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The Experience of Complex Pain Dynamics in Oncology Outpatients: A Longitudinal Qualitative Analysis

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Abstract

Background: Few qualitative studies of cancer patients' everyday experiences with pain exist within the large body of cancer pain research. Longitudinal qualitative studies are particularly sparse and no studies have qualitatively described patients' pain experience over time during participation in a self-management intervention.

Objective: To longitudinally describe patients' pain experiences during a 10-week pain self-management intervention.

Methods: This qualitative study was embedded in a randomized controlled trial (RCT) of a psychoeducational pain management intervention. The data consisted of transcribed audio-recordings of each intervention session. An emergent, interpretive approach was used in this longitudinal qualitative analysis.

Results: Forty-two adult patients were included. The analysis revealed the strikingly dynamic nature of individual patient's pain experiences. Multiple facets of pain contributed to its dynamic nature, including pain in changing locations, co-occurring sources of pain, and varying patterns of pain intensity over time. For individual patients, the cumulative effect of these multiple facets resulted in a phenomenon we termed "complex pain dynamics."

Conclusion: The results contribute to knowledge about the dynamic nature of cancer patients' pain experiences over a relatively short period of time. They suggest the need for a new paradigm for management of pain in cancer patients and raise questions about the interpretation of RCT results in the absence of qualitative data.

Implications for Practice: Frequent assessments and reassessments of pain are needed in cancer patients with the ongoing development of highly individualized self-management strategies. A large repertoire of interventions is needed to effectively manage pain in cancer patients over time.

Keywords

cancer pain management; analgesics; self-care; self-management; longitudinal qualitative research; randomized clinical trial

INTRODUCTION

Cancer pain remains a challenging problem, despite extensive research aimed at reducing it. Prevalence rates have not changed in over 40 years.¹⁻² They remain approximately 55% during cancer treatment and 65% in advanced cancer, despite a better understanding of pain mechanisms and some new therapeutic options.¹⁻² Among oncology outpatients, self-management of pain is crucial for achieving optimal quality of life outcomes. However, multiple systematic reviews found only small to moderate effect sizes in randomized controlled trials (RCTs) designed to enhance patient self-management.³⁻⁷ Given these disappointing results, a better understanding of the phenomenon of cancer pain is needed as the basis for the next generation of pain self-management interventions.

Qualitative research has the potential to provide insights that can inform future self-management interventions. However, qualitative studies of patients' everyday experiences with cancer pain are limited. A small body of research has described patients' experiences within the broad thematic areas of pain perceptions, impacts on functioning and quality of life, and management challenges.⁸⁻¹⁶ One study explored the complexities that multiple types of pain present.¹⁷ A few studies were embedded within larger RCTs of psychoeducational interventions designed to help patients better manage their pain.^{9,12-16} Missing from the qualitative research are longitudinal studies of patients' pain experiences over time. Qualitative studies to date typically were limited to one or two interviews^{8-12,17} or used analytic strategies that did not capture change over time.¹³⁻¹⁶

We sought to address these limitations by conducting a longitudinal qualitative analysis of data collected in a RCT of a nurse-led psychoeducational self-management intervention for oncology outpatients.¹⁸ Audio-recordings of each intervention session allowed us to closely follow patients' pain experiences as they unfolded in real time. Our purpose was to describe patients' pain experiences across the course of the intervention.

METHODS

Design

This longitudinal qualitative analysis was embedded in a RCT of a nurse-led, psychoeducational cancer pain self-management intervention called the Pro-Self[®] Plus Pain Control Program.^{18,19} The intervention consisted of assessment, education, skill development, and individualized coaching for cancer pain management. The purpose of the RCT was to compare the efficacy of two doses of the 10-week intervention. Patients

who were randomized to the high-dose group received 6 home visits and 10 telephone calls, while those in the low-dose group received 4 home visits and 6 calls. Each intervention session was audio-recorded, providing extensive longitudinal qualitative data for each participant. The embedded qualitative study was designed to track patients' pain experiences as they occurred in real time while participating in the intervention. The (Authors' University) Committee on Human Research and the appropriate review board at each clinical site approved the study.

Setting and Sample

Recruitment took place in eight outpatient oncology settings in Northern California. The sample consisted of adults who were receiving outpatient treatment for cancer and who had somatic or visceral pain with an average pain intensity score of at least 3 on a 0–10 numeric rating scale, a life expectancy of at least 6 months, and a Karnofsky Performance Status (KPS) of at least 50. After written informed consent was obtained, patients were randomized to the high-dose or low-dose group. Two hundred twenty-two patients comprised the RCT sample as a whole.

A subsample was selected for this qualitative analysis. Initially, consecutively enrolled patients were selected as their qualitative data became available. Later, purposive sampling²⁰ was used to achieve variation based on gender, race/ethnicity, socioeconomic status, group assignment (high- or low-dose), and challenging pain management issues. Patients with challenging pain management issues were identified by the investigators and intervention nurses during team meetings. Forty-two patients comprised the sample for this qualitative analysis.

Longitudinal Qualitative Data Collection and Analysis

The qualitative data consisted of verbatim transcripts of the audio-recorded intervention sessions and nurses' narrative field notes. Data were organized by case in MAXQDA[®],²¹ with a "case" consisting of all qualitative data for an individual patient. Each case included up to 16 transcripts (from both visits and calls) for those in the high-dose group and up to 10 transcripts for those in the low-dose group.

