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Feasibility of e-Pain Reporter

A Digital Pain Management Tool for Informal Caregivers in Home Hospice

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Informal hospice caregivers often have difficulty managing patient pain at home. We developed a digital application, e-Pain Reporter, for informal caregivers to record and providers to monitor patient pain and pain management. The purpose of this study was (1) to assess the feasibility of informal caregivers using the e-Pain Reporter for 9 days in home hospice by investigating recruitment and retention and caregiver satisfaction with and frequency of use of the e-Pain Reporter and (2) describe patient pain characteristics and caregiver's barriers to pain management and self-efficacy in providing patient care in the home. One-group pre-post design was used. Patient-caregiver dyads were recruited from 1 hospice agency. Caregivers were asked to report all patient pain and pain management using the e-Pain Reporter. Feasibility of the e-Pain Reporter was assessed by the average number of times caregivers recorded breakthrough and daily pain and caregiver satisfaction with the app. The 27-item Barriers Questionnaire II and 21-item Caregiver Self-efficacy Scale were administered at baseline. Fourteen dyads enrolled, 2 patients died, and 12 dyads completed the study. Mean number of pain reports over 9 days was 10.5. Caregivers reported high overall satisfaction with the e-Pain Reporter. Barriers scores were moderately high, suggesting erroneous beliefs and misconceptions about pain reporting and use of analgesics, but self-efficacy in managing pain was also high (93% confidence). Findings suggest that the e-Pain Reporter is a feasible method to report and monitor caregiver management of pain at home. Caregiver high barriers and high overconfidence suggest the need for an educational component to the e-Pain Reporter to address misconceptions about pain and pain management.

KEY WORDS

adherence, analgesics, caregivers, hospice, opioid, pain management

Pain is the most common symptom at the end of life and is reported by 66.3% of cancer patients receiving palliative care.[1] Dying in pain is one of the most common fears of hospice patients. Even though effective pain management is one of the main goals of hospice care,[2] a large number of hospice patients still suffer severe pain during the end-of-life stage.[3] Poorly managed pain has resulted in adverse outcomes for both patients and their caregivers. Undertreated pain contributes to increased depressive symptoms and poor quality of life in patients.[4] Likewise, higher patient pain is associated with increased caregiver burden and decreased caregiver emotional well-being.[5]

Reluctance on the part of informal hospice caregivers (family and friends) to administer analgesics and to report pain to the hospice nurse is a major obstacle to effective pain management in the home hospice setting.[6] Informal caregivers' barriers to analgesic administration spring from misconceptions about the harmful effects of analgesics, poor communication with health care providers, and a sense of fatalism.[7] Informal caregivers fear analgesic adverse effects such as nausea, constipation, and dizziness, as well as tolerance and addiction.[8] Informal caregivers are often reluctant to report pain to health

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care providers because they do not want to be seen as "complainers." Finally, barriers associated with fatalism involve the belief that pain cannot be controlled.[6]

Many informal caregivers lack pain management knowledge and are unable to recognize different pain types and select appropriate analgesic and nonpharmacological interventions. This contributes to their lack of confidence or self-efficacy in their ability to manage pain and avoid making mistakes when administering analgesics.[8] Further, informal caregivers' low self-efficacy in managing pain has been associated with decreased patient physical well-being and increased caregiver depressive symptoms.[9] If hospice nurses are able to monitor informal hospice caregivers' adherence to analgesic regimen, they can assist in providing confidence-building feedback to the caregiver and directly impact patient pain outcomes.[7]

