A Canadian online survey of oncology nurses' perspectives on the defining characteristics and assessment of breakthrough pain in cancer

by Margaret I. Fitch, Alison McAndrew and Stephanie Burlein-Hall

Abstract

This paper explores oncology nurses' recognition of breakthrough pain in cancer (BTPc), methods they used for identification and assessment, and their perception of the burden to patients. An online questionnaire was distributed to 688 oncology nurses across Canada, and 201 participated. Sixty-four per cent of nurses surveyed reported that 41% to 80% of their patients experience BTPc, but many were unsure of the basic characteristics of the profile of a BTPc episode. Although a minority of respondents (33%) reported they did not use pain assessment tools/guidelines to help diagnose BTPc, those who did largely endorsed their use. Survey findings support the debilitating impact of BTPc, but further education is needed to advance the quality and consistency in pain assessment.

Key words: breakthrough cancer pain, nursing, pain management, Canadian

Breakthrough pain in cancer (BTPc) has been defined as a transient exacerbation of pain that occurs despite well managed background pain, although the precise definition is under debate in the literature (Davies, 2011; Haugen, Hjermstad, Hagen, Caraceni, & Kaasa, 2010; Mercadante et al., 2002). Definitions of BTPc have been shown to vary depending on the clinical practice setting, region of the world, and nuances of the language spoken (Haugen et al., 2010; Mercadante et al., 2002). The lack of a clear and consistent definition for BTPc makes prevalence difficult to establish. For instance, diverse estimates of BTPc ranging from 20-95% have been put forward depending on the setting (Mercadante et al., 2002; Portenoy & Hagen, 1990; Zeppetella & Ribeiro, 2003).

Most definitions suggest that BTP can only be identified when background pain is under adequate control (Haugen et al., 2010), but some include pain that exceeds background level regardless of treatment efficacy, such as during end-of-dose failure (Haugen et al., 2010; Mercadante et al., 2002). Background pain is characterized by a continuous pain that, if left untreated, persists for a prolonged period of time (e.g., a full day) (Zeppetella & Ribeiro, 2003). Certain associations in Canada refer to BTP as that which occurs between (or "breaks through") regular doses of analgesic (Canadian Cancer Society, 2011; Cancer Care Ontario [CCO], 2008; Green et al., 2010; Registered Nurses Association of Ontario [RNAO], 2002).

Without a standard, widely accepted definition, identifying BTPc can be a challenge for health care professionals in clinical practice. The need for properly identifying BTPc is apparent from the serious implications that this form of pain can have on patients' daily functioning, psychological health, and social interactions (Zeppetella, 2009). Experts have called for the establishment of appropriate definitions, tools, and guidelines to help identify and assess BTPc and support the development of individualized treatment plans. As an initial step toward designing educational supports, there is a need to understand the current knowledge of oncology nurses about BTPc.

Literature review

Oncology nurses play a critical role in assessing pain, planning a pain-control regimen, and evaluating the effectiveness of therapies (Mahfudh, 2011). Some barriers that nurses may face when attempting to optimize pain therapy include lack of specialized knowledge, misinformation about pain treatments such as addiction risk in opioids, and the need for formal, standardized procedures for assessing pain (Pargeon & Hailey, 1999). Nurses may also receive inadequate education/training in pain management due to deficiencies in academic curricula (Grant, Ferrell, Hanson, Sun, & Uman, 2011; Pargeon & Hailey, 1999; Twycross, 2002).