The longitudinal qualitative analysis was conducted by two co-investigators (KS & VPC), using an interpretive/emergent approach.^{20,22} The initial phase included reading the set of transcripts for each case in its entirety, following by line-by-line coding, and organization of codes into larger categories at each point in time. As the coding categories were developed, we used multiple strategies to further an interpretive level of analysis, including creating narrative case summaries and memos to record the researchers' reflections and interpretive insights.

The size and scope of the database permitted us to design a series of focused qualitative analyses based on initial coding. We previously reported our focused analysis of pain medication management processes.^{15,16} Here, we report on another prominent aspect of patients' pain experiences, namely the dynamic nature of their pain. While the "ideal" pain experience was a consistent and sustained reduction in pain with the initiation of more effective pain management strategies, our early analysis revealed that the actual pain

experience was quite dynamic. Early reflective memos included frequent comments on the ever-changing nature of the pain experienced by individual patients. The prominence of changing pain experiences over time noted early in the analysis was the impetus for a focused analysis of pain dynamics.

To develop the focus on pain dynamics and to capitalize on the extensive longitudinal data, we created diagrams to track each case's day-to-day experiences with pain. We called these diagrams *pain experience graphs*. This procedure built on existing strategies for displaying longitudinal qualitative data, such as growth gradient graphic displays²³ and turning point analyses,²⁴ to capture both the amount of and contexts for change in a phenomenon of interest. A key feature of the graphs was that they were based on patients' verbal descriptions of their pain in conversation with the nurses. Occasionally, patients referred to a numerical pain score when describing their pain (e.g., "easily a 7 or 8."). More commonly, they provided narrative descriptions of their pains, such as "pretty good," "feels like it is going to explode," and "excruciating," and made comparisons between different pains and between points in time. We chose this approach to keep our analysis focused on patients' unique representations of their pain.

Each hand-sketched pain experience graph tracked the relative intensity of the different pains experienced over the 10 weeks. We recorded key contextual information on the graphs that described what was happening at times when pain intensity changed and when new pains appeared. The two analysts compared and discussed their graphs to ensure consensus in the representation of the patient's pain experience. Ultimately, these pain experience graphs proved to be a highly useful strategy for summarizing and interpreting each patient's day-to-day pain experience over the 10-week study period. In addition, the individual graphs provided the basis for cross-case analyses in which we identified patterns of pain intensity over time. Case examples (in which all names are pseudonyms) and pain experience graphs are used to illustrate our findings.

Multiple strategies were used to insure the rigor and completeness of the qualitative analysis.²⁵ The two primary analysts met weekly to discuss the data and develop a consensus about key findings. Interpretations were also triangulated with the nurses' fieldnotes and with participants' retrospective comments about events that had occurred in earlier weeks of the intervention. Emerging results were shared periodically with the principal investigator (CM) and other research team members. A few research team meetings included the intervention nurses so that they could share their experiences and reflections. These meetings were used to refine the analysis and identify directions for subsequent purposeful and theoretical sampling. An extensive audit trail, in the form of meeting notes and memos, was kept on analytic strategies and decisions.

RESULTS

Sample Characteristics

The sample for this qualitative analysis consisted of 42 oncology outpatients with advanced cancer. Their mean age was 64.0 (s.d. = 10.9). Most were male (59.5%) and White (73.8%). Years of education ranged from 7 to 23, with a mean of 15.7 (s.d. = 2.8). Patients had

the following types of cancer: prostate (40.5%), breast (33.3%), lung (14.3%), and other (11.9%). Current treatments included chemotherapy (59.5%), hormonal therapy (35.7%), and radiation therapy (14.3%). The mean Karnofsky Performance Status score was 69.5 (s.d. = 11.8).

Qualitative Results

A key aspect of patients' pain experiences was their strikingly dynamic nature. Patients experienced multiple pains, each of which had its own characteristics and implications for management. New pains emerged at different points during the 10-week intervention, while other pains receded. Study participant Howard described his experience with pain over time this way: "I thought we had this thing pretty down pat, but I can see it doesn't work that way. It's just not once you think you have it. That's just for that moment because it certainly can change" (Week 6).

Multiple facets of the pain experience contributed to its dynamic nature, including: (1) pain in changing locations, (2) co-occurring sources of pain, and (3) varying patterns of pain intensity. Within individual cases, the combination of changing locations, co-occurring sources, and varying patterns of intensity resulted in a phenomenon we termed "complex pain dynamics." Patients' experiences of complex pain dynamics shaped the ways in which the Pro-Self[®] Plus intervention was tailored to patients' pain experience over time. The three facets of the pain experience and the over-arching phenomenon of complex pain dynamics are detailed below. Although space considerations preclude an in-depth description of the nurse-patient interactions around complex pain dynamics, key intervention processes are described briefly.

Pain in Changing Locations

One facet of the dynamic nature of individual patients' pain was the way it occurred in changing locations over the 10-week study. Across the qualitative sample as a whole, pain occurred throughout the body. Back, hip, pelvic, and/or leg pain were most common. However, patients described pain in numerous other locations, including head, mouth, neck, ribs, sternum, arms, wrists, hands, esophagus, abdomen, perineum, groin, knees, ankles, and feet. In addition, they described non-specific aching of the whole body.

