para que puede uno tomarlos. Para no abusar.
- Para no abusar porque todo tiene una medida tambien.

Cree que seria util saber como trabajan los calmantes?

- Si, es bueno saber. Bueno. Es una buena informacion.
- Buenisima. Si. Me gustaria muchisimo porque si yo se como funciona algo, cuando tenga la necesidad de ello la voy a utilizar.
- Si. Entre mas personas lo sepan le pueden dar la informacion a otras. No tomes esto o lo otro.
- En su medida correcta, como yo pueda manejarlo, perfecto.

Que desearia saber Ud. respecto a los efectos secundarios de los calmantes.

- Bueno, es bueno saberlo porque ....
- Es bueno saber como alivian y las consecuencias que tienen. Las dos cosas. Por eso es muy bueno leer esa informacion.
- Exacto. Porque tambien cuando uno sabe que determinada medicina funciona, muchas veces uno abusa de ello. Entonces, si uno sabe que eso funciona pero que puede tener no buenas consecuencias si uno abusa de esa medicina, es muy bueno.

Como podemos animar a la gente que padece de cancer para que se tome su medicina.

Que lo haga en un horario regular.

- Viendo a las personas que lo han superado, que estan bien. Que han sido persistentes a las medicinas, como en mi caso, a mi no me dieron quimioterapia, ni me dieron irradiaciones pero tomo Tamoxifen. Yo hace 2 años que lo tomo y nunca lo he dejado de tomar y fisicamente me veo bien. Entonces yo viendo estos ejemplos que la gente ponga fe en la medicina, no lo deja de tomar.

- Yo pienso que todo entra por los ojos. Si la publicidad se vende es porque esta entrando por los ojos. Entonces, si queremos que nuestro pueblo se mantenga fisicamente bien, le tenemos que mostrar muchos videos. Y cuando vienen estas personas y les podemos mostrar videos de que cuidadosamente la persona a la hora que se levanta, a la hora que se acuesta, con sus alimentos, esta tomando su medicina, entonces, y luego se le ve bien, puede ir a trabajar, puede ir inclusive al gimnasio, apuntarle bastante lo importante que es la no dejar su medicina, no? Porque yo pienso que todo, todo entra por los ojos. Una campana fuerte pero visual es bien importante. Bien, bien importante.

- Y sobre todo las medicinas que te dan reaccion como te da el mismo Tamoxifen que es especificamente para el cancer, pues uno le va buscando. La persona misma le va buscando el juego. No me la tomo asi, me la tomo mas tarde y va basandola, pasa la reaccion de la medicina. Que eso hay muchas personas que cuando una medicina te da una reaccion, ay yo no me tomo eso y la deja. No. La persona misma tiene que ir buscando el modo que la medicina tu cuerpo la asimile y sus reacciones.

- Te esta preguntando a ti.

- Si. Yo creo que es verdad. Que la medicina es todo para la salud porque si no se trata no va a tener resultados, asi que yo creo que poniendo interes en tomar medicina como la mandan va a tener un resultado bueno.

- Pero para Ud. como se puede. Ella explica en que manera se puede hacer ese interes. Que Ud. opina que seria la manera de poner ese interes en la persona de tomarse la medicina regularmente.

- Bueno. Yo creo que la misma persona debe tener el interes. Porque ponte a pensar. Yo me tomo la medicina de la presion, tomo la de tiroides y yo soy la que tengo que tomarme el interes. Porque si no, el vecino no va a venirmela a dar ni el otro. Tengo que ser yo. Pensar que esta es mi salud.

Ud. no toma medicina de cancer?

- No yo nunca he tomado. ....

- ....porque le salio irradiaciones. Entonces, ese es un modo y este es otro.

- Y no he tomado ninguna, como le llaman. Tratamiento para la .... hay un tratamiento para la hormona y eso.... a mi no me la han puesto. Porque puede ser, este, la hormona le puede desarrollar mas bien cancer algunas veces. No siempre todas las personas estan elegibles para tomar las hormonas.

- Si, porque eso el problema de tratamiento con las hormonas y eso, juega con la persona que reproduzca hormonas y tambien juega con la edad. Las edades se hace distinto tipo de tratamiento.

- Que le preocupa a Ud. sobre los calmantès que Ud. tiene. Por ejemplo, le preocupa que pueda volverse adicta?

- Yo no creo eso. Que yo me pueda volver adicta a un calmante. Yo lo tomo si lo necesito, si no, no lo tomo.

- Yo tambien opino eso. Yo creo que yo no me pueda volver adicta a nada. Si yo lo necesito, eso va en la persona que se vuelva adicta a las cosas. Pero si es muy necesaria la informacion.

- La pregunta especifica era como hacer para que la gente en si no se vuelva adicta, no?

A Ud. le preocupa como paciente que sufre de cancer, le preocupa que pueda volverse adicta a los calmantes?

- A mi no. En lo absoluto. Con mi manera de ser, no.

Y le preocupa a Ud. lo que su familia o sus amistades puedan pensar de Ud. cuando sepan que toma esos calmantes?

- No creo que pueda tener... como se llama.... que eso me cause ninguna mala informacion a mi por eso. Yo no creo.

- Yo no entiendo que me pueda ocasionar nada con mis amistades ni mi familia porque tome ninguna medicina sobre el cancer.

- No. Para mi tampoco. Por el contrario. Las amistades y la familia estan para eso.

- Para apoyar.

- Para apoyar.

Le preocupa que la medicina, que los calmantes no le funcionen y que el dolor sea mas severo?

- Bueno. Si debe de preocuparle a uno, porque ya cuando el dolor es mas que el

calmante es porque ya esta en un estado avanzado. Entonces debe preocuparte.

- Si. A veces uno se preocupa cuando el calmante no le funciona. Pero a veces el calmante no le funciona por el estado de nervios que cogio uno. Entonces la preocupacion, y a veces los nervios influyen mucho en la persona.

Le preocupa que Ud. no sea lo suficientemente fuerte y que dependa mucho de los calmantes?

- Bueno, si me preocuparia eso. Porque quiere decir que el estado de animo mio esta muy decaido.

- Si, yo estoy igualmente.... simpatizo con ella, que de acuerdo a mi estado de animo me va a hacer preocuparme por ponerme dependiente de la medicina porque si mi estado animico esta bien bajo, entonces va a hacer que yo consuma mas medicina para poder sentirme mejor.

- Si. Lo mismo. Es lo que te dije. Que el estado de animo de uno, los nervios de uno son los que te traicionan mas que la enfermedad. Que si tu estas bien en ese aspecto te ayuda a vencerlo todo mas facil.

- El estado de animo juega un papel bien importante.

Le preocupa que si Ud. habla sobre el dolor, el doctor le pondria menos atencion al tratamiento del cancer?

- Creo que me ayudaria a pasarlo y buscaria la causa a ver si es cierto que tengo dolor o es mental porque a veces uno tiene dolor mental.

Pero digo, si Ud. se queja a su medico de que tiene mucho dolor, piensa que no va a tratar de curar, de tratar el cancer?

- No. Yo creo que no. Que irian las dos cosas juntas.

- Si. Yo pienso igual.

Le preocupa que si toma calmantes fuertes como la morfina esto significa que se va a morir, que Ud. se va a morir pronto?

- No. Antiguamente uno pensaba, creo yo, que cuando te ponian la morfina era ya porque te ibas a morir. Eran las ultimas. Hoy en dia mas o menos uno sabe que hay muchos tratamientos que te pueden poner en morfina hasta bien fuerte. Cuando te operan, cuando tienes dolor fuerte, y despues ya haces tu vida normal. No es porque te vas a morir.



Que opina Ud.?

- Yo la verdad nunca he usado ninguna droga de esas pero pienso que deben dar resultado al dolor.

No. Pero la pregunta es que si la persona o Ud. esta tomando morfina, que es una medicina demasiado fuerte, si Ud. piensa que eso seria la indicacion que se va a morir.

- Bueno yo creo que cuando ya ponen esas medicinas, son bien fuertes, es cuando el caso ya esta bien avanzado.

- Yo no tengo la informacion que tiene ella pero la verdad que si a mi me empiezan a aplicar morfina yo si me preocuparia porque la morfina es el ultimo proceso de la medicina. Es la medicina mas fuerte. Quizá no tenga el conocimiento, quizá ella tenga mucho mas conocimiento acerca de la medicina del cancer. Que por supuesto que lo es, pero yo particularmente si me preocuparia mucho.

- No. Yo no entiendo que .... vaya, asi en este caso ya eso es como se decia, era la ultima etapa. Pero hoy en dia en los adelantos que existen se usan para tratamiento, cuando te operan, por eso te ponen medicinas fuertes asi y no te pasa nada.

- Si. Si.

- Si. Lo ponen y no pasa nada. Es un tratamiento mas para aliviar a la persona. No es porque te vas a morir. Que es la ultima antesala de la muerte. Creo yo.

Le preocupa que su medico o la enfermera piensen que Ud. se esta quejando si les comenta respecto al dolor?

- Bueno, yo no. Si me quejo es porque me duele.

- Yo tampoco.

- No. No me preocupa en absoluto porque la que esta viviendo el momento soy yo.

Y Ud. que dice Rosa Maria?

- Bueno. Yo no creo que nadie se queje por gusto. Sera porque siente el dolor. No voy a creer que el medico va a creer que yo me queje por gusto sino .....

Le preocupa a Ud., o se preocupa por los efectos secundarios de los calmantes que sean peores que el dolor?

- Eso si. A mi si.

- Si debe haber una informacion muy plena sobre el calmante para evitar los efectos secundarios porque despues cuando uno tiene un dolor y tiene una enfermedad pues que le venga otra cosa por el calmante, es bien desagradable.

- Claro, claro que si. Definitivamente.

Le preocupa a Ud. por que su doctor no sabe acerca del dolor y toma cartas en el asunto o lo trata.

- Bueno, yo creo que ellos tienen el conocimiento indicado cuando uno le dice que tiene un dolor y te manden alguna cosa. Quizá de inmediato no te resuelva porque la vida es esa y te cambian para otra pero yo creo que si están bien capacitados para tomar esa decision.

Ud. que opina. Rosa Maria?

- Yo no dudo que los doctores estén capacitados pero me si esta doliendo y yo veo que continua el dolor es por algo y si el medico me dice que no tengo nada, tratare de que me refieran a otro medico o consultar una opinion mas, porque realmente es a mi a la que le duele no a el. Y si tienen que sacarme las radiografias y los analisis respectivos, y si el dice que no es nada, pues tratare de referirme a otro medico a ver que opina al respecto, no?

Le preocupa que los calmantes no funcionen con Ud.? no le sirvan?

- Claro. Eso siempre me preocuparia si yo tomara los calmantes.

Y que accion Ud. tomaria.

- Bueno, buscaria a otra alternativa.

- Me preocuparia si yo le diria al medico porque es el mas indicado en darme el que realmente necesite y buscar la causa por que no me sirve ese calmante, si es que tengo algo que necesite una dosis mas fuerte u otro tipo de calmante.

- Si, yo haria lo mismo tambien, por supuesto. Me preocuparia e iria inmediatamente al medico a ver que sucede o por que me esta pasando esto. Quizá estos calmantes no funcionan conmigo y tiene que utilizar otro tipo de calmantes.