Adherence to analgesics is especially important in hospice where the majority of patients experience breakthrough pain. Breakthrough pain is an episode of pain exacerbation in patients who already have chronic pain. It may occur when pain medication is inadequate or wears off and can occur even when the pain is relatively stable and usually controlled with routine analgesics.[10] In our earlier work with 46 informal hospice caregivers, we found more than 422 pain diary reports of breakthrough pain over 3 days.[11] This suggests that informal caregivers were willing to report pain information. More importantly, it suggests the need for a mechanism to report this information in real time so adjustments or assistance in patient pain management can be handled promptly and breakthrough pain decreased. To supplement home visits by hospice nurses, we developed the e-Pain Reporter, a digital pain and medication diary for informal hospice caregiver reporting and nurse monitoring of pain management in real time.[12] The purposes of this study were (1) to assess the feasibility of informal caregivers using the e-Pain Reporter for 9 days in home hospice by investigating recruitment and retention, caregiver satisfaction with use, and frequency of use of the e-Pain Reporter and (2) to describe patient pain characteristics and patient caregivers' barriers to patient pain management and their self-efficacy in providing patient care in the home.

METHODS

Study Design

A descriptive single-group pre-post design was used.

Sample and Setting

Hospice patients and their informal caregivers were recruited from a hospice agency located in a large metropolitan area. Inclusion criteria for patients were as follows: (*a*) received services from the hospice agency, (*b*) received prescribed analgesics for pain, (*c*) had a nurse-rated Palliative Performance Scale Score (PPS)[13] on consciousness of at least 30%, (*d*) able to speak and understand English, (*e*) 18 years or older, and (*f*) had an informal caregiver. The PPS is a validated functional scale designed for hospice and palliative care patients. Consciousness is scored on an 11-point scale from 100% = full consciousness to 0% = drowsy or coma. A 30% score indicates full consciousness or drowsy and that the majority of patients will survive 7 days or longer.[14,15] Inclusion criteria for informal caregivers were as follows: (*a*) able to speak and understand English, (*b*) identified by the patient as a primary caregiver, and (*c*) 18 years or older.

Nurse managers at the hospice agency identified patients who were 18 years or older, received analgesics for their pain, and had a score 30% or higher on the PPS. At a routine visit, the nurse gave the caregiver and patient a study flyer. The flyer included the purpose of the study, incentives, and contact information (phone and email). The nurse asked them if they would be willing to be contacted by the investigator and offered them the option of contacting the investigator directly to learn more about the study. Patients and/or caregivers who expressed interest in learning more were contacted by research staff by phone to further explain the study, assess interest, and confirm eligibility. Potential participants were informed that both patients and caregivers needed to agree to participate to be included in the study. If they met the eligibility criteria, a baseline meeting was set up in their homes.

The e-Pain Reporter

The e-Pain Reporter described in detail earlier[12] is a self-administered, digital pain application delivered on a tablet computer with 2 elements: (*a*) a breakthrough pain report and (*b*) a daily pain report. Users are asked to complete a breakthrough pain report every time the patient experiences pain. The breakthrough pain report consists of an assessment section in which users are asked to identify pain location, quality, and intensity. Pain location(s) is identified on a large graphic image of the human body with a touch screen. Pain quality is selected from a list of 21 pain descriptors. Pain intensity is rated on a 0- to 10-point scale depicted on a thermometer shape. For each report of breakthrough pain, analgesic and nonpharmacological management is recorded. If analgesics are given, users select time of administration, analgesics used, route, and dosage of all as-needed (PRN) pain medications. If the patient was not administered analgesics at the time of breakthrough pain, the reason can be selected from a dropdown menu: (*a*) gave/took something else, (*b*) did something else, (*c*) patient refused, and (*d*) decided not to give/take. If they select "gave/took something else," they are given a dropdown menu of alternative medications. Also, there is an "other" option in which a medication can be typed in. If they select "did something else," they are provided a dropdown list of nonpharmacological interventions, such as massage, cold and heat, and aromatherapy, as well as an "other" option where their alternative treatment can be manually entered.

Caregivers are asked to complete the daily pain report (summary) once a day before they go to bed. Caregivers report patients' worst pain intensity on the 0- to 10-point thermometer over the past 24 hours. Also, caregivers respond to questions to determine average pain episode frequency and average daily duration of moderate to severe pain (>4 on 0- to 10-point scale) over the past 24 hours. For each regularly scheduled and PRN analgesic prescribed, caregivers report how many times the patient received the analgesic in the past 24 hours. Prior to use, information is entered regarding the patient's analgesic regimen (ie, name, frequency, route, and dose) for all regularly scheduled and PRN medications.