However, a simple list of various pain locations does not capture their dynamic nature. Individual patients experienced pain in numerous locations and these locations typically changed over time. As Dee said, "It's all about where your pain is and this last couple of weeks it's been the esophagus." Over the course of Dee's study participation, the dynamics of her pain in changing locations went like this: Upon enrollment, she had pain in her hips with episodes of severe breakthrough pain. By the Week 1 visit, Dee had less hip pain (with new analgesics), but she now had esophageal pain, plus a migraine headache. At Week 2, she still had a headache, but the esophageal pain was less. At Week 3, she described knee pain for the first time. During Weeks 4 and 5 she had no new pain locations and minimal pain anywhere. In Week 6, she described back pain for the first time, but noted that she no longer had hip pain. Back pain continued in Weeks 7–9. In Week 8, she described soreness all over her entire body for the first time. In week 10, she described pain in her mouth at a biopsy

site. While the specific pain locations and the week-to-week changes were unique for each patient, the experience of pain in changing locations occurred across the sample. Patients' references to pain in a new location played a key role in the implementation of the Pro-Self[®] Plus intervention, as pain in a new location was typically the trigger for a new and detailed assessment by the intervention nurses.

Co-occurring Sources of Pain

Another important facet of the pain experience was how it involved co-occurring sources of pain. Shannon described the sources of her pain as "all over the map." Cancer-related pain was experienced by every patient, as it was a criterion for study participation. Additionally, patients described pain from multiple types of cancer treatment, including surgery, radiation, chemotherapy, bisphosphonates, and bone marrow stimulants. Chronic non-cancer pain from various sources occurred, as well as acutely painful conditions that may or may not have been related to cancer. Some patients experienced pain from lifestyle activities, such as household tasks and recreational pursuits that were not clearly related to any disease condition.

A key finding was that individual patients experienced the co-occurrence of multiple sources of pain over the 10 weeks. Furthermore, different combinations of co-occurring sources of pain emerged at different points during the study. The sources of pain in the changing locations that Dee experienced (as described above) included bone metastases, radiation therapy, oral chemotherapy, other medication side effects, golf, yard work, and biopsy of a new lesion. Valerie described pain from bone metastases and chemotherapy-related neuropathic pain in her hands throughout the 10 weeks. She also had a painful chemotherapy-related rash (Weeks 1 and 10), pain at the site of a previous leg fracture (Week 3), and soreness after a massage (Week 4).

Furthermore, multiple sources of pain interacted with each other, contributing to the dynamic nature of the pain experience. Some patients had chronic back pain related to arthritis or a previous injury, which seemed to become worse in the context of bone metastases in the spine. Other patients experienced a cascade of multiple pains with one source leading to another. For example, Mary's use of opioids for bone metastases led to constipation, which led to abdominal pain and a painful "butt situation." Ultimately, such cascades could make patients reluctant to continue opioid use, leading to increased bone pain.

When patients described pain in a new location, the detailed assessment initiated by the intervention nurses included identification of potential sources of the new pain along with management strategies tailored to that particular source. In some instances, the source of pain was readily apparent, such as pain in a radiation field or muscle and joint aches after a bisphosphonate treatment. At other times, a new pain led to a referral for a diagnostic evaluation by the patient's clinician. Similarly, some strategies for the management of a new source of pain fell within the scope of the patient's current pain management regimen. At other times, a referral to a clinician was needed for a new or revised regimen.

Varying Patterns of Pain Intensity

Patients' descriptions of pain in changing locations from co-occurring sources revealed varying levels of pain intensity over time. As we diagrammed each patient's pain experience, multiple patterns of pain intensity were evident. Thus, varying patterns of pain intensity emerged as the third facet of patients' pain experiences. We classified these patterns into five categories: sustained decrease, waxing and waning, spikes, temporary relief, and unchanging (Figure 1).

Sustained decrease.—The sustained decrease pattern was characterized by a steady reduction in pain, followed by an acceptable level of pain for the rest of the study. It was commonly associated with early adoption of an effective pain management regimen that remained effective. Typically, a patient had severe cancer-related pain prior to enrollment, received a new analgesic prescription, and learned to use it effectively. For example, Brian was in severe pain at the beginning of the study, but his pain lessened with an increase in the dose of his fentanyl patch. He was feeling better by Week 3 and “really good” by Week 8. He remained satisfied with his pain control thereafter. Other patients experienced decreases in pain from palliative radiation or chemotherapy that began concurrently with enrollment in the study.

Waxing and waning.—The waxing and waning pattern was characterized by reoccurring wave-like increases and decreases in pain. The regularity of waxing/waning cycles gave this pattern some predictability. However, the timeframes for cycles varied considerably, ranging from as short as 24 hours to as long as weeks. One typical timeframe was waxing and waning of pain over the days or weeks associated with the administration of cancer therapies, including chemotherapy, bisphosphonates, and bone marrow stimulants. Pain would gradually increase over a few days and then decrease in wave-like cycles that repeated with each administration. Ronald described the cycle of treatment-related pain as a “roller coaster,” and explained: “As I go through this chemo treatment, the first week isn't too bad; the second week is a little worse; the third week I feel almost perfect, just great...and then I take the chemo again and it starts over.” The nurse observed, “You've learned the curve of how things go” (Week 2).