Como podemos convencer a la mujer que los calmantes fuertes, o narcoticos, son seguros y que no forman habito cuando se toman segun lo prescrito por el medico.

- Con mucha informacion. Mucha informacion es lo que ayuda a la persona a no hacerse adicta a nada y ayudarse.

- Si exacto. Con la informacion clara y en el momento. En el momento que me recetan determinado medicamento que me expliquen. Esto es asi, esto funciona asi. Si tu abusas de esto te puede suceder esto, pero mientras no abuses, todo va a ir bien. Te va a calmar, te va a ayudar.

Rosa Maria tiene alguna opinion?

- La verdad....lo mismo. Si.

Habla Ud. con su medico o con la enfermera sobre el dolor del cancer o cualquier otro sintoma relacionado con el cancer.

- Si.

- Si. Hablo con ellos.

- Aunque los medicos sobre todo te deben detectar un poquito mas de asuntos. Porque por ejemplo casi siempre las personas asi como nosotras que no tenemos seguro, que dependemos del hospital, pues cada vez que uno viene a la consulta es otro medico, entonces te atiende en 5 minutos. No es como mas o menos el medico que estamos adaptados nosotros en nuestros paises que te siguen, no. Entonces, hay medicos que tienen una paciencia extraordinaria, otros te miran y se van. Entonces tiene que ayudar mucho que el medico te ayude.

Que sucede cuando habla con su medico o la enfermera sobre el dolor y otros sintomas?

- Bueno, yo con la explicacion que el medico me de o la enfermera, tengo una mas comprension de lo que tengo.

- Siempre que he tenido algun problema y eso yo me he acercado al medico y el me ha ayudado a salir de este batch y a pasar este momento mas. Hasta ahora siempre he recibido el apoyo de el.

Entonces la experiencia que han tenido sobre hablar con su medico o la enfermera ha sido toda positiva? Sobre el dolor.

- Si, si. Yo por lo menos he tenido, como te explique, ese dolor tan fuerte en el brazo, que fue de los ganglios y eso. Vine inclusive al cuerpo de guardia porque era fantastico pero como le hacen tantas antesalas para tu llegar al cuerpo de guardia aqui del Jackson, en una antesala el medico me explico que eran los linfaticos. Pues yo no espere porque habia que llamar al oncologo de guardia y todas esas cosas y me iba a dar el amanecer del otro dia, pues me fui para mi casa. Me tome un calmante, me ayudo a pasar el dolor y llame a la clinica del cancer y saque mi turno. Y fue cuando la doctora me explico todo lo que... que por que habia sido y que yo tenia que hacer en ese momento que me tocara, que me volviera a suceder cualquier cosa. Me dio una tarjetica con su nombre e

inmediatamente que la llamara. Pero me dio la explicacion que que labores yo habia hecho, que era un movimiento que yo le estaba haciendo al brazo. Por eso te vuelvo y te repito que la informacion es muy favorable en el caso de nosotras.

- Que haria mas facil para Ud., como le seria mas facil hablar con su medico o con la enfermera sobre el dolor u otros sintomas. Que haria que le fuera mas facil. Hay algo que la animaria a hablar?

- No nada.

-A mi no me anima nada. El dolor es dolor.....

- Lo que yo tengo. Voy y hablo, no... no... Voy y planteo lo que tengo, la situacion que tengo en este momento, tu sabes.

Que haria que la informacion sobre el tratamiento del dolor fuera mas facil de comprender.

-Que uno lo este aceptando bien que te calme el dolor. El tratamiento que te esten dando eso ayuda a la persona a entender el dolor.

- Claro. Si me estan dando la medicina correcta para mi organismo, definitivamente el dolor me va a ir calmando. Y si no pues voy a tener que hablar con mi medico para que me cambie a otro tipo de medicina.

- De tratamiento.

- Exacto.

Rosa Maria es muy calladita, diga, opine.

- Yo creo que sea eso de que si uno se siente de ir al medico, si se siente dolor es lo mas necesario ir al medico.

Pero que cosa seria.... Que haria que la informacion recibida sobre el tratamiento para el dolor fuera mas facil para que Ud. lo comprendiera.

- Que lo aliviara. Si no le alivia ....

Por ejemplo, la informacion para tratar el dolor, la medicina o algo asi. Que informacion seria mas facil para Ud. entender eso.

- No hay otra forma de ponerlo. Cual seria la manera de dar la informacion sobre el dolor o el tratamiento para el dolor. Que haria para que Ud. lo pudiera comprender.

- Pues que el doctor me explicara por que estoy sintiendo ese dolor. Porque esta danada

determinada area o porque ....

- Es lo mismo que yo te dije que yo ya comprendi y sabia que me dolia por el problema de los linfaticos, lo entendi asi que era asi. Y yo estaba bien asustada y dije ay! Dios mio! que ya tengo de nuevo. Y no sabia que era el movimiento con los linfaticos que me faltan me hizo sentir ese dolor tan fuerte, por eso....

Entonces, aun la informacion escrita, el medico tambien deberia tener esta informacion para que fuera mejor de entender.

- Claro. Porque si el medico me explica debido a que es el dolor y la medicina que me esta dando va a aliviar ese dolor, me es mucho mas comprensible entender que si estoy consumiendo esa medicina es por algo determinado, no?

Ud. llama a su medico o a la enfermera si su dolor u otro sintoma fisico se incrementa?

- Si.

- Si. Lo llamaria para que me explique por que se me ha incrementado los dolores.

Y Ud. que dice?

- Si yo tambien acudiria a ellos.

- Si definitivamente. Si no me para el dolor tengo que ir al medico. De repente esta sucediendo otra cosa, que por no ir al medico, pues avanza, no?

Como se podria animar a que las mujeres llamen a su medico o a la enfermera cuando el dolor aumenta y antes de que se convierta en ..... o llegue a ser mas severo.

- Eso quien anima a la persona, que tenemos el padecimiento, y le da confianza de poder llamar al medico o a la enfermera, es el medico y la enfermera. Que uno sienta que va a tener en ellos un apoyo, no un rechazo. Ni que uno no sienta ni piense que esta molestando ni nada, sino que uno tiene un apoyo en el medico, y sobre todo aqui en las empleadas mucho que trabajan, que son bastante crueles. Los medicos aqui son bien dulces pero el personal asistente de oficina es bastante crudo cuando uno viene a buscar una ayuda .

Entonces Ud. dice que seria bueno que ellas reciban una educacion sobre como asistir a las personas que lleguen, o buscando ese alivio, no?

- Si. Los medicos son mas conscientes que el personal de oficina. Por ejemplo, las que estan en los burocos y que te cobran y esas cosas, son bastante rudas con uno. Los medicos no mas te dicen no sabemos y no se a donde tienes que ir y no te.... porque a mi me ha pasado que como ya te dije vine con ese dolor. Todo lo contrario. Que el dia que

ya paso 15 dias que me habia calmado la doctora cuando fui me dio su tarjetica. Mira tu me tienes que llamar, cualquier dia que te pase cualquier cosa, todo exacto. Asi a mi me inspira de que manana yo tenga un dolor, y poderla llamar a ella. Te das cuenta. Esto es lo que le da la confianza a la mujer, al enfermo, de cualquier indole que sea, llamar a su medico. .... bastante rechazo, y si vienes por el cuerpo de guardia, te matan.

Cree Ud. que debemos de incluir a miembros de la familia en el video?

- Si quieren participar porque la familia es muy necesaria en los apoyos estos. Las amistades.

- Las amistades .

Cree que debemos incluir otra informacion sobre el tratamiento, ademas de la medicina? Estos tratamientos incluyen tecnicas de relajacion, distraccion, hipnosis, o compresas de agua fria o caliente.

- Si. Eso seria muy necesario.

- Si. Eso es una terapia, no?

- Si, Por supuesto que si. Es bien importante. Todo lo que Ud. acaba de mencionar es bien importante para relajar el cuerpo. Cuando uno esta demasiado tenso, no? Es bien, bien importante.

Que idea Uds. podrian tener para incluir este tipo de metodos.

- Bueno los planes, que te informen, los videos, como ella te dijo anteriormente, la informacion. Que uno se pueda dirigir y estar bien atendido en tal lugar cuando tu tienes tal cosa. Porque a veces uno a veces no sabe a donde se va a dirigir, ni como vas a ser recibida y entonces la persona siente rechazo y no va a ningun lado y sigue con el padecimiento. Mas informacion y saber uno el lugar donde se puede llegar cuando tiene estos problemas y coger todos esos planes.

Que clase de..., para un poquito mas saber como es la tecnica que Ud. piensa. Que clase de tecnica Ud. puede decir que seria buena.

- Yo estuve viendo un programa de television hace 3 o 4 dias y hablaba acerca de muchas tecnicas mentales tambien que hay, conjuntamente con la medicina, claro. Tecnicas como las que acaban de mencionar. Tecnicas de relajacion, tecnicas mentales, como respirar, aprender a respirar nuevamente, la visualizacion. Tambien existen otras alternativas conjuntamente con la medicina, claro, pero que te ayudan mucho.

Que clase de informacion respecto al dolor del cancer en otros pacientes seria util para Ud.

- No entendi.

Que clase de informacion sobre el dolor del cancer por parte de otros pacientes le seria util.

- Bueno, seria util porque a traves de otra persona yo aprenderia a usarla si a mi me ocasionara ese dolor. Si yo lo tuviera pues sabria por la otra persona como ayudarme a combatirlo.
- Si. Claro que si. Me ayudaria bastante porque si ya otra persona lo ha vivido, sabe cuales son los sintomas. Entonces conversando con esa persona me va a indicar bueno, si, yo sentia esto, tu que sientes, siento eso tambien, entonces acude al medico .

Cual seria la mejor manera o el mejor termino para usar para las 24 horas, tomar la medicina en un horario regular.

- Que termino.

Que termino se podria utilizar

-- para indicar eso, para indicar que la persona se tome la medicina las 24 horas.

- Bueno, lo que el medico fije, pero como te dije segun la medicina y segun tu cuerpo lo asimile. Por ejemplo el Tamoxifen hay que tomarlo 2 veces al dia. Tienes que tomarlo por la manana con las comidas y yo no lo asimilo asi, porque tu sabes que eso da mucha reaccion e inclusive las enfermeras me lo empezaron a dar asi y me daba mucha reaccion. Entonces ya yo misma me fui educando como lo podia tomar.
- Bueno. La pregunta quiere decir el termino, por ejemplo usando un termino para indicar como tomar una medicina.
- Como circuito.
- Si. Que termino para indicar cada 8 horas, o sea las 3. mientras da la vuelta el reloj tres 8 horas, si? Seria las 24 horas.
- No se decirte porque si dice cada 8 horas, es cada 8 horas. No se puede cambiar el ciclo.

Si que entiendan que es las 24 horas.

- Si pero eso lo tiene que entender la persona. Pero si, exacto. Si lo tienes que tomar cada 8 horas y te toca a la madrugada pones tu despertador y que te despierte, tomas tu

pastillita.

Pero no hay un termino que podamos usar. Como en ingles que se dice "around the clock". Alrededor del reloj. Eso indica... se entiende.