Measures

Demographics

Demographic information for patients and informal caregivers included age, gender, ethnicity, and educational level. Diagnosis was included for patients. For caregivers, information included their employment status and relationship to the patient.

Frequency of Use of the e-Pain Reporter

Two measures of frequency of the e-Pain Reporter use were obtained based on the breakthrough and daily pain reports; they are as follows: (*a*) the average number of times per day over 9 days that patient breakthrough pain was recorded and (*b*) the average number of days over 9 days that daily pain was reported.

Satisfaction With the e-Pain Reporter

Informal caregivers' satisfaction with the e-Pain Reporter was assessed at baseline using a satisfaction survey, which was adapted from studies that investigated the feasibility of a digital tool in a palliative care[16] and community setting.[17] The satisfaction survey included 7 questions assessing overall satisfaction (1 item), the ease of use (4 items), and usefulness (2 items) of the e-Pain Reporter. The overall satisfaction item was measured on a scale from 0 to 3, ease-of-use items were measured on a scale from 0 to 2, and usefulness items were measured on a scale from 0 to 1. Higher scores indicated higher satisfaction. Usefulness of the e-Pain Reporter was also assessed by 2 open-ended questions. Informal caregivers were asked to answer the following open-ended questions: (1) "Do you think that your contact with hospice nurses has been affected by the use of the e-Pain Reporter?" and (2) "How do you think that this technology (e-Pain Reporter) can affect quality of care?" There was also an opportunity to write in any additional comments.

Patient Pain Characteristics

There were 3 measures of patient breakthrough pain characteristics obtained from the daily pain report of the e-Pain Reporter. The measures included the worst pain over the past 24 hours, the number of pain episodes over the past 24 hours, and the average daily duration of moderate to severe pain over the past 24 hours. Each daily pain measure was summed over 9 days and a mean obtained.

Caregiver Barriers to Pain Management

Caregiver barriers to pain management were measured at baseline by the revised 27-item Barriers Questionnaire II (BQ-II).[18] The measure has been widely used to assess caregivers' concerns about pain reporting and use of analgesics. The BQ-II is based on erroneous beliefs and misconceptions about pain reporting and use of analgesics. The questionnaire consists of 4 subscales: physiological effects (12 items), fatalism (3 items), communication (6 items), and harmful effects (6 items). Caregivers rate their agreement with each item on a scale from 0 ("do not agree at all") to 5 ("agree very much"). The items are summed overall and averaged for a range of 0 to 5. A lower score indicates a lower level of concern, and a higher score indicates a higher level of concern about a particular barrier. Construct validity was demonstrated through positive correlation between the total score on the BQ-II and scores on a brief pain intensity inventory, a pain duration scale, a positive/negative mood scale, and a global quality-of-life index. The α coefficient was 0.89 in an earlier study.[18]

Caregiver Self-efficacy

Caregiver self-efficacy was measured at baseline by the 21-item Caregiver Self-efficacy Scale.[19] The measure has 4 subscales: resilience, self-maintenance, emotional connectively, and instrumental caregiving. Caregivers were asked various questions associated with caregiving and asked to rate their level of confidence in providing patient care using an 11-point scale, which ranged from 0% (lower confidence) to 100%. (higher confidence). The 11 items were summed overall and a mean obtained. Construct validity was demonstrated by convergent relationship between the Caregiver Self-efficacy Scale and the Emotional Support on the Brief Cope[20] and Family Appraisals for Caregiving Questionnaire for Palliative Care.[21] The test-retest reliability for the subscales ranged from 0.73 to 0.94, and the internal consistency ranged from 0.81 to 0.94.[19]

