

ORIGINAL RESEARCH

Shared Decision-Making in Managing Breakthrough Cancer Pain in Patients With Advanced Cancer

JEANNINE M. BRANT,¹ PhD, APRN, AOCN®, FAAN, DEBRA WUJCIK,² PhD, RN, FAAN, WILLIAM N. DUDLEY,³ PhD, ALISON PETOK,⁴ MSW, LSW, BROOKE WORSTER,⁴ MD, DIANE JONES,¹ MSN, NP, KIM BOSKET,¹ RN, BSN, OCN®, CHRISTIAN BRADY,¹ MSN, AGNP, APRN, and CARRIE TOMPKINS STRICKER,⁴ PhD, RN, ANP-BC

From ¹Billings Clinic, Billings, Montana; ²Carevive Systems, Inc., Nashville, Tennessee; ³Piedmont, Greensboro, North Carolina; ⁴Thomas Jefferson University, Philadelphia, Pennsylvania

Authors' disclosures of conflicts of interest are found at the end of this article.

Correspondence to: Jeannine M. Brant, PhD, APRN, AOCN®, FAAN, Billings Clinic, 2800 10th Avenue North, Billings, MT 59102.
E-mail: jbrant@coh.org

<https://doi.org/10.6004/jadpro.2022.13.1.2>

© 2022 Harborside™

Abstract

Background: Pain is a significant problem in patients with cancer. Breakthrough cancer pain contributes to the pain experience, but it is often underassessed and underrecognized. Shared decision-making (SDM), where patient preferences, goals, and concerns are discussed and integrated into a shared decision, can potentially foster earlier identification of pain, including breakthrough cancer pain, and improve pain management. **Objectives:** To explore the use of SDM to evaluate its impact on cancer pain management. **Methods:** This prospective, multisite study engaged patients with advanced cancer to explore the use of SDM in managing cancer pain using a digital platform with an expanded pain assessment. Decision preferences were noted and incorporated into care. Outcomes included pain and patient-perceived pain care quality. **Results:** 51 patients with advanced cancer enrolled in the study. The mean pain score was 5 out of 10 throughout the three study time points. 88% of patients experienced breakthrough cancer pain of severe intensity at baseline and approximately 70% at visits two and three. The majority of breakthrough cancer pain episodes lasted longer than 30 minutes. The majority (86%) of participating patients desired shared decision-making or patient-driven decision-making. Most patients expressed satisfaction with the level of shared decision-making in managing their cancer pain. Breakthrough cancer pain remained significant for most patients. **Conclusions:** SDM incorporated into pain discussions has the potential to improve pain outcomes, but significant challenges remain in managing breakthrough cancer pain.

Pain is a significant problem in patients with cancer. A meta-analysis of 22 studies indicates that pain is prevalent in 55.0% of patients undergoing active anticancer treatment and in 66.4% of patients with advanced, metastatic, or end-stage disease. Pain is uncontrolled and rated as moderate to severe in 38.0% of patients (van den Beuken-van Everdingen et al., 2016). Breakthrough cancer pain, a transient exacerbation of pain that occurs within the context of stable and adequately controlled background pain, is part of this complex problem. Breakthrough cancer pain occurs in approximately 40% to 93% of patients, and this wide range in prevalence is due to many factors, including the lack of adequate assessment of breakthrough cancer pain and variable definitions across studies (Sperlinga et al., 2015). The highest prevalence rates of breakthrough cancer pain occur in patients with end-stage disease, with estimates at 80.5% in this population (Deandrea et al., 2014). One of the biggest problems with breakthrough cancer pain is its underassessment, and it is therefore underrecognized. Pain assessment usually consists of questions about pain location, intensity, quality, and temporal factors. However, a lack of standardized assessment approaches exists for breakthrough cancer pain (Brant & Stringer, 2018).

Compounding the issue of poor pain control is patient choice. Patients at times choose to not take analgesics due to sedation and other adverse events (Gunnarsdottir et al., 2017). It is also possible that patients are not adequately informed of or engaged in their pain management plan of care, which could increase the gap in achieving comfort care goals. Shared decision-making (SDM), where providers and patients make health-related decisions collaboratively based on both the best available evidence and patient preferences, goals, and values, can potentially foster earlier identification and improved management of pain (Bernabeo & Holmboe, 2013). While some evidence suggests that nurses and nurse practitioners commonly engage in SDM with patients throughout the cancer continuum (Tariman et al., 2016), knowledge of how the oncology care team utilizes SDM is limited. The greatest understanding of and likelihood for SDM employment in cancer care is for deciding on cancer treatment options, particularly

when multiple options are available and when a chosen treatment impacts quality of life (Glatzer et al., 2018; Kane et al., 2014).

There is a dearth of information about the use and impact of SDM in relation to cancer pain management. For example, a PubMed search using the terms “shared decision-making,” “cancer,” and “pain” in September 2020 resulted in 75 articles being identified, but a review of the abstracts revealed only one that addressed SDM in managing cancer pain. This qualitative study revealed that a novel digital application promoted SDM in pain management (Adam et al., 2020). One integrative review of 34 studies analyzed the related concept, “patient empowerment,” in cancer pain management, and proposed a conceptual model of this topic, but only a handful of these articles addressed patient involvement in active decision-making (Te Boveltdt et al., 2014).