Spikes.—“Spikes” is an *in vivo* term that patients used to describe a pattern with sharp, episodic increases in pain that punctuated periods of relative pain relief. Pain spikes were not as predictable as waxing and waning pain. They could be associated with any of the sources of pain described above and could last for varying lengths of time, ranging from a few minutes or hours to several days or weeks. Cramping abdominal pain related to diarrhea could be brief but intense. Paul described his abdominal pain during an episode of diarrhea as a 10. A pain spike from an acute injury or over-exertion could last for days. Sharp increases in treatment-related pain, such as localized pain from radiation therapy or hand and foot syndrome, could last for several weeks. Ellen had an episode of excruciating chest pain for which she went to the emergency room. Brenda's pain spiked after a day of gardening.

Temporary relief.—Temporary relief was characterized by decreasing pain early in the study, followed by a short-lived period of relief and then steadily increasing pain in later

weeks. For example, Howard experienced relief from severe pain in the first weeks of the study - so much so that he increased his activities significantly. He began working in his yard and playing basketball. These activities resulted in muscle aching, but it was mild compared to his earlier severe pain and he noted that “life has been good” (Week 4). However, in Week 6, he had a sudden increase in pain that was so bad “it’ll knock you down.” After that, his pain levels remained elevated.

Unchanging.—Unchanging pain was characterized by a persistent level of pain intensity. This pattern typically was associated with pain that was particularly difficult to treat, such as neuropathic pain. For example, Nancy had pain in one arm throughout the study, associated with a tumor in her brachial plexus and lymphedema. Paul had chemotherapy-related neuropathic pain in his feet and legs that remained essentially unchanged, despite multiple management strategies.

Identification of patterns of pain intensity involved very detailed interactions between nurses and patients that occurred across multiple encounters. They identified pain patterns through patients’ narrative descriptions of their pain experiences; discussions about the data recorded in daily diaries; and brain-storming to identify similarities and differences in individual patient’s pain experiences over time. Identification of patterns of pain intensity required ongoing assessment throughout the course of the 10-week intervention.

Complex Pain Dynamics

Although some patients experienced pain in consistent locations from a single source in a recognizable pattern over time, more complex experiences with multiple pains were common in our sample. When analyzed longitudinally, the dynamic nature of the pain experience was readily apparent. We termed such experiences *complex pain dynamics*, adopting an *in vivo* term used by Alan:

So the pain is sharp and kind of a sharp throbbing type, kind of constant pain with kind of sharp nuisances to it in my groin area. And then with my back and hip there are very, very sharp pains and that’s where I say a pinched nerve type pain. And then the third set of pain is what I’m having right now is kind of my muscles on both sides on my lower back are just really aching. I certainly experience certain types of pain. A lot of times I have both pains. If I have a complex pain I’ll take both of those [referring to his pain medications].

We found that the complexity of a patient’s pain dynamics was most effectively captured by considering the facets of location, source, and intensity for each pain that the patient described. It was only by considering variations in all three facets of changing pain that we could adequately understand patients’ pain experiences. Thus, we defined complex pain dynamics as *the experience of multiple pains over time in changing locations, from co-occurring sources, with varying patterns of intensity that required different but interrelated management strategies*. A key characteristic of complex pain dynamics was the overlap of multiple types of pain within a given period of time, each with its own typical location(s), sources, and pattern of intensity. The cumulative effect of complex pain dynamics was an exceedingly intricate pain management challenge. We present three case descriptions with

their corresponding pain experience graphs to illustrate the experience of complex pain dynamics and its variability among patients.

As illustrated in Figure 2, Raymond's experience of complex pain dynamics included pain in numerous locations, from multiple overlapping sources with different patterns of intensity over the 10-week study. As the study began, he had a significant reduction in the intensity of his metastatic bone pain with the adoption of a more effective pain management regimen. Thereafter, he had little bone pain until the last weeks of the study. Meanwhile, multiple pains from different sources emerged, each of which had its own pattern and required its own management strategy. In Week 2, he had a severe flare-up of chronic knee pain that he described as "bad," whereas the bone pain was now "just a little bit." Ibuprofen helped the knee pain, but he had to discontinue it to become eligible for a clinical trial. Eventually, he saw an orthopedist and had a cortisone injection, which relieved the knee pain. Later, he had "excruciating" pain several times a day from a constipation-related fissure. A gastroenterologist treated this pain with a topical cream and Raymond adopted a more effective constipation management regimen. Subsequently, he had pain from a muscle strain that occurred when he pulled himself out of the bathtub ("which scared me a little bit"), and pain from another pulled muscle when running to catch a bus. His bone pain increased late in the study and he had another change in his pain management regimen. In Week 10, Raymond summarized the challenge of documenting his complex pain dynamics: "The one bad thing about all this from the study standpoint is you've got 'pain' recorded in this (diary). It's not really bone pain."

Doris also experienced complex pain dynamics, as depicted in Figure 3. She had multiple pains and was not always sure which were caused by the cancer. As the study began, she described pain in her legs and heels, side, and back, with the back pain attributed to bone metastases. She also had stomach pain with nausea. Her back pain improved quickly with more effective use of her pain management regimen by Week 2. This pain was "down, down, down," except for one day when she had to withhold her pain medications prior to a surgical procedure and in Week 5 when she forgot to take her medication for several days. Thereafter, she had a brief but severe muscle spasm with a stressful event, pain in her Achilles tendon, and what she described as sciatic nerve pain. In Weeks 6 and 7, she described a new, "excruciating" pain in her forearm. In Weeks 8 and 9, Doris had pain in her throat and esophagus from radiation. She described Week 10 as a "roller coaster week," in which her pain spiked and "went crazy" and then dropped quickly when her physician prescribed a new pain management regimen. Doris' pain and her pain management strategies were in flux for the entire study. Some of her pain followed a predictable pattern, such as the radiation-induced pain. Other pains occurred unpredictably and required in-depth assessments each week, along with new management strategies.