Procedures

At the baseline meeting with informal caregivers and patients in their homes, a research staff member explained the study, and both caregivers and patients were asked to read and sign an informed consent. Next, the informal caregivers and patients completed the baseline questionnaires. They were given a digital tablet computer and trained on its use and use of the

TABLE 1 Caregiver and Patient Demographics, Patient Pain Characteristics

	Caregiver	Patient
Demographics	**n = 12**	**n = 12**
Age, mean (SD) [range], y	53.7 (11.6) [37-69]	67.8 (18.1) [35-96]
Female gender, n (%)	11 (91.7)	7 (58.3)
Race/ethnicity, n (%)		
White	9 (75.0)	10 (83.3)
Other	3 (25.0)	2 (16.7)
Non-Hispanic	10 (83.3)	12 (100)
Education, n (%)		
Less than high school or high school graduate	6 (50.0)	7 (58.3)
College graduate or greater	6 (50.0)	5 (41.7)
Employment status, n (%)		
Full-time	7 (58.3)	—
Not employed	3 (25.0)	—
Retired	2 (16.7)	—
Relationships to patient, n (%)		
Spouse	4 (33.3)	—
Adult children	3 (25.0)	—
Family member (parent, sibling, other)	2 (16.7)	—
Friends	3 (25.0)	—
Diagnosis, n (%)	—	
Cancer	—	6 (50.0)
Dementia	—	2 (16.7)
Congestive heart failure	—	2 (16.7)
Other	—	2 (16.7)
Pain characteristics, mean (SD) [range]	—	
Worst pain over past 24 h	—	6.3 (0.9) [2.17-10.0]
No. of pain episodes over past 24 h	—	3.0 (0.5) [1.0-6.2]
Average daily duration of pain over the past 24 h	—	(2.1) [0.5-24]

e-Pain Reporter application. On opening the application, caregivers saw an introduction with contact information for assistance, instructions for use, and a home page where they could select either the breakthrough or daily pain reports. Manuals were available in both hard copy and on the device for easy reference. The manual included the project email and phone number. The informal caregivers were asked to do a return demonstration until they were comfortable with using the e-Pain Reporter and were instructed to contact the research study staff with any questions or concerns. Over the course of 9 days, the informal caregivers used the e-Pain Reporter. Informal caregiver reports on the e-Pain Reporter were monitored by the principal investigator, a certified palliative care nurse. Reminder calls were made by a research staff member to the informal caregiver if no data were entered for 5 days. The principal investigator met individually with the nurse case managers at the agency every week after their team meeting to provide a report on their patient's pain and analgesic home management. The research staff member made a home visit at 9 days post baseline to administer the final questionnaires, retrieve the tablet computer, and give a $10 gift card to both the patient and informal caregiver.

Data Analysis

SPSS for Windows v24 (IBM, Armonk, New York) was used for data management and statistical analysis. The feasibility of using the e-Pain Reporter was evaluated by examining means and SDs of caregiver use of the e-Pain Reporter (breakthrough pain report and daily pain report) and caregiver satisfaction with the e-Pain Reporter. A narrative analysis was conducted for open-ended questions on satisfaction with the e-Pain Reporter. Descriptive statistics including means, SDs, and ranges were used to evaluate patient and caregiver demographic characteristics, patient pain characteristics, caregiver barriers, and caregiver self-efficacy.

RESULTS

Recruitment and Retention and Patient and Informal Caregiver Characteristics

A total of 42 informal caregiver-patient dyads were screened for the study. Of these, 22 caregiver-patient dyads declined to participate. Of the 20 who agreed to be screened, 6 did not meet the inclusion criteria (1 patient was too ill, 1 patient was hospitalized, 1 patient did not have a caregiver who was involved with patient care, 1 caregiver had health issues, 1 caregiver was available only at night, and 1 caregiver did not speak English). Of the 14 eligible caregiver-patient dyads who consented to participate, 1 patient died before the baseline appointment and was never consented, and another patient died after baseline. As a result, 12 informal caregivers completed the intervention.