Integration of electronic algorithms for the treatment of pain have the potential to further drive evidence-based care. The Carevive Care Planning System (CPS) was developed to overcome these challenges by providing an efficient, clinically integrated solution for assessment of patient goals, decision-making preferences, and concerns, along with a comprehensive digital symptom assessment, including a detailed pain assessment. Our previous study using the Carevive CPS demonstrated the effective use of individualized supportive care plans, linked to reported symptoms, that can be shared with the patient and family (Brant et al., 2019). While the care plans used in the prior study were designed to incorporate goals of treatment and preferences for symptom management, they did not exclusively focus on pain, nor did they address SDM. One of our conclusions from this prior work was that processes and technologies that facilitate better integration of SDM, pain assessment, and pain management strategies into the oncology team’s clinical workflow were lacking.

The purpose of this prospective, exploratory pilot study was to build upon and extend our previous work and to evaluate the feasibility of incorporating SDM into the management of chronic and breakthrough pain in patients with metastatic cancer, supported by the Carevive CPS digital tool described above. Quality Oncology Practice Initia-

tive (QOPI) metrics were also evaluated as indicators of quality pain outcomes, including (a) pain assessed by the second office visit, (b) pain intensity quantified by the second office visit, and (c) plan of care for moderate/severe pain was documented. Patient satisfaction with pain care quality was a secondary aim.

METHODS

Design

This prospective, quantitative, longitudinal, single-arm pilot study engaged patients with advanced cancer to explore the feasibility of using SDM in managing cancer pain during three office visits and the impact of SDM on quality measures for pain management and patient satisfaction with pain care.

Sample and Setting

The study took place at three large US cancer centers. One was a rural community cancer center in the northwestern part of the US. The other two were cancer centers located in or just outside a large metropolitan city in the northeastern US; one was the urban hub of a large academic cancer center, and the second was a community-based network site. Two sites relied on an advanced practitioner as the sole supportive care provider, while one site used a physician provider.

A convenience sample of patients with advanced cancer 18 years of age or older and a positive screen for pain or taking an opioid for the management of chronic cancer-related pain were invited to participate in the study. Prior to enrollment, the study was approved by Advarra central Institutional Review Board.

Procedures

Providers, nurses, and care navigators from the three research organizations were trained on the use of the Carevive CPS, which included a dashboard to review patient-reported outcomes (PROs) and patient preferences in SDM, symptom management clinical decision support (CDS), and generation of supportive care plans for individual patients that detailed resources and self-management strategies for dealing with pain and other reported symptoms. Following training, certified research nurses recruited eligible patients to the

study by screening upcoming clinic schedules and collaborating with participating providers to identify eligible patients prior to their planned clinic appointments. Information about the study was then presented to eligible participants either on the phone or in person prior to the scheduled visit. Patients who were interested in participating in the study arrived early to their scheduled appointment and provided written informed consent to participate in the study.

Patients were then introduced to the Carevive CPS platform by research staff, who assisted them in completing baseline measures with the assistance of a research assistant or nurse. Measures are described in the following section. Next, patients met with a nurse navigator or provider (oncologist or nurse practitioner) to discuss their symptoms; clinicians reviewed the baseline measures, discussed the plan of care with the patient according to their stated preferences for role in SDM, and generated an individualized supportive care plan. Patients were given a paper or electronic copy of the plan via email that could be referred to between visits.

Patients again interacted with the system at a second visit and—if still able and willing to participate—a third ambulatory visit, wherein the patient's pain was reassessed along with perceived effectiveness of the previously prescribed pain management intervention(s). Barriers to nonadherence to the intervention were also evaluated. Patients were sent a pain care quality survey following their final visit.

Measures

Control Preferences Scale (CPS). The Control Preferences Scale is a brief measure used to examine patient preferences regarding decision-making. At baseline, patients were asked how much decision-making control they wanted to have. There are five response categories: two patient driven, one collaborative, and two provider driven. The tool has demonstrated construct validity (Singh et al., 2010).

Expanded Pain Assessment (EPA). The EPA was developed by three investigators of this study, one of whom is an expert in pain assessment and management. Development was an iterative process that included a review of current cancer pain

management literature and existing pain surveys (Brant et al., 2017; Sperlinga et al., 2015). Questions drilled down to the presence of pain flares, number per day, length of each flare, and whether they were insidious or related to an event (incident). Pain intensity was embedded within the EPA for overall pain intensity and intensity of pain flairs. Pain intensity was measured on a scale of 0 to 10, with “0” being no pain and “10” being worst possible pain. Investigators then validated the new EPA survey questions through cognitive interviews in patients with cancer. Figure 1 includes the algorithm and components of the Expanded Pain Assessment. Patients completed the EPA prior to each visit.