En espanol se dice las 24 horas. Cuando el medico le dice a uno las 24 horas, ya sabe que es las 24 horas .

Piensa que este termino las 24 horas seria util, que se pueda usar?

- Si es necesario si.
- Si, como un reloj, no? Mientras mantengas tu organismo como un reloj todo va a ir bien.



# Appendix VI

July 15, 1997

## FRED HUTCHINSON CANCER RESEARCH CENTER CLINICAL NUTRITION DEPARTMENT

(Slide 1) Introduction Title - Feeling Better with Food

(Slide 2) Title Slide - Good Nutrition for People Undergoing Therapy

(Slide 3) Food, that is the last thing you want to think about now. (Slide 4) It is

true, cancer and its treatments can cause some real problems and eating foods

may just not taste good. (Slide 5) Why, sometimes eating or drinking even

brings memories of nausea or discomfort, (Slide 6) and your mouth feels too dry,

or sore and burning. (Slide 7) Even normal portions seem overwhelming,

especially if you have not eaten in a long time. (Slide 8) You may ask "why think

of food?" because, believe it or not, eating can make you feel better. (Slide 9)

Eating can be a pleasant experience, and eating right has other benefits. In fact,

you would be amazed at the role eating and good nutrition play in how you feel.

(Slide 10) It is so important that today more and more attention is being paid to

nutrition, one of the newest biological sciences. (Slide 11) Nutrition is a science

that sits at the crossroads of all other medical sciences. A dietitian is someone who has studied nutrition and can offer practical solutions to nutritional problems.

(Slide 12) A dietitian is different from the nutrition enthusiast or salesperson who make unrealistic nutrition and diet promises based on emotional appeal versus sound scientific knowledge. (Slide 13) Now, the main harm done by following a fad diet is that people are prevented from eating the foods they really need.

(Slide 14) While we know that vitamins and minerals are essential, huge doses of pills do not substitute for eating a variety of foods. An excess of most vitamins simply is not used by the body. (Slide 15) Some vitamins that are stored in the body can even be dangerous if large doses are consumed regularly.

(Slide 16) Okay, what is good nutrition? It is getting all the calories, protein, vitamins, minerals, fats and fluids you need. (Slide 17) And just as people vary, so do their needs for these nutrients. Age, body size, sex and amount of activity

for the most part determine your nutritional needs. (Slide 18) Physical stress increases these needs. Surgery, chemotherapy and radiation treatments are stresses, so your nutritional needs while undergoing therapy will be greater.

(Slide 19) Protein and calories play the leading roles in an all-star cast of nutrients. Protein is what we're made of. Calories give us energy, or horse power. Protein and calories, they are the superstars. (Slide 20) Proteins are essential for health and vitality. They are the building-blocks of tissues, like hair, muscle, skin. (Slide 21) Children need extra protein to build new tissue and grow, (Slide 22) so it makes sense that if you are trying to build yourself back up after treatment or weight loss, you need extra protein.

(Slide 23) As a valiant warrior, protein helps you fight infection. (Slide 24) One way to get protein is by eating protein foods like eggs, cheese, milk, meat, fish and poultry. (Slide 25) Another way is by combining beans, grains, nuts, peas

and breads. Together they become excellent sources of protein, and they are found in every-day foods. (Slide 26) Like a peanut-butter sandwich (Slide 27) or macaroni and cheese. (Slide 28) But protein alone is not very efficient. For protein to do its important jobs of tissue-building and repair, and warding off infections, it must have adequate energy. (Slide 29) Without adequate energy, protein will have to act as energy instead of doing its own jobs.

Now, calories are how we measure energy, like horse power, so we need to talk about calories. (Slide 30) Calories are things most of us have tried to avoid, but this is not the time to lose the weight you have been meaning to lose.

(Slide 31) Even while we're asleep we need about 60 calories an hour just to keep our brain working, our heart pumping, and our lungs breathing. (Slide 32) Each additional activity requires more calories, (Slide 33) and a fever burns even more calories. (Slide 34) It is possible to get the calories you need even when

you do not feel like eating much. The trick is to know which foods have more calories, (Slide 35) and there are tricks to adding calories. Notice how a pat of butter will disappear in warm bread. (Slide 36) Try the butter trick on hot soups, popcorn, cereals, and casseroles. (Slide 37) Eggs or powdered milk will disappear in shakes and casseroles, boosting your foods with extra calories and protein. (Slide 38) With enough calories, protein can do its jobs, and one of the most important is maintaining muscle. The way to keep your muscles strong is to exercise.

(Slide 39) Exercise doesn't have to be strenuous. (Slide 40) Try walking, moving your joints, sitting up. It not only feels good, but exercise also improves the appetite.

(Slide 41) Now, we have talked about the importance of exercise, protein and calories in good nutrition, but let us not forget about another essential ingredient, the support of others.

(Slide 42) Eating is a social activity, and family and friends can play a large role in encouraging good nutrition, (Slide 43) but an overbearing approach may backfire. (Slide 44) If there are other people involved, make them aware of your needs. (Slide 45) Some days you may just want to be by yourself, and that's okay. It's really up to you. (Slide 46) Which brings us to the moral of our story. (Slide 47) Eating right is something nice you can do for yourself. Nice, because it helps you feel better overall, and it will give you energy to do the things you want to do. (Slide 48) The food you choose does matter, and it does not take lots of money to get proper nutrition. (Slide 49) Some sound nutrition knowledge and practice will go a long way in helping your body recover from the unpleasant effects of therapy.

(Slide 50) And you can do it by thinking about proteins and calories working together when choosing your foods. (Slide 51) And do not forget exercise as part of your nutrition program. (Slide 52) The important thing is to make your eating fit your needs. Learn what you need. Enjoy. And make each day a celebration. (Slide 53) All it takes is a little determination and a little know-how, (Slide 54) and a couple of good friends.

(Slide 55) Produced by: (read slide) Stella Mandel, etc.

(Slide 56) (read slide): From the book: Guide to Good Nutrition, etc.

(Slide 57) Copyright slide: Fred Hutchinson Cancer Research Center, 1997.

## Slides Translation from the Video “Feeling Better with Food”

- (Slide 1) Introduction Title: Sintiéndose Mejor con Alimentos
- (Slide 2) Title Slide: Buena nutrición para las personas que inician la terapia
- (Slide 3) Comida, es la última cosa en la que Ud. Quiere pensar ahora.
- (Slide 4) Es verdad, el cáncer y su tratamiento pueden causar verdaderos problemas y al comer los alimentos puede que éstos no tengan buen sabor.
- (Slide 5) Pues algunas veces sólo comer o beber traen recuerdos de náusea o incomodidad.
- (Slide 6) y su boca se siente muy seca, irritada o quemante.
- (Slide 7) Hasta las porciones normales parecen agobiantes, especialmente si Ud. No ha comido en largo tiempo.
- (Slide 8) Ud. Puede preguntarse, ¿Por qué pensar en la comida? Porque créalo o no; comer le puede hacer sentirse mejor.
- (Slide 9) Comer puede ser una experiencia placentera y comer bien también tiene otros beneficios. De hecho, Ud. Se sorprendería de saber el papel que juegan alimentarse y la buena nutrición en como Ud. Se siente
- (Slide 10) Es tan importante, que actualmente se pone más y más atención a la nutrición, una de las mas nuevas ciencias biológicas.
- (Slide 11) La nutrición es una ciencia que queda en la intersección de otras ciencias médicas. Una dietista, es alguien que ha estudiado nutrición y puede ofrecer soluciones prácticas a problemas nutricionales.
- (Slide 12) Una dietista es diferente de los aficionados de la nutrición o de los vendedores que



hacen promesas no realistas basadas en preferencias emocionales y que van contra el sentido común del conocimiento científico

(Slide 13) Bien, el mayor daño por seguir una dieta de moda es que a las personas no se les permite comer los alimentos que verdaderamente necesitan.

(Slide 14) Mientras que nosotros sabemos que las vitaminas y minerales son esenciales, las grandes dosis de píldoras no pueden substituir el comer una gran variedad de alimentos.

(Slide 15) Algunas vitaminas son almacenadas en el cuerpo y puede ser peligroso si se consumen grandes dosis de ellas regularmente.

(Slide 16) Muy bien, ¿Qué es una buena nutrición? Es recibir todas las calorías, proteínas, vitaminas, minerales, grasas y líquidos que Ud. Necesita.

(Slide 17) Y así como las personas son diferentes, también lo son sus necesidades de nutrientes. La edad, tamaño o complexión, sexo y la cantidad de actividad física que realizan son en su mayor parte, los factores que determinan las necesidades nutricionales.

(Slide 18) El esfuerzo o estrés físico, aumenta estas necesidades. La cirugía, la quimioterapia y el tratamiento con radiaciones también son un tipo de estrés, así que sus necesidades nutricionales al recibir estas terapias serán mas grandes.

(Slide 19) Las proteínas y las calorías juegan los papeles principales de entre todos los nutrientes. Las proteínas son de lo que nosotros estamos hechos. Las calorías nos dan energía o caballos de fuerza. Las proteínas y las calorías son las superestrellas.

(Slide 20) Las proteínas son esenciales para la salud y la vitalidad. Ellas son los ladrillos con los que están hechos los tejidos, como el cabello, los músculos, la piel.

(Slide 21) Los niños necesitan proteínas extra para construir nuevos tejidos y crecer,

(Slide 22) así que tiene sentido que si Ud. Esta tratando de recuperarse después de un tratamiento o pérdida de peso, Ud. Necesite proteínas extra.

(Slide 23) Como un guerrero valiente, las proteínas le defienden contra las infecciones.

(Slide 24) Una manera de obtener proteínas es comiendo alimentos como huevos, queso, leche, carne, pescado y pollo.

(Slide 25) Otra manera es comiendo frijoles, granos, nueces, chícharos y panes. Todos estos alimentos juntos son una excelente fuente de proteínas y se encuentran en los alimentos de todos los días.

(Slide 26) Como en un emparedado de mantequilla de cacahuate

(Slide 27) o los macarrones con queso.

(Slide 28) Pero las proteínas por si solas, no son muy eficientes. Para que las proteínas puedan efectuar su importante trabajo de construir tejidos y repararlos, y de mantener las infecciones alejadas, deben tener la energía adecuada.

(Slide 29) Sin la energía adecuada, las proteínas tendrían que convertirse en energía en vez de hacer su trabajo.

Ahora, las calorías es como medimos la energía; como los caballos de fuerza, por eso necesitamos hablar acerca de las calorías.

(Slide 30) Las calorías están en las comidas que más tratamos de evitar, pero éste no es el tiempo de perder el peso que siempre habíamos querido perder.

(Slide 31) Hasta cuando estamos dormidos necesitamos como 60 calorías por hora solo para

mantener nuestro cerebro funcionando, nuestro corazón trabajando y nuestros pulmones respirando.

(Slide 32) Cada actividad adicional requiere de mas calorías,

(Slide 33) y la fiebre quema aún más calorías.

(Slide 34) Es posible obtener las calorías que Ud. Necesita aunque no sienta muchas ganas de comer. El truco es saber cuales comidas tienen mas calorías,

(Slide 35) y hay trucos para agregar calorías. Fíjese como un trozo de mantequilla desaparece en una rebanada de pan caliente.