TABLE 2 Caregiver Pain Report Measures and Caregiver Satisfaction (n = 12)

Caregiver Pain Report Measures	
Breakthrough pain report, mean (SD) [range], times per day	10.5 (9.3) [2-30]
Worst pain report, mean (SD) [range], d/9 d	5.9 (3.1) [1-10]
Caregiver satisfaction	
Overall satisfaction (0-3, 0 = very unsatisfied, 3 = very satisfied)	
How Satisfied were you with e-Pain Reporter? Mean (SD)	2.0 (1.0)
Ease of use (0-2, 0 = very hard, 1 = a little bit hard, 2 = satisfied)	
How hard was it for you to use e-Pain Reporter? Mean (SD)	1.8 (0.6)
How hard is it to use e-Pain Reporter on a regular basis? Mean (SD)	1.7 (0.5)
Did you find e-Pain Reporter understandable? Mean (SD)	0.8 (0.4)
Amount of time spent using e-Pain Reporter, Mean (SD)	1.8 (0.6)
Usefulness (0-1, 0 = no, 1 = yes)	
Received enough instructions to use e-Pain Reporter, n (%)	12 (100)
Contact with hospice nurse has been improved with e-Pain Reporter? n (%)	6 (50)
Barriers to pain management, mean (SD)[a]	
Total barriers	2.1 (0.7)
Physiological	2.6 (1.2)
Fatalism	1.2 (1.1)
Harmful effect	3.6 (1.2)
Communication	1.4 (0.9)
Self-efficacy for providing patient care, mean (SD)	93.5 (6.4)

[a] *n = 11 because 1 caregiver did not fill out the questionnaire.*

The mean informal caregiver age was 53.7 years (range, 37-69 years), and the majority were female and white (Table 1). Half of the caregivers were college graduates. Close to 80% of the caregivers were a spouse, adult child, or another family member. The average age of patients was 67.8 years (range, 35-96 years). Most patients were female (58.3%) and white (83.3%). Forty percent of the patients were college graduates. Six of the 12 patients had a cancer diagnosis (50.0%), 2 (16.7%) had dementia, 2 (16.7%) had congestive heart failure, and 2 (16.7%) had other illnesses.

Frequency of Use

Over 9 days, the mean number of daily breakthrough pain reports made by the caregivers was 10.5 (range, 2-30), and the mean number of days the caregivers completed a daily pain report was 5.89 (range, 2-9) (Table 2).

Caregiver Satisfaction With e-Pain Reporter

Of the 12 caregiver-patient dyads who completed the study, the mean overall satisfaction score was 2.0 on a 0- to 3-point Likert scale, indicating the caregivers were satisfied with the e-Pain Reporter (Table 2). The mean ease-of-use scores ranged from 0.8 to 1.8 on a 0- to 2-point Likert scale, indicating the caregivers found the e-Pain Reporter was easy to use.

Although this is a feasibility study and the e-Pain Reporter was not fully integrated into the hospice medical record, half of the caregivers felt that the e-Pain Reporter helped improve their pain reports to hospice nurses. Two caregivers stated that it was easier for them to report pain through the e-Pain Reporter than talking directly to hospice nurses. One stated "I am more honest to the tablet than to the hospice nurse about my use of pain medication," and another stated "it is easier to respond to text [yes/no] questions." Caregivers also acknowledge that the e-Pain Reporter had the potential to improve pain management because it helped "monitor pain better." One caregiver believed nurses increased patient's pain medication doses based on receiving feedback of the e-Pain Reporter data from the nurse interventionist. Some caregivers felt the e-Pain Reporter helped facilitate conversations with their hospice nurses. For example, a caregiver stated that "it [e-Pain Reporter] helped me to talk with the nurse." While our study focused on informal caregivers, we found that many of the hospice patients wanted to report their pain themselves and expressed a desire to complete the e-Pain Reporter reports.