Figure 4 depicts Hazel's experience with complex pain dynamics throughout the 10 weeks of the intervention. She was managing so many different pains that when the nurse asked about her pain in Week 2, Hazel replied "What kind of pain?" to clarify which of her pains the nurse was asking about. Along with pain from bone metastases (in her ribs, sternum, and possibly back), she started the study with severe, throbbing pain from hand and foot syndrome and a sore neck from twisting it in a funny way. She also had pain from arthritis in

her knees, which flared up with activity and in response to the chemotherapy treatment. She experienced waxing and waning pain in her back, ribs, and sternum with each chemotherapy infusion. The cyclical one-week-on, one-week-off pain pattern was evident by Week 4. Her worst pain occurred during Week 5, when Hazel's knee pain was so "excruciating" that she could not walk. Hazel's pain subsided several times during the study, but the relief of only a "dull pain" was never long lasting.

While Raymond, Doris, and Hazel each experienced complex pain dynamics, the nature of the experience was unique to the individual as illustrated by Figures 2–4. The uniqueness, overlap, and cumulative effect of multiple pains over the 10 weeks gave complex pain dynamics an emergent quality that was not predictable at the beginning of the intervention, nor at any particular subsequent time within the 10 weeks. In all three cases, implementation of the Pro-Self[®] Plus Pain Control Program was characterized by ongoing processes of assessment, strategizing, reassessment, and re-strategizing as patients and nurses sought the most effective approach for each pain as it occurred and changed. Analysis of these processes revealed intervention implementation to be highly dynamic and individualized, rather than a progressive, linear process of education and skills development.

DISCUSSION

This study is the first longitudinal qualitative analysis of cancer patients' experiences with pain as they participated in a nurse-led pain self-management intervention. Our results demonstrate the complex dynamics of pain that patients experience during a relatively short period of 10 weeks. Specifically, overlapping multiple pains in changing locations, from multiple co-occurring sources, and with varying patterns of intensity represent an exceedingly dynamic phenomenon. These results provide a novel way to conceptualize the pain experience that confronts oncology outpatients and their clinicians over time. Frequent assessments and reassessments with ongoing development of highly individualized management strategies characterized the intervention processes as patients and nurses responded to complex pain dynamics.

Our results suggest that the traditional focus on "cancer pain management" should be replaced by a focus on "management of pain in cancer patients" to better address this complexity. This shift in focus acknowledges that patients with cancer experience typically both cancer- and treatment-related pain as well as non-cancer pain in changing locations and with varying patterns of intensity. Furthermore, our data suggest that cancer- and non-cancer pain interact and complicate the management of both types of pain.

The study design, in which extensive longitudinal data were collected at frequent time points, was essential for revealing the exceedingly dynamic nature of patients' pain experiences. Longitudinal qualitative analyses are labor-intensive, especially when several time points are involved.²⁴ However, this approach is unique in its ability to reveal the dynamic nature of patients' real-life experiences. The use of pain experience graphs contributed not only to the recognition of the phenomenon of complex pain dynamics during the analysis, but to some efficiencies of effort. The graphs concisely encapsulated multiple facets of patients' experiences more economically than text. As large qualitative

datasets become more common, increased use of visualization methods for both analysis and presentation of results will be an important approach.²⁶

Our findings are consistent with and add to previous reports on the complexity of cancer pain and the multiple types of pain experienced by cancer patients.^{17,27,28} Our unique contribution is a detailed description of day-to-day pain dynamics at the individual level. These findings extend previous quantitative research by our group, in which baseline predictors of *inter*-individual differences in pain trajectories over the six weeks of a previous RCT were examined.^{29,30} The current analysis of *intra*-individual pain experiences suggests that complex pain dynamics contribute to variability in pain trajectories. In the future, analytic models that include both baseline predictors and time-varying co-variables are needed to advance a more complete understanding of pain dynamics.

Clinical Implications

Our results, along with the conclusions of others,³¹ support the need for a new paradigm for pain management in cancer patients that accounts for multi-faceted, dynamic pain experiences. Although the traditional gold standard of extended release and short-acting opioids is effective for some patients, it has significant limitations for the effective management of pain in patients with complex pain dynamics. A large, multi-modal repertoire of pain management interventions is needed to address cancer- and treatment-related pain along with acute and chronic non-cancer pain.³² Moreover, the presence of multiple types of pain simultaneously and/or in rapid succession in short timeframes calls for ongoing, in-depth assessments of each type of pain and individualized, patient-centered pain management regimens.