(Slide 36) Pruebe el truco de la mantequilla en las sopas calientes, palomitas de maíz, cereales y cacerolas.

(Slide 37) Los huevos y la leche en polvo desaparecerán en batidos y cacerolas, reforzando su comida con calorías extra y con proteínas.

(Slide 38) Con suficientes calorías, las proteínas podrán hacer su trabajo y uno de los mas importantes es mantener los músculos. La manera de mantener sus músculos fuertes es haciendo ejercicios.

(Slide 39) El ejercicio no tiene que ser extenuante.

(Slide 40) Pruebe caminar, mover sus extremidades y levantarse. No sólo se sentirá mejor sino que además el ejercicio mejora el apetito.

(Slide 41) Ahora, hemos hablado de la importancia del ejercicio, las proteínas y las calorías en la buena nutrición, pero no olvidemos otro ingrediente esencial que apoya a los demás.

(Slide 42) Comer es una actividad social y la familia y los amigos pueden jugar un papel importante en lograr una buena nutrición,

(Slide 43) pero la sobreprotección puede ser desastrosa.

(Slide 44) Si hay otras personas cerca, hágales saber cuales son sus necesidades.

(Slide 45) Algunos días puede que Ud. Solo quiera estar consigo mismo y eso esta bien. Eso depende de Ud.

(Slide 46) Lo que nos trae una moraleja a nuestra historia.

(Slide 47) Comer bien es algo agradable que Ud. Puede hacer por sí mismo. Agradable porque le ayuda a sentirse mejor y le dará energía para hacer las cosas que Ud. Quiere hacer.

(Slide 48) Los alimentos que Ud. Escoje son importantes y no cuesta mucho dinero comer bien.

(Slide 49) Con algunos conocimientos de nutrición y el ponerlos en práctica le ayudarán a recuperarse de los efectos no placenteros de la terapia.

(Slide 50) Y Ud. Puede hacerlo pensando en las proteínas y las calorías trabajando juntas cuando escoja sus alimentos.

(Slide 51) Y no olvide el ejercicio como parte de su programa de nutrición.

(Slide 52) Lo más importante es hacer que Ud. Coma de acuerdo con sus necesidades. Aprenda qué es lo que Ud. Necesita y haga de cada día una celebración.

(Slide 53) Todo lo que se necesita es un poco de determinación y un poco de conocimiento,

(Slide 54) y un par de buenos amigos. Las proteínas y las calorías.

(Slide 55) Producción: (lea la transparencia) Stella Mandel, etc.

(Slide 56) (lea la transparencia): Tomado del libro: Guía de la buena nutrición, etc.

(Slide 57) Transparencia de Copyright: Fred Hutchinson Cancer Center, 1997.

Traducción de Marilou Cárdenas, MD. Para el MD Anderson Cancer Center, Pain Research Group.

# Appendix VII

**Spanish version: "Feeling Good - Nutritional Planning to Improve Your Cancer Therapy"**

Cover:

**SENTIRSE BIEN** (title over purple shadow)

Plan nutricional para mejorar su terapia de cáncer. (Subtitle)

Internal cover:

**SENTIRSE BIEN** (title over a purple shadow)

Plan nutricional para mejorar su terapia de cáncer. (Subtitle)

Por: Abby S. Bloch, M.S., R.D.

Director, Clínica Nutricional

Support Kitchen, Memorial

Sloan Ketterin Cancer Center.

Joyce Daly Margie, M.S.

Page 1:

## **Qué es el cáncer?**

Cáncer es un término general usado para un grupo de unas 250 enfermedades caracterizadas por el crecimiento anormal de células. Cada tipo de cáncer tiene su propio nombre, tratamiento y diferencias de manejo o curación. Aunque las causas y factores de riesgo están empezando a ser identificados, el cáncer es todavía una enfermedad inexplicada. Bajo condiciones normales cada célula en su cuerpo se desarrolla en forma ordenada: cuando una célula muere, es reemplazada por una nueva. En el caso del cáncer, una célula se descontrola, crece anormalmente y se forma una masa (tumor). Si esas células anormales permanecen exactamente en el sitio donde se formaron, se dice que la masa está localizada. Si las células se esparcen para pegarse a tejidos u órganos o son transportadas a otras partes del cuerpo, la masa se llama regional o con metástasis. Cada paso evoluciona progresivamente, por lo tanto; la localización temprana y el diagnóstico acertado son fundamentales para un tratamiento exitoso.

## **Tratamiento del cáncer.**

Cuando el cáncer ya ha sido diagnosticado, es importante aprender todo lo más que pueda acerca de ese tipo específico de cáncer y su tratamiento. Mientras más información tenga usted, mejor participará en su programa de tratamiento. Actualmente los tratamientos más comunes para el cáncer son la cirugía, la quimioterapia y terapia con radiación.

Page 2:

### **Quién es quién?**

Sin importar cual sea su programa de tratamiento, usted va a encontrar muchas caras nuevas. La mayoría de los hospitales funcionan usando el enfoque de grupo y usted será visto por el siguiente personal médico:

**Oncólogo:** Médico especializado en el tratamiento de cáncer.

**Radiólogo:** Médico especializado en el tratamiento e interpretación de rayos X.

**Terapeuta de radiación:** Médico especializado en el tratamiento con radiación para manejar la enfermedad.

**Tecnólogo en terapia con radiación:** Técnico que asiste al terapeuta de radiación.

**Anestesiólogo:** Médico preparado para administrar anestesia, consultor y especialista en dolor.

**Dietista o nutricionista:** Persona con especialización en la relación de la comida con la salud y la enfermedad.

**Enfermera de Quimioterapia:** Enfermera especializada en administrar quimioterapia.

**Enfermera Clínica especializada:** Enfermera especializada en el tratamiento de una enfermedad o problema de salud particular.

Page 3:

**Psiquiatra, psicólogo o trabajador social psiquiátrico:** Profesionales de la salud mental que se especializan en confortar personas afectadas por la presión psicológica o problemas emocionales.

**Terapeuta ocupacional:** Persona especializada en tratamientos y métodos para convalecencia y rehabilitación.

**Terapeuta Físico o fisioterapeuta:** Especialista entrenado en remedios o curas físicas como masajes y ejercicio.

**Farmacéutico:** Profesional médico entrenado en el uso y preparación de medicinas.

### **La Nutrición es una parte importante de su tratamiento.** (Title over a purple shadow).

La nutrición es un aspecto importante de su plan de tratamiento.

Si usted no considera las consecuencias de no comer lo suficiente y con las clases adecuadas de comida, se alimenta Ud. mal, pierde peso y siente mucha fatiga; no será capaz de esforzarse para el tratamiento. Y sus mejores esfuerzos son los que necesita para combatir esta enfermedad.

Nadie puede forzarlo a comer adecuadamente o a trabajar duro para mantenerse nutricionalmente y volverlo un miembro activo de su equipo médico.

Se han desarrollado nuevas y maravillosas técnicas de alimentación y productos mejorados que hacen posible que casi todos - aun aquellos con problemas nutritivos complicados - mejoren su nivel nutricional. Pero para el caso específico del tratamiento del cáncer, no hay curas mágicas o soluciones secretas. Los programas nutricionales necesitan ser desarrollados para cada caso individual. Sea insistente en la búsqueda de comidas y productos que lo ayuden a mantener su nivel nutritivo.

Page 4:

### **Métodos para el tratamiento del Cáncer.** (Title over purple shadow).

**Cirugía** fue el primer método usado para el tratamiento de cáncer y se considera el tipo primario de terapia.

Su estado nutricional puede ser un determinante crítico para soportar la demanda física impuesta por una cirugía. Las cirugías incrementan en su cuerpo la necesidad de calorías, para proveerle de la energía y de las proteínas necesarias en la reconstrucción de tejidos dañados. Después de la cirugía, si usted no tiene apetito o no es capaz de comer por algún problema mecánico como dificultad al tragar o llagas en la boca, traté de aplicar algunas de las sugerencias que se dan en este folleto.

**Quimioterapia** es un método para el tratamiento del cáncer que emplea gran variedad de agentes químicos para destruir o frenar el crecimiento de células anormales. Desafortunadamente mucha gente se asusta con la palabra Quimioterapia, porque ellos han oído historias a cerca de los efectos colaterales. La verdad del asunto es que las reacciones dependen de la droga o drogas usadas, que pueden ser de una gran variedad. Cada persona dentro del mismo programa de tratamiento puede reaccionar de manera muy diferente. Algunas personas sienten pocos efectos colaterales y otras experimentan varios efectos temporales durante el mismo programa de tratamiento. La mayoría de las personas no experimentan problemas colaterales serios. Los mas comunes ocurren en áreas del cuerpo donde hay rápido crecimiento celular como son la médula ósea, los folículos pilosos y el tracto gastrointestinal.

Muchos agentes de quimioterapia afectan áreas que provocan indisposición en las vías gastro intestinales asi como falta o pérdida del apetito.

Es fácil llegar a estar mal alimentado si usted no tiene apetito o tiene el estómago indispuerto. Planear por adelantado y el reconocimiento de los problemas potenciales secundarios a la quimioterapia, pueden ayudarle a sobreponerse de posibles recaídas.

**Radiación**, es el tercer método de tratamiento del cáncer. Es un sistema sofisticado, altamente especializado que emplea rayos de radiación, isótopos radioactivos o implantes radioactivos para destruir rápidamente las células en division. Como en la quimioterapia, algunas personas experimentan varios grados de efectos secundarios; otras no. Por ejemplo; la radiación en la

cabeza y el cuello, puede causar resequedad y llagas en la boca y garganta, así como cambios en las sensaciones de sabor y olor que pueden limitar la ingestión de la comida.

Page 5:

La radiación abdominal puede causar náuseas, vómito, calambres o diarrea en algunas personas. Si los síntomas se presentan el día del tratamiento, no se force a comer; solo trate de mantener el balance de los líquidos y electrolitos. Cuando se sienta mejor empiece con comidas suaves y blandas o beba líquidos de suplemento nutricional y gradualmente regrese a su dieta normal. Durante los días que no sienta efectos secundarios trate de abastecerse para aquellos en que no sea Ud. capaz de comer.

**Inmunoterapia** es un tratamiento relativamente nuevo que está siendo usado para tratar algunos tumores. Este método de terapia del cáncer intenta usar el sistema inmunológico de su cuerpo para reconocer y rechazar las células cancerosas que se están dividiendo en forma rápida y anormal.

Algunos ejemplos de tipos de cáncer que han respondido a la inmunoterapia son: algunos tipos de leucemias, cáncer de riñón, melanomas y lipomas. La respuesta no es universal y los resultados varían según los diferentes tipos de cáncer.

### **Comida y nutrición.** (Title over a purple shadow).

Los nutrientes son la base de los ingredientes que las células, tejidos y órganos de su cuerpo requieren para reproducirse, mantenerse y repararse a sí mismos. Su cuerpo requiere nutrientes - proteínas, carbohidratos, grasa, vitaminas, minerales y agua - regularmente y en las cantidades adecuadas para funcionar eficientemente. Esos nutrientes son digeridos y absorbidos a través de la pared del intestino y son transportados por su sangre a cada una de las células de todo el cuerpo. Una función importante es mantener el sistema natural de defensa de su cuerpo. Estas defensas internas ayudan a su organismo a resistir infecciones y dependen en gran parte de una buena nutrición.