Patient Pain Characteristics, Caregiver Barriers, and Self-efficacy

There was a wide range of frequencies in pain reports (2-30). Despite receiving prescribed analgesics, the patients in this study experienced frequent breakthrough pain throughout the day (mean, 10.5), and overall their pain was not well controlled (worst pain = 5.9) (Table 2).

Eleven caregivers were able to complete the barrier questionnaire administered at baseline (Table 2). The caregivers' mean scores on the subscales for barriers to pain management varied from 1.2 (fatalism) to 3.6 (harmful effects). These scores indicated caregiver barriers associated with fatalism (1.2) and communication (1.4) subscales were all relatively low, indicating that caregivers had relatively few barriers regarding fatalistic beliefs such as pain cannot be managed or communication such as the desire to be a good patient. However, caregivers scored high on physiological effects (2.6), indicating they have many concerns about adverse effects of analgesics. The highest mean score was for concerns related to the harmful effects (3.6) of pain management (ie, fear of addiction).

The mean baseline self-efficacy scale score was high (93.5% [81.9-100]), indicating the majority of informal caregivers reported confidence in providing excellent care to the patients.

DISCUSSION

We successfully recruited 14 patients and caregivers to the study, and the only 2 patients lost to follow-up passed away. Further, satisfaction with the e-Pain Reporter was high overall and for ease of use and usefulness. Despite the availability of analgesics to address their pain, caregivers reported frequent patient breakthrough pain in real time throughout the day on the e-Pain Reporter. There are 3 earlier studies that also used technology including a voice response system and short message service,[22] handheld computer with a digital pen,[23] and a tablet computer[24] to assess patient pain in the hospice and palliative care setting. However, in these studies, patient pain was assessed by prompting patients or caregivers to report pain only 1 to 3 times a day, and none assessed breakthrough pain, which occurs spontaneously throughout a day.

An advantage of the e-Pain Reporter is the ability for caregivers to report breakthrough pain in real time as it occurs. It is interesting to note that on average the caregivers reported the overall daily pain just over half of the days (5/9). Caregivers may be more inclined to record patient pain at the time of occurrence when it may be more accurate than when recalled.

The mean worst pain intensity reported in this study (6.3 on a 0- to 10-point scale) is consistent with a pain study of home hospice patients (7.2 on a 0- to 10-point scale).[3] In both studies, pain intensity was greater than or equal to 6, which is categorized as moderate pain.[25] Thus, both the frequency of breakthrough pain and severity of pain identified with use of the e-Pain Reporter support the need to improve caregiver management of pain in home hospice.

The mean total caregiver barrier score reported in this study (2.1) tended toward caregivers having a moderate level of erroneous beliefs and misconceptions about pain reporting and use of analgesics and suggests a lack of knowledge about pain management. This score was similar to the mean total barrier score (2.7) reported in a previous study of home hospice caregivers.[3] The high levels of caregiver self-efficacy or confidence in managing patient pain (93%) seen in our study, however, are in contrast to 2 prior studies that reported low levels of caregiver self-efficacy.[26,27] The prior studies suggested that low self-efficacy interferes with effective administration of analgesics.[26,27] Johnson and Fowler,[28] however, speculated that caregivers were overconfident in their incorrect knowledge of analgesic use. They suggested that overconfidence can lead to "faulty assessments, unrealistic expectations, and hazardous decisions." [28(p317)] This may help to explain our findings showing that caregivers tended to have moderate levels of erroneous beliefs and misconceptions about pain management (suggesting low knowledge) but report having high confidence in caring for hospice patients with pain. This paradoxical finding of lower knowledge scores but high confidence was also reported among a sample of African American caregivers in a study of hospice pain management.[7]

Overconfidence among informal caregivers is a concern because they can make mistakes when they manage patient pain based on their erroneous beliefs. For example, caregivers may be highly confident in withholding analgesics based on the erroneous belief that medications lead to addiction.[29] Overconfident caregivers may also be resistant to changing their ways of managing patient pain. Although we were unable to find any studies specific to informal hospice caregivers, overconfidence in providers has been associated with medical errors and difficulties in admitting their mistake.[30] Remote monitoring by a hospice nurse of patient pain and analgesics use with the e-Pain Reporter may be an effective way to detect problems and provide caregivers with additional knowledge and help to deliver more effective pain management. This feedback could potentially counterbalance the impact of caregiver overconfidence. Further, the relatively high level of pain in the pain reports made by caregivers suggests that use of the e-Pain Reporter may be particularly relevant for patients with poorly controlled pain.