Pain Care Quality Survey (PainCQ). The PainCQ is a 20-item tool that measures the quality of nursing and interdisciplinary care related to pain management (Beck et al., 2010; Pett et al., 2012). This study used 14 of the 20 items to capture patient satisfaction with pain care, which includes SDM between the health-care team and the patient in managing pain. The PainCQ has demonstrated internal reliability with alpha exceeding

0.80. Patients responded to the PainCQ following their final visit.

Data Analysis

Data were directly entered by patients into the electronic Carevive CPS and uploaded to a cloud, which could only be accessed by the Carevive biostatistician. Data were exported into SPSS version 23 for analysis. Descriptive statistics including percentages, means, and standard deviations were used to summarize data. Student’s t-tests were used to compare means of continuous variables such as pain intensity. Quality Oncology Practice Initiative outcomes were measured by the percentage of attainment.

RESULTS

Sample Characteristics

Fifty-one patients enrolled in the study; 49 from palliative care clinics embedded in the ambulatory oncology department and two from medical oncology ambulatory clinics. One patient had missing data (i.e., demographics were reported but pain scores were lacking) during each of the

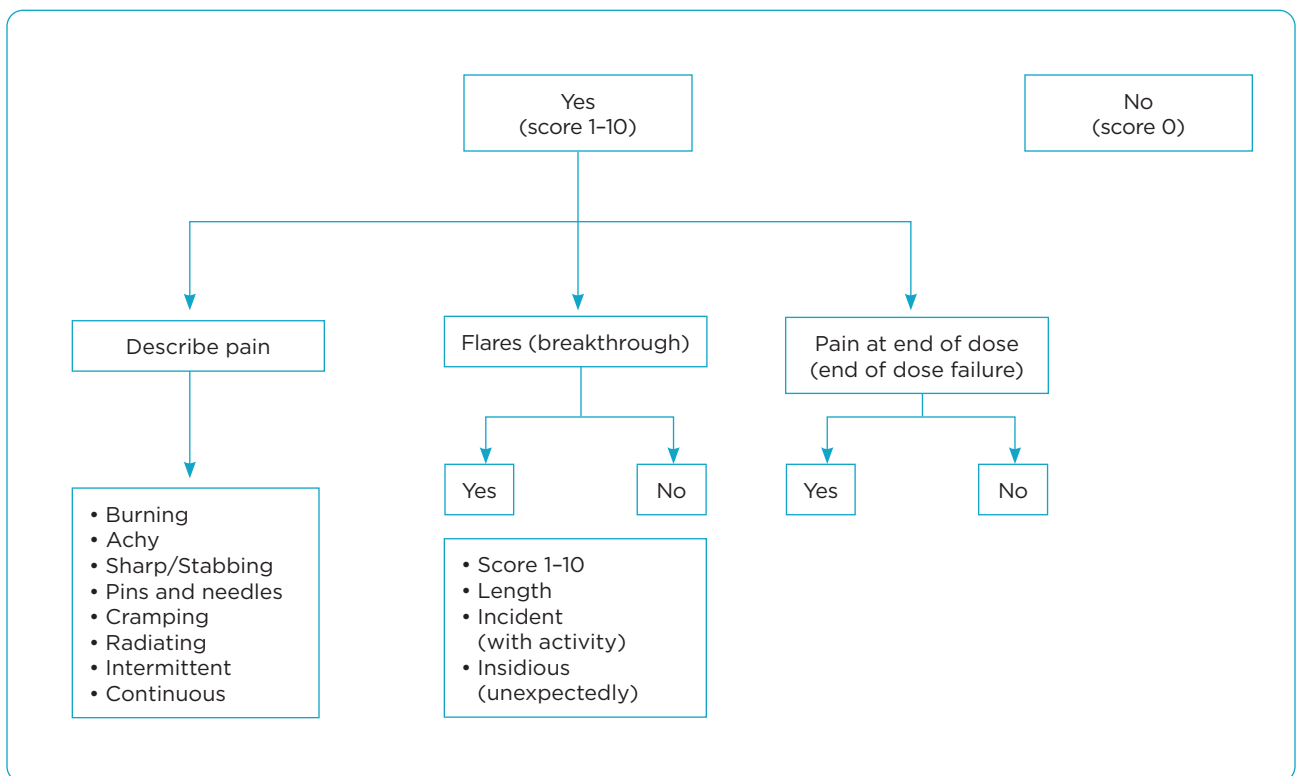


Figure 1. Breakthrough pain assessment algorithm and tool components.

three visits. The mean age was 56.33 years; patients ranged in age from 20 to 93 years. The majority were female (62.7%) and Caucasian (68.9%) with various types of cancer (Table 1). While 51 patients were enrolled in the study, only 72.5% (n = 37) completed measures at visit two, and 25.5 % (n = 13) completed visit three measures. A total of 17 patients (n = 33.3%) completed the PainCQ. Six were unable to complete the measures because they were deceased or their care had been transferred to hospice, and 28 did not return the final survey.