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Ninguna comida por sí sola, puede sustituir todos los nutrientes que se necesitan cada día. A menos que usted haga una buena selección de sus comidas, usted no tendrá una buena dieta. Para comer correctamente, necesita seleccionar comidas de una variedad de fuentes y así obtener el balance correcto de nutrientes. La necesidad por algunos nutrientes se puede incrementar o



modificar cuando el cuerpo esta sometido a un esfuerzo adicional, por ejemplo; una cirugía, infección o enfermedad. Los suplementos nutricionales líquidos pueden ayudar a cubrir los extras que Ud. necesita, especialmente si las comidas completas regulares no estan siempre presentes.

Verifique con su dietista sus necesidades específicas.

### **Calorias.**

Caloria es el nombre usado para las unidades de energia requeridas por el cuerpo a través de la comida que tomamos.

Los nutrientes básicos, proteínas, grasas y carbohidratos son encontrados en proporciones variadas en toda la comida que consumimos.

Cuando la comida es digerida, proporciona la energía necesaria para mantener el cuerpo en funcionamiento.

Durante una enfermedad la demanda de energía del cuerpo se incrementa. Además, lo que usted come ahora puede hacer una gran diferencia en la forma como su organismo podrá combatir la enfermedad y volver al mejor estado de salud posible.

### **Proteínas.**

Las proteínas en las comidas abastecen de los aminoácidos que son usados por su cuerpo para construir y reparar tejidos, crear anticuerpos, combatir infecciones y ayudar a muchas funciones del organismo. Si usted esta consumiendo las calorías suficientes para abastecer sus necesidades energéticas, medio gramo de proteína por libra de su peso corporal, es mas que suficiente para un adulto promedio. De todas maneras sus requerimientos proteínicos pueden ser mayores si el tratamiento o la enfermedad han causado grandes daños en los tejidos o desgaste muscular.

La carne, pescado, aves, huevos, leche, queso, nueces, frijoles y chícharos (habichuelas) deshidratados; son buenas fuentes de proteínas. Si usted no es capaz de tomar las comidas regulares de forma suficiente para mantener sus necesidades proteínicas, considere el uso de un suplemento alto en proteínas.

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### **Grasas.**

La grasa proporciona las calorías necesarias para mantener la temperatura corporal, soportar el

trabajo físico y abastecer los “ácidos grasos esenciales ” necesarios para el crecimiento, la producción de hormonas, las membranas de la estructura celular y el transporte de vitaminas ( A, D, E, K ) que no son solubles en agua.

El cuerpo almacena exceso de calorías en forma de grasa. La grasa almacenada actúa como fuente de reserva de energía.

Las principales comidas que proporcionan grasas son: mantequilla, margarina, aceite vegetal, natas de leche, aderezos para ensaladas, carnes grasosas, productos de leche entera, crema y nueces.

### **Carbohidratos.**

Su cuerpo usa carbohidratos para abastecerse de energía y calor para realizar el trabajo mecánico. Algunas comidas altas en carbohidratos contribuyen con invaluable vitaminas, minerales y fibra para su dieta. Los carbohidratos son baratos y relativamente fáciles de conseguir.

Son buenas fuentes de carbohidratos las frutas, vegetales, harinas, granos, pan, cereales y pasta. Los carbohidratos concentrados (como la miel, melaza, jarabes y azúcar de mesa ) pueden añadir una buena cantidad de calorías a su ingesta total sin sumarle volumen extra.

De todas maneras los carbohidratos no adicionan ningún otro nutriente a su dieta.

### **Vitaminas, minerales y agua.**

Las vitaminas y minerales son nutrientes esenciales en la dieta, porque son los encargados de activar, regular y controlar muchas de las funciones metabólicas que se suceden en el cuerpo. Las cantidades requeridas de muchas vitaminas y minerales son generalmente abastecidas por una dieta regular si usted esta comiendo correctamente. Si usted no esta comiendo lo debido y cree que necesita un suplemento vitamínico o mineral, primero verifique con su Oncólogo, para evitar cualquier posible interacción entre las vitaminas y su tratamiento. Si está usando una dieta líquida suplementaria, asegúrese que contiene las vitaminas y minerales adecuados.

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A menos que se le haya indicado que reduzca la toma de líquidos, trate de beber de 6 a 8 vasos de agua cada día. Asegúrese de seguir las instrucciones del doctor o farmacólogo acerca de la toma de fluidos, ya que algunos agentes quimioterapéuticos aumentan su necesidad de agua.

### **La vía Gastro - Intestinal. ( G I ).**

La vía gastro intestinal ( G I ) agrupa a todas las partes de su cuerpo que estan involucradas en la

digestión y absorción de la comida. De manera potencial, algunos problemas que afectan la vía G I pueden afectar adversamente su estado nutricional.

Del 90 al 95 % de la absorción de nutrientes se realiza en el yeyuno, una parte del intestino delgado. La superficie del intestino delgado es una de las áreas de su cuerpo donde hay mas rápido crecimiento de células. Por esta razón; estas células son muy sensibles a la terapia para el cáncer, o la la nutrición deficiente.

Otras áreas asociadas al problema potencial de nutrición son la boca, garganta, esófago, páncreas, hígado y colon.

El cáncer localizado en alguna de estas áreas puede afectar su disponibilidad de mantener el nivel nutricional.

### **Algunos problemas y sus soluciones.**

Los problemas nutricionales asociados con el cáncer y su tratamiento han variado pero la mejor manera de manejar los efectos colaterales es una sola. Observe su progreso cuidadosamente y aprenda a reconocer los problemas apenas aparezcan. No trate de ignorarlos. Así disminuirá los efectos y se enfrentará mejor contra la enfermedad protegiéndose con un buen estado nutricional. Pruebe las siguientes recomendaciones; si no funcionan, hable con su doctor, dietista o enfermera y ellos lo podrán ayudar:

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### **Pérdida del Apetito.**

Si no tiene hambre a la hora de la cena, tome el desayuno, bocados de media mañana y haga del almuerzo la comida principal..

Si no siente deseo de comer en la mañana, coma un bocado ligero y coma mas tarde durante el día cuando se sienta mejor.

No se sienta encerrado dentro de los esquemas convencionales de las comidas. Muchas comidas pequeñas repartidas a lo largo de todo el día pueden alcanzar el mismo objetivo nutricional que las 3 comidas principales.

Haga la cuenta de las comidas que toma. Comiendo solo unos bocados de la comida adecuada cada hora puede contribuir significativamente al total de calorías y/o proteínas que necesita.

Si su pérdida de apetito es causada por ascos o náuseas, coma pequeñas porciones.

Trate de comer alimentos secos como galletas o pan para mantener su estómago en la mañana.

Mas tarde durante el día, cuando se sienta mejor; ocúpese de comidas que tolere bien. Coma con otras personas. Usted puede descubrir que es capaz de relajarse y de disfrutar mas sus comidas si usted socializa con su familia y amigos.

Una copa de vino, cerveza o coctel antes del almuerzo o comida pueden ayudarle a incrementar su apetito ( verifique con su médico ).

No pare de comer porque ha perdido el apetito. Concentre sus esfuerzos en comer regularmente aún cuando no este hambriento.

Piense en comer como una parte esencial del programa de tratamiento.

### **Aversión a la comida y alteración en el olor y sabor.**

Consulte con su dentista para controlar cualquier problema dental.

Pregunte al doctor acerca de sus medicinas. Puede estar tomando una droga que causa cambios en las sensaciones del sabor. Elimine las comidas ofensivas o desagradables y sustitúyalas con otras de valor nutricional equivalente.

Si las comidas parecen perder sabor, use vinos, ensaladas y condimentos fuertes en la preparación. Mezcle jugos saborizados fuertes o aderezos.

Trate de cocinar y servir en recipientes plásticos para reducir el sabor amargo de la comida.

Si las carnes rojas empiezan a tener sabor amargo, remójelas o cocinélas en salsa de soya, jugo de fruta o vino o marínelas antes de cocinarlas.

Sustituya las carnes rojas por pollo, pavo, huevos, pescado, pudines altos en proteínas, jamón, flanes, mantequilla de maní, helados, malteadas, yogurt, queso, chícharos (habichuelas). habas, nueces o macarroni y queso.

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Si su percepción del sabor esta disminuída, intensifique el aroma de la comida y tome alimentos con texturas particulares.

Para superar el sabor “metálico”, coma limones; cualquier fruta de sabor agrio o golosinas de frutas saborizadas.

Cambie la temperatura de las comidas. Frecuentemente los alimentos sabrán mejor fríos o

congelados.

Tome el suplemento nutricional frío, en un recipiente cubierto a través de un popote o paja, sobre todo cuando la proteína o vitamina huele desagradable.

### **Boca seca**

Coma alimentos suaves, mezclados con gravy, salsas, aderezos para ensaladas, caldo de pollo, crema amarga o mayonesa para humedecer la comida.

Use saliva artificial.

Mastique gomas de mascar, chicles sin azúcar o chupe cubos de hielo.

Ensaye sopas y platos a la cacerola.

Tome líquidos con sus comidas. Asegúrese que son altos en calorías si necesita ganar peso.

Tome comidas frías.

Moje las comidas secas en una sopa o bebida.

Fíjese en los líquidos nutritivos que sean fáciles de tragar.

### **Boca y garganta doloridas.**

Coma con variedad alimentos suaves, fáciles de tragar, como sopas, huevos, pescado desmenuzado, pastas, quiches, souffés, platillos a base de queso, productos lácteos y comidas líquidas.

Carne estofada en vez de parrillada o frita.

Evite exceso de sazón o condimentos, picante, sabores agrios y ácidos y cigarrillos o bebidas alcohólicas.

Corte los alimentos en pedazos muy pequeños.

Macere, mezcle, haga puré la comida, o ensaye con alimento para bebés.

Consuma bebidas altas en calorías y proteínas; sopas que sean fáciles de tragar.

Los alimentos deben estar fríos o a temperatura ambiente.

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Use un popote o paja para las bebidas y una taza o vaso en vez de cuchara para líquidos como la sopa.

Si tiene mucha dificultad al tragar, pregunte a su doctor por un terapeuta ocupacional que le pueda ayudar a encontrar equipo especial o por un terapeuta de lenguaje que pueda enseñarle nuevas técnicas para tragar.

Pregunte a su médico a cerca de pastillas anestésicas y sprays para adormilar la boca y garganta.

Después de las comidas lávese la boca con la mezcla de una cucharadita de bicarbonato de soda en una taza de agua tibia.

### **Sensación de llenura.**

Coma en pequeñas cantidades de 6 a 8 veces por día.

Prepare mini comidas altas en calorías y proteínas.

Tome líquidos “después” de la comida sólida, no durante la alimentación con sólidos.

Ejercítase entre las comidas.

Coma de una manera relajada y tranquila.

Aliméntese despacio en un ambiente agradable.

Si está hospitalizado, evite comer en la cama todo el tiempo.

### **Naúsea.**

No se force a comer. Chupe cubos de hielo o algo helado.

Para las náuseas temprano en la mañana o antes de las comidas, tome alimento suave y seco, como una galleta seca tipo cracker.

