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Examining Cancer-Related Pain and Study Enrollment Challenges in the Home Care Setting

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Examining Cancer-Related Pain and Study Enrollment Challenges in the Home Care Setting

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Introduction

- Despite the availability of effective pain management techniques in the United States, relief of cancer-related pain is frequently inadequate (NCCN, 2012; ACS, 2012; APS, 2008).
- The main purpose of this pilot study was to examine cancerrelated pain and quality of life (QOL) as reported by oncology patients receiving home care (HC) services. A secondary purpose was to describe study enrollment challenges encountered in the home setting and possible strategies for dealing with them.
- The study's theoretical framework was an adaptation of Michael Harrison's (1987) model in which the healthcare organization is conceptualized as an open system (Alley, 2001).

Study Objectives

- To describe the severity and nature of cancer-related pain experienced by oncology patients receiving HC services.
- To examine relationships between selected pain and quality of life variables.
- To evaluate the feasibility and strengths/weaknesses of study protocols and improve methods/tools for future studies.

Methods

- Design: Prospective, observational cohort study using a convenience sample of oncology patients receiving HC.
- Data: Quantitative data on self-reported pain, pain management, and perceived QOL.
- Sample and Setting: 50 cancer patients receiving HC services. Inclusion criteria: current cancer diagnosis, no surgeries within past 4 weeks, and able to communicate in English.
- Self-Report Measures: 1)Cleeland's Brief Pain Inventory (BPI); 2) Ferrans and Powers Quality of Life Index (FP-QLI); 3) European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30); and 4) Investigator-developed 5-Day Pain Diary.
- **Procedure:** 354 HC patients were screened to obtain the sample of 50 subjects. The 3 most common reasons for nonenrollment were: being discharged from HC (48%); not meeting inclusion criteria (17%); and declining participation (11%). The study interviewer conducted a one-hour structured in-home interview and assigned each subject a Karnofsky Performance Status (KPS) score. Subjects who agreed completed the 5-Day Pain Diary.

Results

I. Demographics

Table 1. Subject Characteristics	n	%
Female	35	(70%)
Age	63	(13)*
Caucasian	45	(90%)
Education		
< High School	11	(22%)
High School graduate	17	(34%)
Some college or more	22	(44%)
Karnofsky Performance Status (KPS)	71	(14)*

* Mean and standard deviation

able 4. Correlations: Pain Interference, KPS and Q

* p < 0.05 (2-tailed); ** p < 0.01 (2-tailed)

FP-QLI Overall QoL

EORTC QLQ-C30 Global Qol

EORTC QLQ-C30 Pain Scale

EORTC QLQ-C30 Global QoL

EORTC QLQ-C30 Pain Scale

	Only Subjects with pain in last week n=40		All subjects n=50	
	M	SD	M	SD
Pain at its worst in the last week	6.6	2.2	5.2	3.3
Pain at its least in the last week	1.8	1.7	1 ^	
Mean pain interference score	3.9	2.9	3.1	3.0

^Median value presented, given that scores were not normally distributed.

BPI Pain Interferenc

FP-QLI Overall QOI

EORTC QLQ-C30 Pain Scale

	M	SD
FP-QLI Overall Quality of Life Score*	20.7	5.4
EORTC QLQ-30 Global Health Status QoL ⁺	52.7	26.3
EORTC QLQ-30 Pain Subscale [®]	41.0	32.9

range from 0 - 100, with <u>higher</u> scores indicating <u>better</u> QOL & [©]Scores range from 0 – 100, with <u>higher</u> scores indicating <u>worse</u>

BPI findings, particularly noteworthy relative to the study's purposes and objectives:

II. Selected Findings from Questionnaires and Pain Diaries

- Of the 40 subjects reporting pain in the last week, 33 (83%) rated their worst pain as >= 5 (0-10 scale) reflecting "substantial" pain intensity ratings (Cleeland et al, 1994).
- For the 40 subjects reporting pain:
 - The mean pain intensity at its worst in the last week was 6.6 (SD=2.2).
 - 75% had an active opioid prescription.
- 2 of 10 subjects who reported <u>no</u> pain in the last week had at least 1 active opioid prescription.
 - Selected Pain Diary Results:
 - All 39 subjects who agreed to complete the 5-Day Pain Diary did so successfully, entering an average of 8 (out of possible 12) pain ratings in their diaries during each 24-hour period for days 2 through 5.
 - sleep habits, naps taken during the day, exercise, and openthe process of being analyzed.
 - - KPS and QOL scores were inversely related to the BPI Pain Interference score; the two QOL scores were strongly correlated; and the KPS was moderately, positively correlated
 - and worse diary pain intensity ratings. BPI lowest and worst ratings were highly and positively correlated with pain diary
 - correlate with pain ratings.

- Subjects recorded additional information in the diaries, such as ended comments about their pain situations. These data are in
- Associations between Pain and Quality of Life (QOL)
 - with QOL scores. - Both QOL scores were inversely correlated with both overall
 - Patient's education, martial status and living situation did not

III. Enrollment Challenges Encountered

Average Worst Diary

 Table 5. Correlations: Average Diary Pain Ratings and QOL Variables

EORTC QLQ-C30 Global QoL

BPI Lowest Pain Rating in last Week

BPI Worst Pain Rating in Last Week

* p< 0.05 (2-tailed); ** p< 0.01 (2-tailed)

- Initially, the recruitment strategy was to send written study advertisements to HC patients and subsequently call them. However, many potential subjects declined because they did not identify study team members as part of the HC team. As a result, they were reluctant to participate in a study that required a home visit from a person with whom they were unfamiliar.
- Enrollment was more successful when the study was introduced by the HC nurse, yet recruitment via this method was difficult since the nurses had competing priorities, and recruiting for the study was above and beyond the tasks they were already required to do.
- Even when subjects agreed to enroll, study completion was often complicated by severity of illness, medical appointments, and/or treatment schedules.
- Subject accrual took 12 months longer than anticipated. Mid-study, an IRB-approved modification in the enrollment process was implemented which allowed the HC nurse to call the study interviewer while in the patients' homes and have potential subjects speak with the study interviewer. This served as an "introduction," resulting in better subject understanding of the study.

Main Study Limitations

- Patients experiencing the most severe pain may not have been well represented in the study sample because of declinations due to their symptom severity.
- Relationships among opioid and non-opioid analgesic use and pain intensity ratings were not examined, given that total amounts taken by subjects were not recorded in the diaries.
- In most cases, a family member stayed in the room with subjects throughout the interview, which may have prevented fully candid responses.
- To minimize the possibility of missing data, tools were not self administered, which may have prevented fully candid responses.
- Most subjects were women and/or Caucasian.

Conclusions and Implications

- Consistent with other cancer pain studies, the majority of subjects experienced significant pain. This warrants increased intervention by healthcare providers to achieve adequate analgesia relief. Better education is needed for both medication use and other home-based comfort measures.
- Pain Diaries appeared easy and not burdensome for subjects to complete. Diaries provided additional information which could help healthcare providers improve cancer pain management.
- Overall, subjects were highly functional based on the KPS and BPI and were not demographically diverse. Future projects should include subjects with a broader range of pain ratings, functional abilities, and demographics, to yield more generalizable results.
- Conducting successful research projects with patient populations outside the hospital setting presents special challenges that require novel approaches.