Shared Decision-Making

As assessed by the Control Preferences Scale, the majority (86%) of participating patients desired active or patient-driven decision-making (Table 2). Almost half of patients (46.9%) stated that they wanted to share responsibility with their provid-

er for choosing which treatment is best. Five patients, or about 10% of the total sample, desired provider-driven decision-making in which the provider makes the final decision.

Pain Outcomes

The mean pain score on a 0 to 10 scale was moderate (approximately 5) at baseline and at both follow-up visits, demonstrating no change in pain severity over time. Most (88%) patients experienced pain flares or breakthrough cancer pain at baseline, which was rated as severe in intensity and lasting more than 30 minutes. This was consistent across all three time periods (baseline, visit two, and visit three), with 70% of reporting patients continuing to have pain flares by visit three. Over 70% of patients had incident pain or pain with movement or activity at baseline, while 70% also experienced insidious breakthrough pain epi-

Table 1. Sample Characteristics (N = 51)

Characteristic	N (%)
Age in years, mean (SD, range)	56.33 (14.95, 20-93)
Sex	
Female	32 (62.7%)
Male	19 (37.3%)
Self-reported race	
Caucasian/White	31 (68.9%)
African American/Black	9 (20.0%)
Hispanic	4 (8.9%)
American Indian	1 (2.2%)
Missing	6
Self-reported ethnicity	
Non-Hispanic/Non-Latino	41 (91.1%)
Hispanic/Latino	4 (8.9%)
Missing	6
Type of cancer	
Breast cancer	9 (17.6%)
Hematologic	8 (15.7%)
Gastrointestinal	11 (21.6%)
Gynecologic	6 (11.8%)
Head and neck	8 (15.7%)
Thoracic	2 (3.9%)
Other	7 (13.7%)

sodes at baseline. Patients often described their pain with more than one quality; common descriptive characteristics selected included burning, aching, sharp, pins and needles, and cramping pain, with burning pain being the most frequently reported. No significant changes in any pain characteristics were noted over time. Table 3 provides pain characteristics and changes over time for the baseline and two follow-up visits.

Pain Care Quality

The PainCQ survey revealed that patient involvement in decision-making was the highest scored item; 94.1% strongly agreed that this occurred. Patients also strongly agreed with how well the team worked together to manage pain, that the nurse asked about their pain, and that the team discussed side effects of pain medications with them. Items that scored the lowest were regarding how well the pain medication kept them comfortable (only 47.1% strongly agreed) and how quickly it worked to ease pain (only 35.3% agreed). Table 4 includes complete results of the PainCQ survey.

Quality Oncology Practice Initiative Metrics

Chart reviews revealed that the documentation of pain having been assessed and rated was complete for 50 of 51 patients (98%). A pain plan of care was documented in the chart for the same 50 of 51 patients. Together, these results indicate providers met the selected QOPI metrics for pain assessment and management for the vast majority (98%) of all patients enrolled in the study.

DISCUSSION

The overall aim of this study was to evaluate the feasibility of incorporating SDM into the management of chronic and breakthrough pain in patients with metastatic cancer, supported by the Carevive CPS digital tool. We were able to successfully assess SDM preferences in all 49 patients prior to their baseline visit, which shows that this tool is feasible to use, even in a very ill patient population. While we collected data on patient SDM preferences, we did not evaluate how providers used this information in managing pain. Further studies are warranted to better investigate how providers incorporate patient SDM preferences into care discussions.

This study also focused on the use of a novel electronic assessment tool to examine breakthrough cancer pain in patients with advanced cancer and their preferences for being involved in pain management. Our study revealed that most patients (89.8%) preferred to have input into clinical decisions, and it appears that this method of decision-making was achieved, as most respondents ($n = 16$, 94.1%) strongly agreed with the PainCQ survey statement that they were involved in decisions about controlling their pain. While almost 10% of patients wanted to rely on their provider to make the decisions for them, it is interesting to note that 100% of patients agreed or strongly agreed that they were involved in pain care decisions anyway. The rates of patient-driven or collaborative decision-making were higher in our study when compared with Singh and colleagues' 2010 study in which the Control Prefer-

Table 2. Shared Decision-Making (N = 51)

Preference	%	Preference choices	N	%
Patient-driven decision-making	42.9	Make the final decision about which treatment I will receive	5	10.2
		Make the final selection after seriously considering my provider's opinion	16	32.7
Shared decision-making	46.9	Have my provider and I share responsibility for deciding which treatment is best	23	46.9
Provider-driven decision-making	10.2	Have the provider make the final decision but consider my opinion	4	8.2
		Leave all decisions regarding treatment to my provider	1	2.0

Note. Data missing for 2 patients.