Recupere calorías perdidas cuando se sienta mejor.

Si siente náuseas durante o después del tratamiento coma algo seco, blando, fácil de digerir, alimentos bajos en grasa varias horas antes del tratamiento.

Tome sus alimentos en un área bien ventilada, libre de olores.

Si el olor de la comida le provoca náuseas, seleccione los alimentos que tengan poco aroma y no se acostumbra a cocinarlos con ajo o sazónadores picantes.

Trate de comer helado o congelado, en vez de tibio o caliente.

Arregle que alguien más cocine o traiga la comida para Ud.

Si esta hospitalizado, pídale a la enfermera que destape su comida antes de entrar a la habitación.

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Coma en una atmósfera fresca y placentera.

Coma y beba lentamente.

Descanse después de comer.

## **Vómito**

Consuma mini - comidas frecuentemente.

Aliméntese lentamente masticando bien la comida.

Absténgase de tomar líquidos una hora antes o después de cada comida con sólidos.

Tome alimentos secos, evitando dulces, frituras o comidas altas en grasa.

Aléjese de olores durante la preparación de los alimentos.

Beba líquidos claros y fríos, como jugo de manzana, ginger ale o bebidas colas.

Descanse después de comer pero no se acueste horizontalmente al menos durante las siguientes 2 horas después de la comida.

Cuando sienta que va a vomitar, recuéstese o descanse con su cabeza y hombros levantados en un cuarto bien ventilado. Despójese de ropas apretadas y aplíquese paños húmedos sobre la cara y cuello.

Si todavía persisten los periodos de vómito, evite todas las comidas y líquidos hasta que desaparezca el malestar.

### **Diarrea y calambres.**

Tome el mínimo de líquido necesario durante las comidas, pero beba entre las comidas para abastecerse de líquidos y electrolitos.

Coma mini - comidas a lo largo del día, en vez de las comidas principales.

Tome todos sus líquidos a temperatura ambiente.

Seleccione comidas bajas en fibra como pescado, pollo, carne molida, huevos, vegetales enlatados o bien cocinados o frutas ( sin cáscara ), bananas maduras, cereales suaves, galletas, pan refinado o productos a base de harina.

Evite comidas grasosas, aceitosas y fritas, jugos de cítricos, aguas carbonatadas, vegetales y frutas crudos. comidas altas en fibra, nueces, cebolla, ajo y vegetales que forman gases.

Si esta usando un suplemento nutricional , utilice uno de bajo residuo en vez de productos altos en fibra.

Disminuya la actividad física entre las comidas.

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Si tiene diarrea severa restrinja sus bebidas a líquidos claros a temperatura ambiente, como caldo o sopa, ginger ale sin gas o jugo de manzana durante un día. Trate de medir la pérdida de líquidos y haga lo necesario para reemplazarlos. Cuando la diarrea sea controlada ensaye otros líquidos y comidas suaves, blandas, bajas en fibra.

Si experimenta calambres o dolor por gases, evite la cerveza, bebidas carbonatadas suaves (gaseosas ) , habas o frijoles, coles, brócoli, coliflor, cebolla, comidas muy dulces o picantes y mastique la comida con la boca cerrada.



Si los calambres continúan o están acompañados por vómito o si la diarrea es incontrolable, persistente o con sangrado, notifíquelo a su doctor.

### **Estreñimiento.**

Beba de 6 a 8 vasos de líquido al día e incremente el consumo de comidas altas en fibra.

Camine o ejércitese después de las comidas.

Si las anteriores medidas no son exitosas, no use laxantes sin permiso del médico.

### **Title on purple shadow: PIENSE QUE CADA BOCADO CUENTA**

Para mantenerse en buena condición nutricional usted debe saber que cada bocado cuenta. Cada vez que prepare la comida piense en algo que pueda adicionarle para hacerla más nutritiva. Si no quiere comer mucho, asegúrese de que lo que come es altamente nutritivo.

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Pequeñas porciones de alimentos altos en carbohidratos le ayudan a reforzar el consumo de calorías. Mantenga bocados altos en carbohidratos disponibles, para cuando quiera comer “justo un poquito”, pueda mordisquear alguno. Golosinas, paletas heladas, galletas, granola, mezcla de frutas con nueces, postres helados o una rebanada de pan alto en calorías untado de una generosa cantidad de mantequilla, lo pueden ayudar a mantener el nivel de calorías. Otros alimentos altos en carbohidratos como el azúcar, miel, mermelada, jalea, siropes, piloncillos y malvaviscos también pueden ser incorporados a las comidas. Los croutones también se le pueden mezclar a las sopas y ensaladas.

El alcohol contiene 7 calorías por gramo. Ensaye con una cucharadita de su licor favorito encima de una crema helada, fruta o tajada de pastel. Ensaye también agregando pequeñas cantidades de comidas altas en grasa como crema dulce batida, crema ácida, mantequilla, margarina, mayonesa, nueces picadas, tocino o una salsa a sus comidas. No intente comer grandes cantidades de grasas o carbohidratos al mismo tiempo. Solo adiciónale un poco extra a lo largo del día y así logrará una diferencia muy significativa en el total de las calorías tomadas.

Si tiene poco apetito o las comidas con proteínas como la carne no le gustan, trate de incrementar

las proteínas de su dieta sumándole alimentos de bajo volumen pero altos en proteínas, como la mantequilla de maní, leche fortificada ( mezclela con 5 cucharaditas de leche descremada a un vaso de 8 onzas de leche bien fría ), suplementos nutricionales altos en proteínas, queso, huevos, pescado, aves , tofu y yogurt.

### **Suplementos Nutricionales.**

Si las comidas regulares no siempre le apetecen, ensaye utilizando un suplemento nutricional que consiga en el mercado. Hay muchos productos fácilmente disponibles. Puede usarlos como substitutos de su alimentación o puede seleccionar uno que le proporcione nutrientes extra, como proteínas, a su comida regular.

Los suplementos líquidos vienen en una gran variedad de sabores y consistencias, usted puede mejorarlos mezclándolos con frutas frescas, jarabes, licores, café instantáneo o polvos saborizantes.

Los helados, mantecados o nieves y las cremas heladas batidas, si son tolerados; son también fuentes excelentes de calorías extras que se pueden usar como mezcladores. Las bebidas se pueden congelar y preparar como raspados.

Los suplementos comerciales también pueden ser usados en muchas recetas como el ingrediente líquido, adicionándole mas proteínas y calorías que la leche regular o el agua.

Los suplementos líquidos comerciales varían con respecto a su nivel nutricional.

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Asegúrese de leer las etiquetas cuidadosamente y comparar el volumen requerido para obtener los nutrientes específicos que Ud. necesita, como proteínas, vitaminas y minerales. Si Ud. no está seguro de cual suplemento escoger, pregúntele a su dietista.

La mayoría de los suplementos nutricionales se venden a través de farmacias. Cerciórese de preguntar al farmaceuta que ordene el producto que Ud. necesita si no lo tiene disponible en el momento. Los farmaceutas le serán de gran utilidad para conseguir el producto y no sienta temor al preguntar.

Recuerde, !comer lo adecuado lo hace un miembro activo de su equipo de terapia!  
Por lo tanto decídase a sentirse mejor y lo logrará.

Final note:

Mayor información acerca de terapia nutricional y mas de 300 recetas, las puede encontrar en el libro: **"Nutrition and the Cancer Patient"** por Joyce Daly Margie, M.S. y Abby S. Bloch, M.S. R.D., disponible en muchas librerías o directamente del editor: Nutrition , Chilton Book Company, Radnor, PA 19089 (\$14.00)

Pae 16: ( Table)

### CONTEO DE CALORIAS ( por cada porcion )

	Peso o medida aproximada	Calorias
<b>Derivados de la leche</b>		
Queso cheddar,	1 onza	113
Queso campesino, cremoso,	1/4 taza	65
Crema, mitad y mitad	1 cucharadita	20
Leche descremada	1 taza	88
Leche líquida completa	1 taza	159
<b>Carne y grupos alternos</b>		
Frijoles secos, enlatados	3/4 taza	233
Ternera, corte magro	3 onzas	212
Hamburguesa de ternera	3 onzas	186
Pollo frito	1/2 pechuga	160
Huevo	1 pieza	72
Salchicha tipo frankfurt	1 pieza	139
<b>?haddock?</b> frito	1 filete	182
Hígado de ternera	2 onzas	130
Mantequilla de Maní	2 cucharaditas	188
Cerdo en chuleta	1 chuleta	305
Atún enlatado	1/2 taza	158
Embutido tipo Bologna	2 onzas	172

**Grupo de los vegetales**

Frijoles verdes	1/2 taza	16
Brocoli	1/2 taza	20
Coles picadas crudas	1/2 taza	11
Zanahoria picada	1/2 taza	23
Maiz enlatado	1/2 taza	87
Lechuga	1 taza	10
Cebolla	1/2 taza	31
Guisantes verdes congelados	1/2 taza	55
Pimientos dulces, verdes, crudos	1/2 medida	8
Papa blanca	1 medida	88
Espinacas	1/2 taza	24
Papa dulce	1 medida	172
Jugo de tomate enlatado	1/2 taza	23

**Grupo de las frutas**

Manzana cruda	1 medida	80
Banana cruda	1 medida	101
Uvas blancas	1/2 medida	46
Jugo de Naranja	1/2 taza	61
Melocotón enlatado	1/2 taza	100
Jugo de piña enlatado	1/2 taza	69
Uvas pasas (deshidratadas)	1/4 taza	105
Fresas crudas	1/2 taza	28

**Grupo de cereales y pan**

Pan blanco enriquecido	1 rebanada	76
Pan completo de trigo	1 tajada	67
Bollo o rollo enriquecido	1 bollo	119
Cereal de maiz fortificado	1 taza	97
Macarroni enriquecido, cocinado	3/4 taza	116
Avena cocinada	2/3 taza	87
Arroz enriquecido, cocinado	3/4 taza	167

**Grupo de las grasas**

Mantequilla o margarina	1 cucharadita	102
Aceites para ensalada o cocinar	1 cucharadita	120
Mayonesa	1 cucharadita	101

**Grupo de los dulces**

Bebidas tipo cola	12 onzas	144
Azúcar granulada	1 cucharadita	46

Los alimentos incluidos en este cuadro estan listos para consumirse. Todas las carnes y vegetales estan ya cocinados, a menos que se indique de otra forma.

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# Feeling Good

Nutritional Planning to Improve Your Cancer Therapy





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Nutritional Planning to Improve Your Cancer Therapy

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## What is cancer?

Cancer is a general term used for a group of some 250 diseases distinguished by abnormal cell growth. Each type of cancer has its own name, treatment, and chances of control or cure. Although the causes and risk factors are being identified, cancer is still an unexplained disease. Under normal conditions, each cell in your body develops in a very orderly fashion: when a cell wears out, it is replaced by a new cell. In cancer, a cell undergoes uncontrolled, abnormal growth and a mass (tumor) is formed. If these abnormal cells stay exactly where they are formed, the mass is said to be localized. If the cells spread to adjoining tissues or organs or are carried

to other parts of the body, the mass is described as regional or metastasized. Each stage is progressively more involved, so early detection and proper diagnosis translate into a better chance for successful treatment.