Implications for Research

Our results have important implications for the interpretation of outcomes in both psychoeducational and pharmacologic pain management RCTs. Complex pain dynamics may obscure the efficacy of an intervention that targets one particular type of pain. While the inclusion of one type of pain increases the scientific rigor of a RCT, the complexity of real life pain management can impact study power and results. Additionally, as patients in this study noted, when multiple pains occur together, pain scores may reflect a summation of the pain experience as a whole, obscuring the complex dynamics underlying a given score. When efficacy determinations are based only on pain intensity measures, the dynamic nature of multiple pains may appear to represent unrelieved pain, when in fact one pain is relieved only to have another emerge. In short, the occurrence of complex pain dynamics may skew conclusions about an intervention's efficacy, despite rigorous eligibility criteria and study design.

These results provide the basis for longitudinal mixed methods approaches in which concurrently recorded narrative accounts and daily pain intensity ratings are examined together.^{19,33,34} Such an integrative approach would provide additional insights into how cancer patients experience pain over time and potentially lead to more comprehensive evaluations of the processes and outcomes of pain management interventions.³⁵

Limitations

Determinations of the sources of pain were based on patients' descriptions and nurses' interpretation of patients' descriptions. We did not collect data that would enable us to reliably assess patients' descriptions of the location and source of their pain in relation to formal diagnoses by clinicians. Integrating objective clinical data with patients' perceptions is an avenue for future research. The sampling strategy for the qualitative analysis resulted in a sample heavily weighted toward "issues," as our overall purpose was to better understand these issues. Thus, the qualitative sample is not necessarily representative of the RCT sample as a whole, nor of the population of cancer patients with pain.

Conclusions

Our findings about complex pain dynamics among oncology outpatients advance knowledge about the multi-faceted, dynamic nature of patients' real life experiences of pain over time. These findings point to the need for a new paradigm for the management of pain in cancer patients and raise questions about the interpretation of RCT results in the absence of qualitative data. Longitudinal mixed methods research designs are needed to further inform the content, processes, and interpretation of future psychoeducational interventions.

Conflicts of Interest and Source of Funding:

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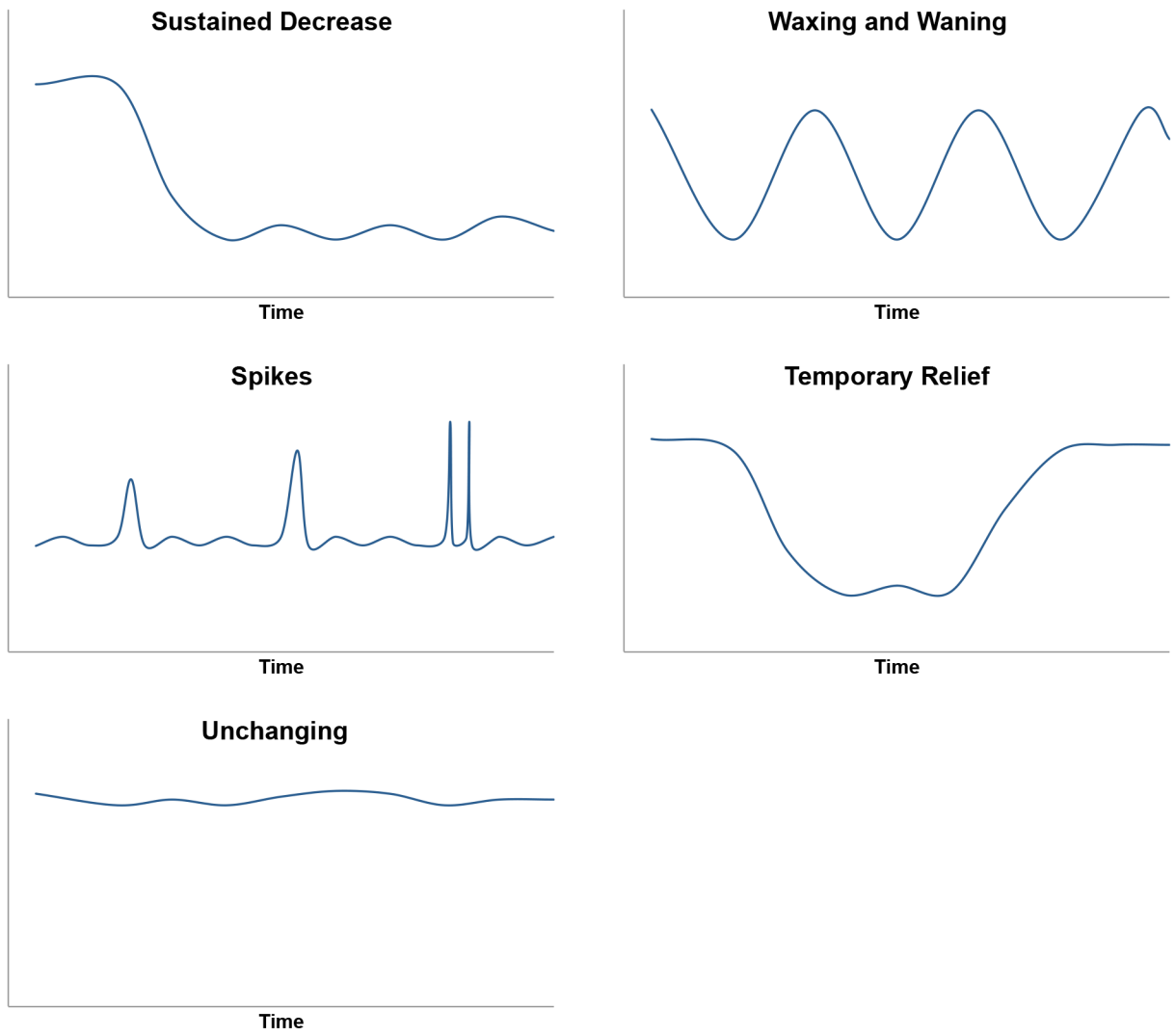


Figure 1.
Qualitatively derived patterns of pain intensity.