A limitation to this study is that the majority of patients and caregivers were white, and the majority of patients had cancer diagnoses, potentially making the findings of the study difficult to generalize. Future studies are needed to ensure that these findings are generalizable to a wider population. In this pilot study, the e-Pain Reporter was not fully integrated into the hospice medical record. Lack of integration may be the reason why only half of caregivers believed the e-Pain Reporter could improve client-provider communication. Further investigation should be conducted after the e-Pain Reporter is fully integrated into the hospice medical records so that we can assess the impact of the e-Pain Reporter on caregiver-provider communication.

Our findings suggest that many hospice patients were capable and willing to report their pain and pain management using the e-Pain Reporter. In future studies, patients as well as caregivers should be allowed to use the e-Pain Reporter. Caregiver overconfidence, in light of their erroneous misconception regarding adequate pain management, suggests that the addition of an educational component in the e-Pain Reporter would be useful. One of the advantages of using computer applications like the e-Pain Reporter is that these applications can be improved and modified relatively easily. Findings suggest that the e-Pain Reporter provides a feasible method of collecting and monitoring pain management data in home hospice and shows promise as a useful tool to identify caregiver errors in using analgesics and monitor home analgesic management.

References

1. Van Lancker A, Velghe A, van Hecke A, et al. Prevalence of symptoms in older cancer patients receiving palliative care: a systematic review and meta-analysis. *J Pain Symptom Manage.* 2014;47(1):90-104.
2. Coyne P, Mulvenon C, Paice JA. American society for pain management nursing and hospice and palliative nurses association position statement: pain management at the end of life. *Pain Manag Nurs.* 2018;19(1):3-7.
3. Wilkie DJ, Ezenwa MO, Yao Y, et al. Pain intensity and misconceptions among hospice patients with cancer and their caregivers: status after 2 decades. *Am J Hosp Palliat Care.* 2017;34(4):318-324.
4. Simone CB 2nd. Pain and quality of life in palliative care. *Ann Palliat Med.* 2015;4(4):E1-E4.
5. Edmond SN, Graves PE, Whiting SE, Karlson CW. Emotional distress and burden among caregivers of children with oncological/hematological disorders. *Fam Syst Health.* 2016;34(2):166-171.
6. Mayahara M, Foreman MD, Wilbur J, Paice JA, Fogg LF. Effect of hospice nonprofessional caregiver barriers to pain management on adherence to analgesic administration recommendations and patient outcomes. *Pain Manag Nurs.* 2015;16(3):249-256.
7. Cagle JG, Zimmerman S, Cohen LW, Porter LS, Hanson LC, Reed D. EMPOWER: an intervention to address barriers to pain management in hospice. *J Pain Symptom Manage.* 2015;49(1):1-12.
8. Chi NC, Demiris G. Family caregivers' pain management in end-of-life care: a systematic review. *Am J Hosp Palliat Care.* 2017;34(5):470-485.
9. Grano C, Lucidi F, Violani C. The relationship between caregiving self-efficacy and depressive symptoms in family caregivers of patients with Alzheimer disease: a longitudinal study. *Int Psychogeriatr.* 2017;29(7):1095-1103.
10. Deandrea S, Corli O, Consonni D, Villani W, Greco MT, Apolone G. Prevalence of breakthrough cancer pain: a systematic review and a pooled analysis of published literature. *J Pain Symptom Manage.* 2014;47(1):57-76.