Table 3. Pain Characteristics at Baseline and Follow-Up Visits

Pain assessment elements	Baseline	Follow-up visit 1	Follow-up visit 2	Significance
Pain intensity (0-10)	N = 50 Mean = 5.24 SD = 2.80	N = 37 Mean = 5.38 SD = 2.75	N = 13 Mean = 5.38 SD = 3.04	0.636
Intensity of flare pain	N = 46 Mean = 8.24 SD = 1.73	N = 28 Mean = 8.18 SD = 1.91	N = 7 Mean = 8.14 SD = 1.77	0.397
Having flares (breakthrough cancer pain)	46 (92%)	28 (77.8%)	7 (70%)	
Length of pain flare				
< 5 min	2 (4.3%)	2 (7.4%)	1 (14.3%)	
6-14 min	4 (8.7%)	2 (7.4%)	1 (14.3%)	
15-30 min	6 (13%)	2 (7.4%)	1 (14.3%)	
> 30 min	34 (73.9%)	21 (77.8%)	4 (57.1%)	
Pain occurs with activity (incident)	32 (72.7%)	19 (70.4%)	5 (71.4%)	
Pain occurs unexpectedly (insidious)	32 (71.1%)	22 (78.6%)	4 (57.1%)	
Having end of dose failure				
Yes	13 (81.3%)	26 (81.3%)	7 (70%)	
No	3 (18.7%)	6 (18.8%)	3 (30%)	
Not asked	36	5	3	
Pain quality				
Burning	14 (27.5%)	9 (24.3%)	4 (30.8%)	
Achy	10 (19.6%)	4 (10.8%)	3 (23.1%)	
Sharp	5 (9.8%)	3 (8.1%)	3 (23.1%)	
Pins and needles	4 (7.8%)	2 (5.4%)	1 (7.7%)	
Cramping	1 (2%)	2 (5.4%)	1 (7.7%)	

Note. *p* values included for continuous primary outcome variables only. End of dose failure question not included at one site for baseline.

ences Scale was originally validated in patients with cancer. Singh and colleagues (2010) found 26% of patients preferred active or patient-driven decision making, 34% preferred collaborative, and 25% passive in which they relied on the provider to make the decision (Singh et al., 2010). This could be related to the evolving shift in care models, from a paternal approach to an SDM, patient-centered approach, in which providers use SDM to some extent inherently, as a fabric of the care provided (Steffensen et al., 2018). Nurses and advanced practitioners may also be early integrators of SDM in practice, as patients have historically turned to them to discuss health-care decisions and further understand and reflect on informa-

tion presented by physicians (Truglio-Londrigan & Slyer, 2018). One study of 30 nurses and nurse practitioners found that nurses commonly engage in SDM with patients throughout the cancer continuum (Tariman et al., 2016). More studies are needed that examine how nurses and advanced practitioners engage in SDM, what tools they use for SDM, and the patient scenarios behind SDM.

Our study also explored the pain experience in patients with advanced cancer and found that while the average level of pain at baseline was moderate, breakthrough cancer pain was common and experienced by 88% of patients at baseline and by at least 70% of patients throughout the entire study period. Breakthrough cancer pain was

Table 4. Pain Care Quality Survey (PainCQ)

Survey question, n (%)	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
My health-care team worked together to manage my pain	0	0	1 (5.9)	1 (5.9)	15 (88.2)
My health-care team explained that taking pain medication may increase my activity level	0	1 (5.9)	2 (11.8)	4 (23.5)	10 (58.8)
My health-care team involved me in decisions about controlling my pain	0	0	0	1 (5.9)	16 (94.1)
My health-care team asked about how my pain affected my relationship with others	0	1 (5.9)	2 (11.8)	4 (23.5)	10 (58.8)
My health-care team responded to change in my pain	0	0	1 (6.3)	2 (12.5)	13 (81.3)
The pain medication kept me comfortable	1 (5.9)	2 (11.8)	0	6 (35.3)	8 (47.1)
The pain medication worked quickly to ease my pain	1 (5.9)	2 (11.8)	0	8 (47.1)	6 (35.3)
My health-care team discussed the side effects of the pain medication with me	0	0	0	2 (11.8)	15 (88.2)
The pain medication worked well to control my pain	0	2 (11.8)	1 (5.9)	4 (23.5)	10 (58.8)
My nurse asked me about my pain	0	0	0	2 (11.8)	15 (88.2)
I had pain medications available when I needed it	0	0	2 (11.8)	0	15 (88.2)
Approaches in addition to medication worked well to control my pain	1 (6.3)	1 (6.3)	1 (6.3)	5 (31.3)	8 (50)

Note. N = 17. 6 deceased or referred to hospice; 28 did not return final survey.

commonly rated as severe and included both incident pain, which is pain with movement and activity, and insidious pain, which is pain that occurs unexpectedly. Length of the pain flares varied but lasted longer than 30 minutes for most patients. Breakthrough cancer pain prevalence in our study is higher than other reports in the literature, where reported rates have ranged between 39.9% and 80.5% (Deandrea et al., 2014). Our entire sample had advanced disease, whereas other studies included patients with all stages of disease, which likely accounts for the higher rates. Pain intensity of breakthrough cancer pain episodes was also higher in our study compared with other studies in the literature. For example, Mercadante and colleagues (2018) evaluated over 4,000 patients with breakthrough cancer pain and found that the mean intensity of breakthrough cancer pain was 7.5, which was slightly lower than the mean breakthrough cancer pain observed in this study,

which ranged from 8.14 to 8.24 across study time-points (Mercadante et al., 2018). The mean duration of episodes was similar in both studies; Mercadante and colleagues (2018) reported episodes lasting an average of 43.3 minutes, much like our report of most patients' episodes lasting over 30 minutes. Interestingly, only 30.5% of patients in the Mercadante and colleagues (2018) study had predictable incident pain, compared with 71.1% of patients in our study. It is possible that the cancer types, stages, and metastatic sites between the two studies accounted for these differences.