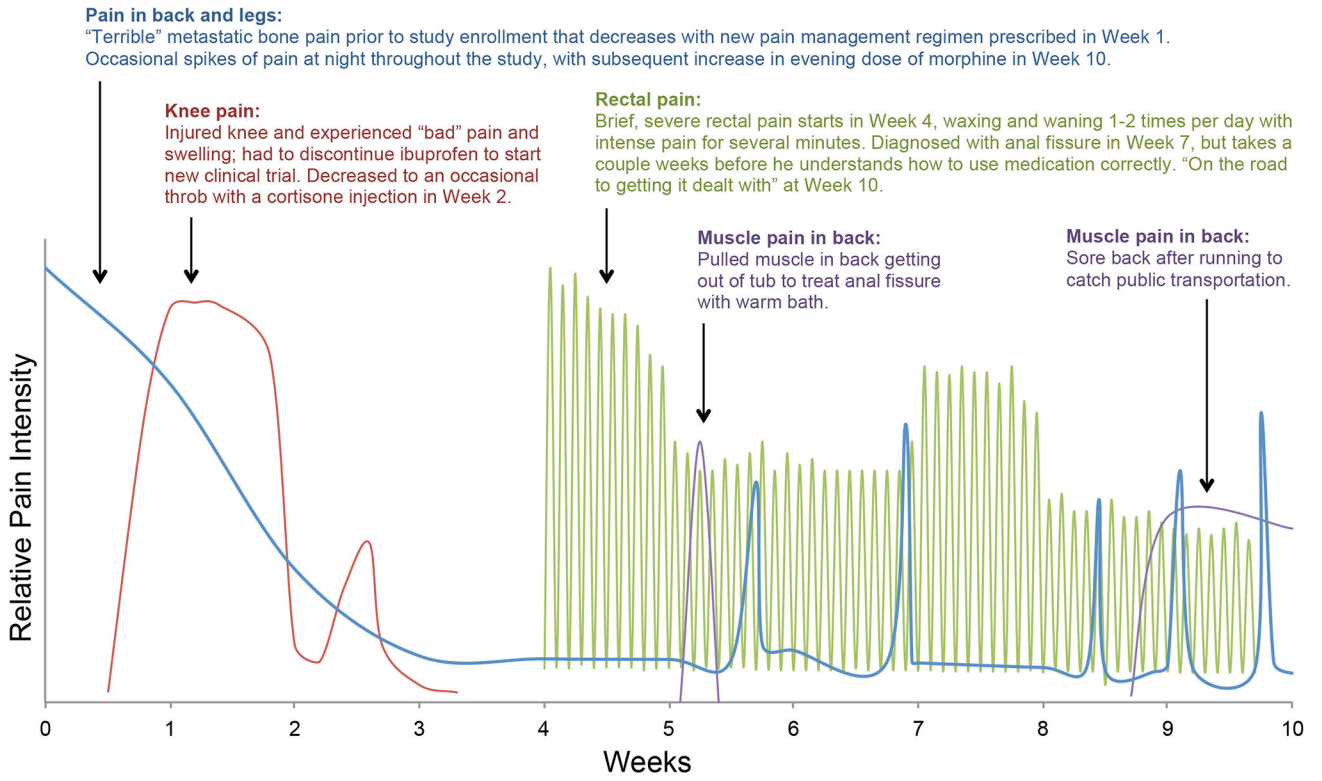


Figure 2.
Pain experience graph of Raymond's experience of complex pain dynamics.

Pain in back:

“Dull” metastatic bone pain at study enrollment that quickly improves “down, down, down” with better implementation of prescribed pain management regimen by Week 2; however, problems occur when has to disrupt regimen for cataract surgery in Week 2 and goes “all berserk” when forgets to take medications for multiple days when visiting family disrupts her morning routine in Week 5. Experiences a “roller coaster ride” when pain spikes in Week 9; changes pain management regimen and then feels good as study ends.