## Treatment of cancer

Once cancer is diagnosed, it is important to learn as much as you can about that specific type of cancer and its treatment. The better informed you are, the better you will be able to participate in your treatment program. At the present time, the most common types of cancer treatment are surgery, chemotherapy, and radiation therapy.



## Who's who



No matter what your particular treatment program is, you will encounter a number of new faces. Since most hospitals use a team approach, you may be seen by one or more of the following medical personnel:

**oncologist**, physician specializing in the treatment of cancer.

**radiologist**, physician with special training in interpreting X-rays.

**radiation therapist**, physician with specialized training for using radiation to treat disease.

**radiation therapy technologist**, specially trained technician who assists the radiation therapist.

**anesthesiologist**, physician trained to administer anesthesia who may be consulted as a pain specialist.

**dietitian or nutritionist**, person with advanced specialized training in the relationship of food and nutrition to health and disease.

**chemotherapy nurse**, nurse who specializes in giving chemotherapy.

**clinical nurse specialist**, nurse who specializes in the treatment of a particular disease or health problem.

**psychiatrist, psychologist, or psychiatric social worker,** mental health professionals who specialize in counselling people affected by stress or emotional problems.

**occupational therapist,** person with special training in the methods of treatment of convalescents and in rehabilitation.

**physical therapist,** trained specialist in physical remedies such as massage and exercise.

**pharmacist,** medical professional trained in the use and preparation of drugs.

to maintain yourself nutritionally makes you an *active* member of your medical team.

Exciting new feeding techniques and new and improved food products have been developed that enable almost everyone—even those with very complicated nutritional problems—to improve their nutritional status. But just as with the treatment of cancer, there are no magical cures or secret solutions. Nutritional programs need to be developed to fit each individual case. Be aggressive in seeking foods and food products that will help *you* maintain *your* nutritional status.

## Nutrition is an important part of your treatment

Nutrition is an important aspect of your treatment plan. If *you* do not make an effort to maintain *yourself* by eating enough of the right kinds of food, you can easily become malnourished, lose weight, feel overly fatigued, and be unable to give forth your best efforts. And your best efforts are what you need to fight this disease. Since no one can force you to eat right, working hard



## Cancer treatment methods

**Surgery** was the first method used for treating cancer, and it remains the primary mode of therapy. Your nutritional status can be a critical determinant in your ability to withstand the physical demands imposed by surgery. Surgery increases your body's need for calories, to supply energy and protein to rebuild damaged tissues. Following surgery, if you have no appetite or are unable to eat because of some mechanical problem, such as difficulty swallowing or a sore mouth, try some of the suggestions outlined in this booklet.

**Chemotherapy** is a method of cancer treatment that employs a variety of chemical agents to destroy or stop the growth of abnormal cells. Unfortunately, many people are frightened just by the word chemotherapy because they have heard stories about side effects. The truth of the matter is that reactions depend on the drug or drugs being used and can vary greatly. Even people in the same treatment program can react quite differently. Some people experience few, if any side effects; others

experience a number of temporary side effects at various times during the treatment program. The majority of people do not experience serious side effects. The most common side effects occur in areas of the body where there is rapid cell turnover, such as the bone marrow, hair follicles, and the lining of the gastrointestinal tract.

Many chemotherapeutic agents affect areas that result in either GI upset or loss of appetite. It's easy to become malnourished if you have no appetite or have an upset stomach. Advanced planning and awareness of potential problems can help you overcome possible setbacks.

**Radiation**, the third method of cancer treatment, is a sophisticated, highly specialized treatment that employs beams of radiation, radioactive isotopes, or radioactive implants to destroy rapidly dividing cells. As with chemotherapy, some people experience varying degrees of side effects; others never do. For example, radiation to the head and neck can cause dry mouth, sore mouth, sore throat, or changes in taste and smell sensations, any of which can limit your food intake.

Abdominal radiation can cause nausea, vomiting, cramps, or diarrhea in some people. If symptoms are acute on the day of treatment, don't force yourself to eat; just try to maintain fluid and electrolyte intake. When you feel better, increase your intake, starting with soft, bland foods or drink a liquid nutritional supplement, and gradually progress to your normal diet. On days when you have no side effects, try to make up for the days when you were unable to eat.

**Immunotherapy** is a relatively new mode of treatment being used to treat some tumors. This method of cancer therapy attempts to use your body's immune system to recognize and reject abnormal, rapidly dividing cancer cells. Some examples of cancers which have responded to immunotherapy are: some leukemias, kidney cancers, melanomas and lymphomas. The response is not universal and different types of cancer vary in their response.

## Food and nutrition

Nutrients are the basic ingredients that cells, tissue, and organs of your body re-



quire to reproduce, maintain, and repair themselves. Your body requires nutrients—protein, carbohydrate, fat, vitamins, minerals, trace minerals, and water—on a regular basis and in the proper amounts to function efficiently. These nutrients are digested and absorbed through the intestinal wall, and then transported via your blood to individual cells throughout your body. Your cells use the nutrients to maintain and rebuild body tissues and to perform all the necessary functions of your body. One important function is maintaining your body's natural defense system. These internal defenses help your body resist infections and are quite dependent on good nutrition.

No one food can supply all the nutrients you need each day and, unless you are selective, you might not be eating a good diet. To eat correctly, you need to select foods from a variety of sources so you will obtain the right balance of nutrients. The need for some nutrients can be increased or modified when the body is stressed—for example, by surgery, infection, or disease. Liquid nutritional supplements can help supply the extra nutrients you need, especially if regular full meals aren't always appealing. Check with your dietitian to find out your specific needs.

## CALORIES

Calories are the term used for the energy units supplied to the body by the food we eat. The basic nutrients—protein, fat and carbohydrate—are found in various proportions in all the food we consume. When digested, the food supplies the energy required to keep the body functioning. During an illness energy demands of the body may be increased. Therefore, what you eat now can make a big difference in how well your body can fight the illness and return to the best state of health.

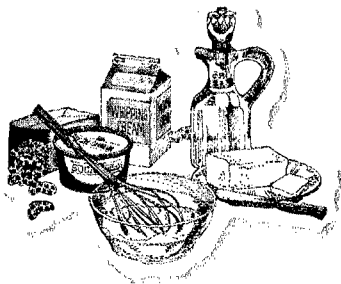
## PROTEIN



The protein in your food provides amino acids which are used by your body to build and repair tissues, to create antibodies, to fight infection, and to assist in numerous body functions. If you are consuming enough calories to meet your energy needs, one-half gram protein per pound of body weight is more than sufficient for an average adult. However, your protein requirements may be higher if treatment or disease has caused extensive tissue damage or muscle wasting.

Meat, fish, poultry, eggs, milk, cheese, nuts, and dried peas and beans, are all good sources of protein. If you are unable to eat enough regular foods to meet your protein needs, consider using a supplement that is high in protein.

## FATS



Fat supplies the calories necessary for warmth and physical work and provides "essential fatty acids" needed for growth, hormone production, cell membrane structure and transportation of vitamins (A, D, E, K) which are not soluble in water. Your body stores excess calories as fat. Stored fat acts as a reserve energy source. The main food sources of fat are butter, margarine, vegetable oil, shortening, salad dressing, fatty meats, whole milk products, cream, and nuts.



## CARBOHYDRATES

Your body uses carbohydrates to supply energy for heat and to do the mechanical work of your body. Some foods high in carbohydrates contribute valuable vitamins, minerals, and fiber to your diet. Carbohydrates are relatively inexpensive and readily available sources of calories. Good sources of carbohydrate are fruits, vegetables, flours, grains, breads, cereals and pasta. Concentrated carbohydrate (like honey, molasses, syrups, and table sugar) can add significant calories to your overall intake without adding much extra bulk. However, they do not contribute any other nutrients to your diet.

## VITAMINS, MINERALS AND WATER

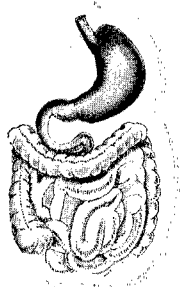
Vitamins and minerals are essential nutrients in your diet because they are needed to activate, regulate, and control many of the metabolic functions that take place in your body. The required amounts of most vitamins and minerals are usually supplied by your regular diet if you are eating correctly. However, if you are not eating very much and think you may need a vitamin/

mineral supplement, check with your oncologist first, to avoid any possible interaction between vitamins and your therapy. If you are using a liquid dietary supplement, be sure it contains adequate vitamins and minerals.

Unless you have been instructed to reduce your fluid intake, try to drink six to eight glasses of water a day. Be sure to follow your doctor or pharmacist's instructions concerning fluid intake, since some chemotherapeutic agents increase your need for water.

percent of nutrient absorption takes place in the jejunum, part of the small intestine. The lining of your small intestine is one of the areas in your body where there is a very rapid turnover of cells. For this reason, these cells are very sensitive to cancer therapy or poor nutrition. Other areas associated with potential nutritional problems are the mouth, throat, esophagus, pancreas, liver and colon. Cancer in any of these areas can affect your ability to maintain your nutritional status.

## THE GI TRACT



The gastrointestinal (GI) tract consists of all those parts of your body that are involved in the digestion and absorption of food. Any problems that affect the GI tract potentially can have an adverse effect on your nutritional status. Ninety to ninety-five

## Some problems and some solutions

The nutritional problems associated with cancer and its treatment are varied, but the best approach to managing side effects is a direct one. Observe your progress carefully, and learn to recognize problems when they first surface. Don't try to ignore them. You will minimize the effect and make better headway against the disease by keeping yourself well-nourished. Try the following suggestions; if they don't work, talk to your doctor, dietitian, or nurse and they may be able to help.

## **LOSS OF APPETITE**

If you are not hungry at dinner time, make breakfast, midmorning snacks, and lunch your main meals.

If you don't feel like eating in the morning, have a light snack, and eat later in the day when you feel better.

Don't feel locked into the conventional meal pattern. Several small meals spread throughout the day can achieve the same nutritional goals as three large meals.

Make the food you eat count. Taking just a few bites or a sip of the right food every hour or so can make a significant contribution to your total calories and/or protein intake.

If your appetite loss is caused by queasiness or nausea, eat small portions. Try to eat dry foods like crackers or bread to settle your stomach in the morning. Later in the day, when you feel better, concentrate on foods you tolerate well. Eat with others. You may well find you are able to relax and enjoy your meals more if you socialize with family and friends.

A glass of wine, beer, or a cocktail before lunch or dinner can help to increase your

appetite (check with your physician).

Do not stop eating because you have lost your appetite. Make a concentrated effort to eat regularly even when you are not hungry.

Think of eating as an essential part of your treatment program.

## **FOOD AVERSIONS AND ALTERATIONS IN TASTE AND SMELL**

Check with your dentist to rule out any dental problems.

Ask your doctor about your medications. You may be taking a drug that is causing changes in taste sensation. Eliminate the offending foods and substitute others of similar nutrient value.

If foods seem to lack flavor, use wines, salad dressings, and strong seasonings in cooking. Add strongly flavored juices or relishes.

Try cooking and serving with plastic to reduce the bitter taste of food.