Pain remained a problem for most patients over the three-visit period, which did not significantly change over time. Sadly, this is consistent with other reports in the literature, in which no or minimal gains are made on pain intensity, even when medication and education strategies are employed (Cowperthwaite & Kozachik, 2019; Herr et al., 2012; Miner et al., 2018). One recent qualita-

tive study found that a digital Can-Pain intervention promoted patient-centered pain management (Adam et al., 2020). One challenging aspect of this literature is that when modest gains do occur, it is difficult to know if these are clinically significant. Patients with advanced cancer may also have ongoing changes in their disease status resulting in unstable pain, where it can quickly become out of control. The incidence of severe pain flares that were not observed at time of the visit but were recalled on the study surveys are indicators that strategies for pain assessment and management that engage patients between visits should be evaluated in this patient population.

Overall, patients were highly satisfied with the pain care quality they received at each of their clinics, particularly regarding their involvement in decision-making about pain control. It is unknown whether this satisfaction was influenced by their participation in the study intervention, as the PainCQ was administered only as a post-test following study participation. Of note, patient satisfaction surveys are often highly inflated, and previous studies have shown patients may feel satisfied with the care they are receiving even though their pain intensity is high (Ezenwa et al., 2016; Svensson et al., 2001).

Important to note is that the items with which patients were the most dissatisfied in our study related to the efficacy of the pain medication. Some patients disagreed or strongly disagreed that the pain medication kept them comfortable and that it worked quickly to ease their pain. Therefore, a significant need exists for advanced practitioners to be more knowledgeable about titrating analgesics effectively and using medications that control pain, especially breakthrough cancer pain. When patients experience an abrupt onset of pain, transmucosal fentanyl has been widely recommended to provide rapid onset and can effectively mimic the breakthrough cancer pain episode pharmacologically (Brant et al., 2017). Unfortunately, such products are highly underutilized, and providers must complete a risk evaluation and mitigation strategy (REMS) program to prescribe them (Pergolizzi et al., 2013). Considerable risk of abuse and diversion of these products exists, and yet advanced practitioners need to learn how to prescribe them appropriately and in the right popula-

tion so that breakthrough cancer pain can be more effectively controlled.

Limitations

Overall, this study had several challenges and limitations, and patient accrual and retention were top among them. This threatened the overall feasibility of using SDM and collection of electronic patient-reported outcomes (ePROs) in patients receiving pain care in a palliative care clinic. A deep dive to understand the barriers at each site provided an opportunity to apply the rapid learning process to assess needed changes for recruitment and enrollment into the study. We discovered that patients with advanced disease, especially those near the end of life, were often fatigued, making it difficult for them to report ePROs prior to the scheduled visit. Ample literature is available echoing the challenges experienced in both recruitment and retention of patients with advanced cancer and terminal disease, including patients with pain.

Barriers include uncontrolled symptoms, reduced ability or inability to complete measures due to respondent burden and fatigue, missed office visits, hospice admissions, and death (Gilbertson-White et al., 2017). We had several reasons for attrition in our study including lack of return to the clinic due to illness severity ($n = 25$), death ($n = 8$), being lost to follow-up ($n = 3$), and referral to hospice ($n = 2$). Illness severity and reasons for a missed visit included fatigue and lack of desire to visit the clinic, the presence of uncontrolled symptoms other than pain, and being bedridden prior to death. Of note, our study was conducted mainly in palliative care clinics, where no-show rates are often high, which limits the ability to generalize our study findings to more general ambulatory oncology settings. Further research on how to overcome the barriers to recruitment and retention of individuals with advanced cancer is needed, as are studies aimed at both developing and testing novel interventions for pain control in advanced cancer patients.

Additionally, research on strategies for optimizing integration of ePRO assessment and reporting in palliative care clinics is warranted. Patients would also arrive late for appointments, making it difficult to complete ePROs prior to the

visit due to interrupted clinic flow. Future studies using mobile platforms could alleviate this concern and allow patients to complete measures at home at a more convenient time. Telemedicine interventions should also be considered, which would allow for palliative care visits for patients who did not feel like coming to the clinic for a scheduled visit.

Sites also noted staff fatigue related to the increased use of technology and a lack of understanding of the importance of patient reported outcomes. Implementing ePROs in any real-world clinical setting can be challenging, and yet the benefits of PROs continue to emerge, including increased patient-clinician communication, symptom awareness, quality of life, and survival (Basch et al., 2018; Brant et al., 2019).