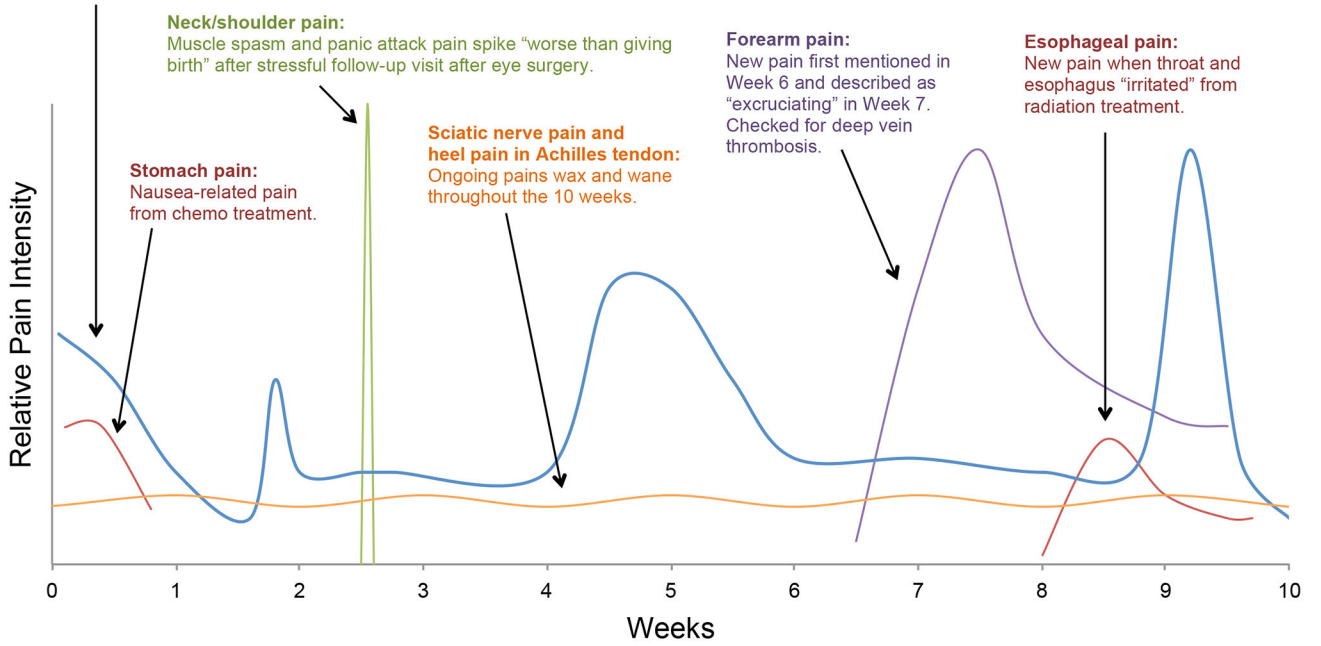


Figure 3.
Pain experience graph of Doris’ experience of complex pain dynamics.

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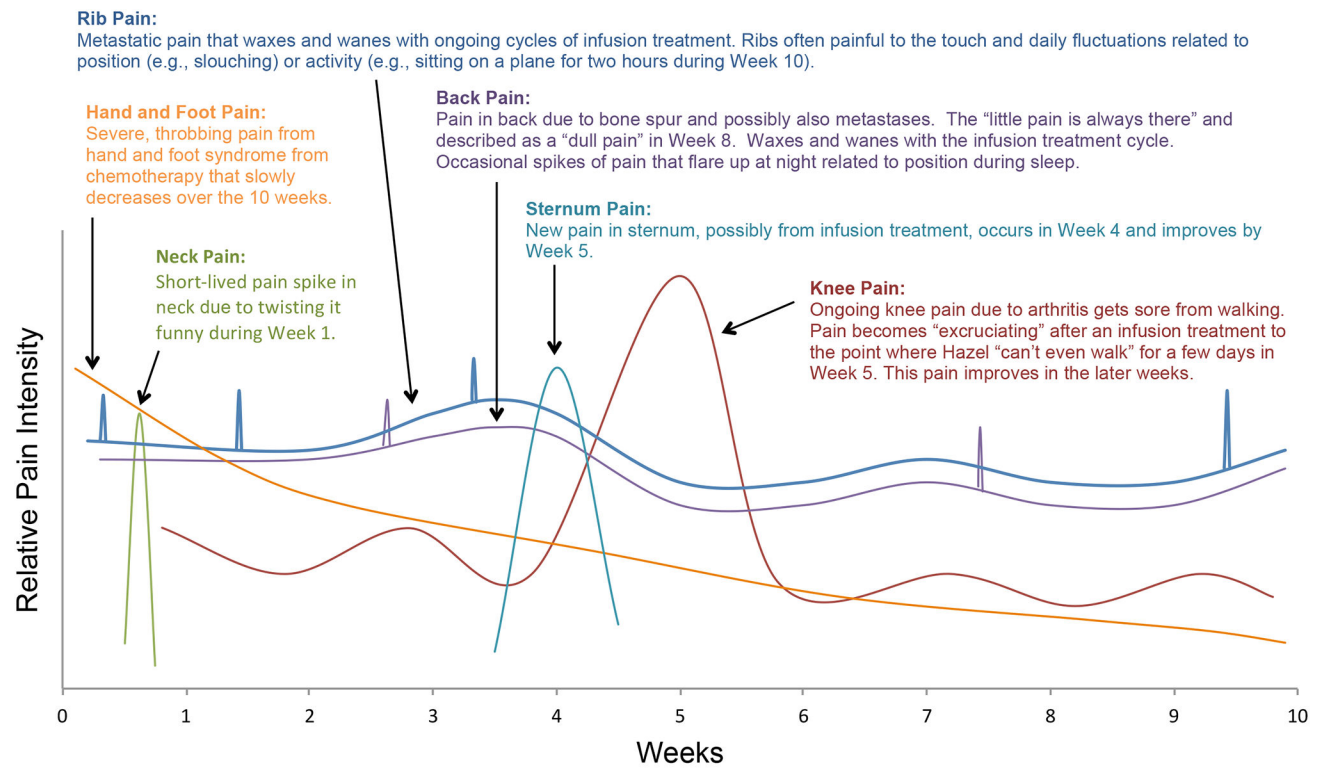


Figure 4.
Pain experience graph of Hazel's experience of complex pain dynamics.