If red meat begins to taste bitter, soak or cook it in soy sauce, fruit juice, or wine, or marinate it before cooking. Substitute chicken, turkey,



eggs, fish, high-protein puddings, ham, custards, peanut butter, ice cream, milkshakes, yogurt, cheese, peas, beans, nuts, or macaroni and cheese for red meats.

If your taste perception is dulled, intensify the aroma of food, and eat food with distinctive textures.

To overcome a metallic taste, eat lemons or other tart fruits or fruit-flavored sour balls.

Change the temperature of food. Frequently, foods will taste better chilled or frozen.

Drink your nutritional supplement cold, in a covered cup, through a straw if protein and vitamin smells are bothersome.

## **DRY MOUTH**

Eat soft foods, add gravies, sauces, salad dressing, broth, sour cream, or mayonnaise to make foods moist.

Use artificial saliva.

Chew sugar-free gum or suck on ice chips.

Try soups and casserole dishes.

Drink liquids with your meals. Be sure they are

high-calorie liquids if you need to gain weight.

Eat cold foods.

Dunk dry foods in a soup or beverage.

Concentrate on nutritious liquids that are easy to swallow.

## **SORE MOUTH AND THROAT**

Eat a variety of soft, easy-to-swallow foods, such as soups, eggs, flaked fish, pastas, quiches, souffles, cheese dishes, dairy products, and liquid meals.

Stew meat instead of broiling or frying it.

Avoid highly seasoned, spicy, tart, acidic foods and cigarette smoking and alcoholic beverages.

Cut food into very small pieces.

Mash, blend, strain or puree food, or try baby foods.

Concentrate on high-calorie, high-protein beverages and soups that are easy to swallow.

Eat things that are cold or at room temperature.

Use a straw for beverages and a cup or glass instead of a spoon for liquids like soup.

If swallowing is extremely difficult, ask your doctor for a referral to an occupational therapist who can help you locate specialty equipment or to a speech therapist who can teach you new swallowing techniques.

Ask your physician about anesthetic lozenges and sprays to numb the mouth and throat.

After meals rinse your mouth with a solution of one teaspoon baking soda to one cup warm water.

## FEELING OF FULLNESS

Eat small amounts of food six to eight times a day.

Make mini-meals that are high in calories and protein.

Drink fluids *after* solid food has been consumed, rather than with the solid food.

Exercise between meals.

Approach meals in a relaxed manner.

Eat slowly in a pleasant setting.

If you are in the hospital, avoid eating in bed all the time.

## NAUSEA

Don't force yourself to eat. Suck ice chips or anything frozen.

For early-morning or pre-meal nausea, eat a dry bland food, like a cracker.

Make up for lost calories when you feel more comfortable.

If you become nauseated during or after treatment, eat dry, bland, easy-to-digest, low-fat foods several hours prior to treatment.

Eat your meals in a well-ventilated area free of odors.

If the odor of the food itself makes you feel squeamish, select those that have little aroma and are unlikely to be cooked with garlic or other pungent seasonings. Try eating food chilled or frozen instead of warm or hot.

Arrange for someone else to cook or to go out for your meals.

If you are in the hospital, ask the nurse to remove the

cover from your plate before bringing it into the room.

Eat in a cool, pleasant atmosphere.

Eat and drink slowly.

Rest after eating.

## **VOMITING**

Eat frequent mini-meals.

Eat slowly and chew food well.

Restrict fluids to one hour before or after eating solid food.

Eat dry food and avoid sweets and fried or fatty food.

Stay away from cooking odors.

Drink clear, cool beverages like apple juice or flat ginger ale, or cola.

Rest after eating, but do not lie down flat for at least two hours.

When you feel you are going to vomit, lie down or rest, with your head and shoulders elevated, in a well-ventilated room. Loosen any tight, constricting clothing, and put cool, damp cloths on your face and neck.

If you do have periods of vomiting, restrict all food and fluid until they subside.

## **DIARRHEA AND CRAMPING**

Keep liquids to a minimum at mealtime, but drink between meals to replace fluids and electrolytes.

Eat small mini-meals throughout the day, instead of large meals.

Drink all your liquids at room temperature.

Select low-fiber foods like fish, chicken, well-ground meat, eggs, canned or well-cooked vegetables or fruits (without skins), ripe bananas, soft cereals, crackers, refined bread or flour products.

Avoid greasy, fatty, and fried foods, citrus juices, carbonated beverages, raw vegetables and fruits, high-fiber foods, nuts, onions, garlic, and gas-forming vegetables.

If you use a nutritional supplement, use a low-residue rather than a high-fiber product.

Keep activity to a minimum after meals.

If you have severe diarrhea, restrict your intake to clear, room-temperature liquids like broth, flat ginger ale, or apple juice for a day. Try to estimate your fluid losses and do your best to replace them. When the diarrhea is controlled, try other liquids and soft, bland, low-fiber food.

If you have occasional cramps or gas pain, avoid beer, carbonated soft drinks, beans, cabbage, broccoli, cauliflower, onions, sweet or highly spiced foods and chew your food with your mouth closed.

If cramping continues or is accompanied by vomiting, or if diarrhea is uncontrollable, persistent, or bloody, notify your doctor.

## CONSTIPATION

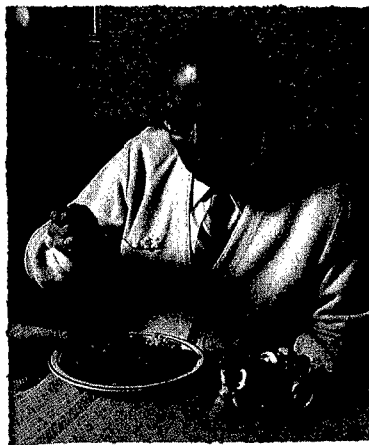
Drink six to eight glasses of fluid a day and increase intake of high-fiber foods.

Take a walk or exercise after eating.

If these measures do not succeed, do not use laxatives without your physician's permission.

## Make every bite count

To keep in good nutritional shape, you need to make every bite count. So every time you prepare food, think of something you can add to make it more nutritious. If you do not feel like eating much, make sure the food you do eat is highly nutritious.



Small servings of high-carbohydrate foods help supplement the number of calories you consume. Keep high-carbohydrate snacks available so that when you feel like eating "just a little something," you can nibble on one. Candy, popsicles, cookies,

granola, fruit-nut mixes, frozen desserts, or a slice of high-calorie bread spread with a generous amount of butter—all will help boost your calorie intake. Other high-carbohydrate foods, such as sugar, honey, jelly, jam, syrup, molasses, and marshmallows can also be incorporated into foods. Croutons can be added to soups and salads.

Alcohol contains 7 Calories per gram. Try a tablespoon of your favorite liqueur on top of ice cream, fruit, or pound cake. Try adding small amounts of high-fat foods like whipped cream, sour cream, butter, margarine, mayonnaise, chopped nuts, bacon, or a sauce to your foods. Don't attempt to eat large amounts of fat or carbohydrate at one sitting. Just adding a little extra throughout the day can make a significant difference in your total calorie intake.

If you have a poor appetite, or protein foods like meat don't appeal to you, try increasing the protein content of your diet by adding nonbulky, high-protein foods like peanut butter, fortified milk (add 5 tablespoons of dried skim milk powder to an 8 ounce glass of very cold milk), high-

protein nutritional supplements, cheese, eggs, fish, poultry, tofu, and yogurt.

## **NUTRITIONAL SUPPLEMENTS**

If regular meals don't always appeal to you, try using a commercial nutritional supplement. There are many products currently available to you. You can use them as your total intake or you can select one that supplies extra nutrients, such as protein, to your regular meals.

Liquid supplements come in a variety of flavors and consistencies, and you can enhance them by blending them with fresh fruits, syrups, liqueurs, instant coffee or powdered flavorings. Ice cream or whipped cream, if tolerated, are also excellent sources of extra calories that can be used as mixers. The drinks can be frozen and made into slushes or slurries.

Commercial supplements can also be used in many recipes as the liquid ingredient, adding more protein and calories than regular milk or water.

Commercial liquid supplements vary with regard to their nutrient levels. Be sure to

read the labels carefully and compare the volume required to get the nutrients you may especially need, such as protein, vitamins and minerals. If you are unsure about which supplement to choose, ask your dietitian.

Most nutritional supplements are sold through pharmacies. Be sure to ask the pharmacist to order the product you want if it is not readily available. Pharmacists are very helpful in getting the products you need, so don't be afraid to ask.

Remember, eating right makes you an active member of your therapy team! So, be determined to feel better—and you will.

More extensive information concerning nutritional therapy and more than 300 recipes can be found in the book, **Nutrition and the Cancer Patient** by Joyce Daly Margie, M.S. and Abby S. Bloch, M.S., R.D., available through most bookstores, or direct from the publisher: Nutrition, Chilton Book Company, Radnor, PA 19089 (\$14.00).

## CALORIE COUNT\* (in single servings)

Milk group	Weight or approx. measure	Calories	Fruit group	Weight or approx. measure	Calories
cheese, cheddar	1 oz.	113	apple, raw	1 med.	80
cheese, cottage, creamed	¼ cup	65	banana, raw	1 med.	101
cream, half & half	1 tbsp.	20	grapefruit, white	½ med.	46
milk, fluid, skim			orange juice	½ cup	61
or buttermilk	1 cup	88	peaches, canned	½ cup	100
milk, fluid, whole	1 cup	159	pineapple juice, canned	½ cup	69
			raisins	¼ cup	105
<b>Meat and Alternates group</b>			strawberries, raw	½ cup	28
beans, dry, canned	¾ cup	233	<b>Bread-Cereal group</b>		
beef, lean chuck	3 oz.	212	bread, white, enriched	1 slice	76
beef, hamburger	3 oz.	186	bread, whole wheat	1 slice	67
chicken, fried	½ breast	160	bun or roll, enriched	1 bun	119
egg	1 med.	72	cornflakes, fortified	1 cup	97
frankfurter	1 med.	139	macaroni, enriched, cooked	¾ cup	116
haddock, fried	1 fillet	182	oatmeal, cooked	¾ cup	87
liver, beef	2 oz.	130	rice, enriched, cooked	¾ cup	167
peanut butter	2 tbsp	188	<b>Fat group</b>		
pork chop	1 chop	305	butter or margarine	1 tbsp.	102
tunafish, canned	½ cup	158	oils, salad or cooking	1 tbsp.	120
sausage, bologna	2 oz.	172	mayonnaise	1 tbsp.	101
<b>Vegetable group</b>			<b>Sweets group</b>		
beans, green	½ cup	16	beverages, cola type	12 oz.	144
broccoli	½ cup	20	sugar, granulated	1 tbsp.	46
cabbage, chopped, raw	½ cup	11			
carrots, diced	½ cup	23			
corn, canned	½ cup	87			
lettuce, head	1 cup	10			
onions	½ cup	31			
peas, green, frozen	½ cup	55			
peppers, sweet, green, raw	½ med.	8			
potato, white	1 med.	88			
spinach	½ cup	24			
sweet potato	1 med.	172			
tomato juice, canned	½ cup	23			

\*Foods on this list are in forms ready to eat. All meats and vegetables are cooked unless otherwise indicated.

# The SUSTACAL Family of Nutritional Supplements



Sustacal® and Sustacal Plus®