IMPLICATIONS FOR ADVANCED PRACTITIONERS

Advanced practitioners in oncology are keenly positioned to employ SDM to manage pain in patients with advanced cancer. First, SDM preferences should be explored to meet the patient expectations and care choices. Second, using appropriate assessment tools that examine background pain along with breakthrough cancer pain are essential in obtaining detailed information about the patient's pain experience so that tailored plans of care can be employed. Using a tool that includes breakthrough cancer pain assessment is essential in this process. Third, more knowledge and education are needed about effective strategies for optimal cancer pain management, including breakthrough cancer pain. Clinicians should take the time to complete the REMS program for using transmucosal fentanyl products so that they can be appropriately employed in select patients. Fourth, monitoring patients between visits via a navigator or triage nurse can allow changes to be made between visits so that strides can be made in the optimal management of cancer-related pain. Finally, it is advanced practitioners who often evaluate patients' symptoms at follow-up visits and hence, leadership in the integration of PROs is essential. While successful integration of these technologies can be challenging, the potential gains far outweigh the burdens, and it is the right thing to do for patient care. ●

Disclosure

The authors have no conflicts of interest to disclose.

References

- Adam, R., Bond, C. M., Burton, C. D., de Bruin, M., & Murchie, P. (2020). Can-Pain-a digital intervention to optimise cancer pain control in the community: Development and feasibility testing. *Supportive Care in Cancer*, 29(2), 759–769. <https://doi.org/10.1007/s00520-020-05510-0>
- Basch, E., Barbera, L., Kerrigan, C. L., & Velikova, G. (2018). Implementation of patient-reported outcomes in routine medical care. *American Society of Clinical Oncology Educational Book*, 38, 122–134. https://doi.org/10.1200/EDBK_200383
- Beck, S. L., Towsley, G. L., Pett, M. A., Berry, P. H., Smith, E. L., Brant, J. M., & Guo, J.-W. (2010). Initial psychometric properties of the Pain Care Quality Survey (PainCQ). *Journal of Pain*, 11(12), 1311–1319. <https://doi.org/10.1016/j.jpain.2010.03.008>
- Bernabeo, E., & Holmboe, E. S. (2013). Patients, providers, and systems need to acquire a specific set of competencies to achieve truly patient-centered care. *Health Affairs (Millwood)*, 32(2), 250–258. <https://doi.org/10.1377/hlthaff.2012.1120>
- Brant, J., Hirschman, K., Keckler, S., Dudley, W., & Stricker, C. (2019). Patient and provider use of electronic care plans generated from patient-reported outcomes. *Oncology Nursing Forum*, 46(6), 715–726. <https://doi.org/10.1188/19.onf.715-726>
- Brant, J., Rodgers, B., Gallagher, E., & Sundaramurthi, T. (2017). Breakthrough cancer pain: A systematic review of pharmacologic management. *Clinical Journal of Oncology Nursing*, 21(3), 71–80. <https://doi.org/10.1188/17.cjon.s3.71-80>
- Brant, J. M., & Stringer, L. H. (2018). Cancer Pain. In C. H. Yarbro, D. Wujcik, & B. H. Gobel (Eds.), *Cancer Nursing: Principles and Practice, 8th Edition* (pp. 781–816). Burlington, MA: Jones and Bartlett.
- Cowperthwaite, S. M., & Kozachik, S. L. (2019). Improving the pain experience for hospitalized patients with cancer. *Oncology Nursing Forum*, 46(2), 198–207.
- Deandrea, S., Corli, O., Consonni, D., Villani, W., Greco, M. T., & Apolone, G. (2014). Prevalence of breakthrough cancer pain: A systematic review and a pooled analysis of published literature. *Journal of Pain and Symptom Management*, 47(1), 57–76. <https://doi.org/10.1016/j.jpainsymman.2013.02.015>
- Ezenwa, M. O., Molokie, R. E., Wang, Z. J., Suarez, M. L., Yao, Y., & Wilkie, D. J. (2016). Satisfied or not satisfied: Pain experiences of patients with sickle cell disease. *Journal of Advanced Nursing*, 72(6), 1398–1408. <https://doi.org/10.1111/jan.12678>
- Gilbertson-White, S., Bohr, N., & Wickersham, K. E. (2017). Conducting biobehavioral research in patients with advanced cancer: Recruitment challenges and solutions. *Biological Research for Nursing*, 19(5), 481–490. <https://doi.org/10.1177/1099800417709529>
- Glatzer, M., Panje, C. M., Siren, C., Cihoric, N., & Putora, P. M. (2018). Decision making criteria in oncology. *Oncology*, 98, 370–378. <https://doi.org/10.1159/000492272>
- Gunnarsdottir, S., Sigurdardottir, V., Kloke, M., Radbruch, L., Sabatowski, R., Kaasa, S., & Klepstad, P. (2017). A multi-