11. Mayahara M, Paice J, Wilbur J, Fogg L, Foreman M. Common errors in using analgesics by home-based nonprofessional hospice caregivers. *J Hosp Palliat Nurs.* 2014;16(3):134-142.
12. Mayahara M, Wilbur J, O'Mahony S, Breitenstein S. E-pain reporter: a digital pain and analgesic diary for home hospice care. *J Palliat Care.* 2017;32(2):77-84.
13. Anderson F, Downing GM, Hill J, Casorso L, Lerch N. Palliative Performance Scale (PPS): a new tool. *J Palliat Care.* 1996;12(1):5-11.
14. Jang RW, Caraiscos VB, Swami N, et al. Simple prognostic model for patients with advanced cancer based on performance status. *J Oncol Pract.* 2014;10(5):e335-e341.
15. Myers J, Kim A, Flanagan J, Selby D. Palliative Performance Scale and survival among outpatients with advanced cancer. *Support Care Cancer.* 2015;23(4):913-918.
16. Lind L, Karlsson D. A system for symptom assessment in advanced palliative home healthcare using digital pens. *Med Inform Internet Med.* 2004;29(3-4):199-210.
17. Breitenstein SM, Gross D. Web-based delivery of a preventive parent training intervention: a feasibility study. *J Child Adolesc Psychiatr Nurs.* 2013;26(2):149-157.
18. Gunnarsdottir S, Donovan HS, Serlin RC, Voge C, Ward S. Patient-related barriers to pain management: the Barriers Questionnaire II (BQ-II). *Pain.* 2002;99(3):385-396.
19. Ugalde A, Krishnasamy M, Schofield P. Development of an instrument to measure self-efficacy in caregivers of people with advanced cancer. *Psychooncology.* 2013;22(6):1428-1434.
20. Cooper B, Kinsella GJ, Picton C. Development and initial validation of a family appraisal of caregiving questionnaire for palliative care. *Psychooncology.* 2006;15(7):613-622.
21. Carver CS. You want to measure coping but your protocol's too long: consider the brief COPE. *Int J Behav Med.* 1997;4(1):92-100.
22. Besse KT, Faber-te Boveldt ND, Janssen GH, Vernooij-Dassen M, Vissers KC, Engels Y. Pain assessment with short message service and interactive voice response in outpatients with cancer and pain: a feasibility study. *Pain Pract.* 2016;16(3):320-326.
23. Lind L, Karlsson D, Fridlund B. Patients' use of digital pens for pain assessment in advanced palliative home healthcare. *Int J Med Inform.* 2008;77(2):129-136.
24. Ezenwa MO, Suarez ML, Carrasco JD, et al. Implementing the PAIN RelieveIt randomized controlled trial in hospice care: mechanisms for success and meeting PCORI methodology standards. *West J Nurs Res.* 2017;39(7):924-941.
25. Boonstra AM, Stewart RE, Köke AJ, et al. Cut-off points for mild, moderate, and severe pain on the numeric rating scale for pain in patients with chronic musculoskeletal pain: variability and influence of sex and catastrophizing. *Front Psychol.* 2016;7:1466.
26. Kizza IB, Muliira JK. The influence of a home-based education intervention on family caregivers' knowledge and self-efficacy for cancer pain management in adult patients within a resource-limited setting. *J Cancer Educ.* 2018.
27. Hendrix CC, Landerman R, Abernethy AP. Effects of an individualized caregiver training intervention on self-efficacy of cancer caregivers. *West J Nurs Res.* 2013;35(5):590-610.
28. Johnson DD, Fowler JH. The evolution of overconfidence. *Nature.* 2011;477:317-320.
29. Sanchez C, Dunning D. Overconfidence among beginners: is a little learning a dangerous thing? *J Pers Soc Psychol.* 2018;114(1):10-28.
30. Brezis M, Orkin-Bedolach Y, Fink D, Kiderman A. Does physician's training induce overconfidence that hampers disclosing errors? [published online ahead of print January 11, 2016]. *J Patient Saf.* 2016.