- center study of attitudinal barriers to cancer pain management. *Supportive Care in Cancer*, 25(11), 3595–3602. <https://doi.org/10.1007/s00520-017-3791-8>
- Herr, K., Titler, M., Fine, P. G., Sanders, S., Cavanaugh, J. E., Swegle, J.,...Forcucci, C. (2012). The effect of a translating research into practice (TRIP)-cancer intervention on cancer pain management in older adults in hospice. *Pain Medicine*, 13(8), 1004–1017. <https://doi.org/10.1111/j.1526-4637.2012.01405.x>
- Kane, H. L., Halpern, M. T., Squiers, L. B., Treiman, K. A., & McCormack, L. A. (2014). Implementing and evaluating shared decision making in oncology practice. *CA: A Cancer Journal for Clinicians*, 64(6), 377–388. <https://doi.org/10.3322/caac.21245>
- Mercadante, S., Marchetti, P., Cuomo, A., Caraceni, A., Mediati, R. D., Vellucci, R.,...Aielli, F. (2018). Factors influencing the clinical presentation of breakthrough pain in cancer patients. *Cancers (Basel)*, 10(6), 175. <https://doi.org/10.3390/cancers10060175>
- Miner, M. B., Stephens, K., Swanson-Bearman, B., Leone, V., & Whiteman, K. (2018). Enhancing cancer pain assessment and management in hospice. *Journal of Hospice & Palliative Nursing*, 20(5), 452–458. <https://doi.org/10.1097/njh.0000000000000467>
- Pergolizzi, J. V., Gharibo, C. G., Gudín, J. A., & Nalamachu, S. R. (2013). Development of federally mandated risk evaluation and mitigation strategies (REMS) for transmucosal immediate-release fentanyl products. *Pain Practice*, 13(4), 259–263. <https://doi.org/10.1111/papr.12040>
- Pett, M. A., Beck, S. L., Guo, J. W., Towsley, G. L., Brant, J. M., Lavoie Smith, E. M.,...Donaldson, G. W. (2012). Confirmatory factor analysis of the Pain Care Quality Surveys (PainCQ®). *Health Services Research*, 48(3), 1018–1038. <https://doi.org/10.1111/1475-6773.12014>
- Singh, J. A., Sloan, J. A., Atherton, P. J., Smith, T., Hack, T. F., Huschka, M. M.,...Degner, L. F. (2010). Preferred roles in treatment decision making among patients with cancer: A pooled analysis of studies using the Control Preferences Scale. *American Journal of Managed Care*, 16(9), 688–696. <https://www.ncbi.nlm.nih.gov/pubmed/20873956>
- Singh, S., Butow, P., Charles, M., & Tattersall, M. H. (2010). Shared decision making in oncology: Assessing oncologist behavior in consultations in which adjuvant therapy is considered after primary surgical treatment. *Health Expectations*, 13(3), 244–257. <https://doi.org/10.1111/j.1369-7625.2009.00587.x>
- Sperlinga, R., Campagna, S., Berruti, A., Laciura, P., Ginosa, I., Paoletti, S.,...Saini, A. (2015). Alberta Breakthrough Pain Assessment Tool: A validation multicentre study in cancer patients with breakthrough pain. *European Journal of Pain*, 19(7), 881–888. <https://doi.org/10.1002/ejp.612>
- Steffensen, K. D., Vinter, M., Cruger, D., Dankl, K., Coulter, A., Stuart, B., & Berry, L. L. (2018). Lessons in integrating shared decision-making into cancer care. *JCO Oncology Practice*, 14(4), 229–235. <https://doi.org/10.1200/jop.18.00019>
- Svensson, I., Sjöström, B., & Haljamae, H. (2001). Influence of expectations and actual pain experiences on satisfaction with postoperative pain management. *European Journal of Pain*, 5(2), 125–133. <https://doi.org/10.1053/eujp.2001.0227>
- Tariman, J. D., Mehmeti, E., Spawn, N., McCarter, S. P., Bishop-Royse, J., Garcia, I.,...Szubski, K. (2016). Oncology nursing and shared decision making for cancer treatment. *Clinical Journal of Oncology Nursing*, 20(5), 560–563. <https://doi.org/10.1188/16.Cjon.560-563>
- Te Bovelde, N., Vernooij-Dassen, M., Leppink, I., Samwel, H., Vissers, K., & Engels, Y. (2014). Patient empowerment in cancer pain management: An integrative literature review. *Psychooncology*, 23(11), 1203–1211. <https://doi.org/10.1002/pon.3573>
- Truglio-Londrigan, M., & Slyer, J. T. (2018). Shared decision-making for nursing practice: an integrative review. *Open Nursing Journal*, 12, 1–14. <https://doi.org/10.2174/1874434601812010001>
- van den Beuken-van Everdingen, M. H., Hochstenbach, L. M., Joosten, E. A., Tjan-Heijnen, V. C., & Janssen, D. J. (2016). Update on prevalence of pain in patients with cancer: Systematic review and meta-analysis. *Journal of Pain and Symptom Management*, 51(6), 1070–1090.E9. <https://doi.org/10.1016/j.jpainsymman.2015.12.340>