Since first being identified as a distinct entity in the scientific literature just over 20 years ago, BTPc has provided a further consideration for optimizing pain management (Portenoy & Hagen, 1989, 1990). To date, there is still no widely agreed upon definition for what constitutes BTPc, and some controversy exists as to whether BTPc can only be identified in patients whose background pain is well controlled, or whether its diagnosis is irrespective of background level of analgesic control (Haugen et al., 2010; Mercadante et al., 2002). Further, no fully clinically validated standardized tools are currently available for independent assessment of BTPc intensity (Haugen et al., 2010; Parlow et al., 2005), and the specific tools/ diagnostic algorithms that exist (Biondo, Nekolaichuk, Stiles, Fainsinger, & Hagen, 2008; Hagen et al., 2008; Haugen et al., 2010) are not necessarily consistently applied within or across clinical practices. Guidelines with a specific focus on BTPc are few (Davies, Dickman, Reid, Stevens, & Zeppetella, 2009; European Oncology Nursing Society, 2011a; European Oncology

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Nursing Society, 2011b), although some generalized guidelines/consensus documents include recommendations for BTPc management (Cancer Care Ontario [CCO], 2008; Green et al., 2010; Steering, 1998). Such a lack of formalized and widely accepted guidance around the assessment and management of BTPc highlights the importance of implementing standardized measures for identification of BTPc (Caraceni et al., 2004).

In the widely recognized three-step framework for providing analgesia published by the World Health Organization (World Health Organization, 1996), BTPc is not distinguished from background pain. Nevertheless, studies that have gathered the perspectives of oncology patients, nurses and physicians have highlighted the substantial impact of BTPc on those affected (Bertram et al., 2010; Davies, Vriens, Kennett, & McTaggart, 2008; Davies et al., 2011; European Oncology Nursing Society, 2011a; European Oncology Nursing Society, 2011b; Mercadante, Villari, & Casuccio, 2011). Such studies call for specialized educational/training programs on BTPc and improved consistency with respect to assessment and management practices in various regions around the world.

Purpose

The purpose of this study was to explore the perspectives of Canadian oncology nurses regarding the recognition of BTPc, methods used for its identification and assessment, and the burden BTPc imposes on patients.

Methodology

Design

Between June 10 and July 4, 2011, an online survey questionnaire was posted on a survey platform (SimpleSurvey, a division of OutSideSoft Solutions Inc). The survey company (SimpleSurvey) sent an email request to all nurses on the Canadian Association of Nurses in Oncology (CANO) membership list with valid email addresses (N=668) to participate in the survey. A series of three email blasts were subsequently sent by SimpleSurvey to all non-responders each week until the survey close. Careful attention was made to ensure the members understood that this survey was a non-drug-related pharmaceutical company survey that was endorsed by CANO. but in no way were members being requested to participate by CANO. Contact details were collected for provision of the stipend for survey participation. However, all results were anonymized before submission by SimpleSurvey to the data analysis team. This cross-sectional sample was chosen as a population representative of the broader oncology nursing workforce in Canada, as there is no currently available Canada wide registry of oncology nurses. In all, CANO membership includes more than 1,000 oncology nurses across Canada who joined on a volunteer basis. The survey questionnaire was available in English and French.

Participant accrual and data collection

The survey was designed for the purpose of this study. The initial three questions served to screen the participants on the basis of the following criteria: 1) must work with patients with cancer, 2) must treat cancer patients for the pain related to their cancer (alone or with a physician), and 3) must see at least 10 patients per month. Those who met all three criteria were then able to proceed with the survey. The main researcher-developed questionnaire included 43 questions, and took approximately 30 minutes to complete online. Questions in the overall survey related to nurses' perceptions of the prevalence, severity, and characteristics of BTPc; impact of BTPc on patients' quality of life (QoL); patient satisfaction with current management; and desired qualities of treatment.

Survey questions were selected using as a model a recent patient survey questionnaire, such that results of our survey of nurses' views of the patient experience could be assessed with respect to published patient survey findings (Davies et al., 2011; Fitch et al., 2012). The questionnaire and survey methodology underwent extensive scientific review, including by the CANO Scientific Committee. Questions were largely closed-ended and presented in the following formats: 1) demographic questions, 2) rating scale questions (e.g., Likert-type scale of response items ranging from 1 to 10), 3) dichotomous questions requiring a "yes" or "no" response, 4) balanced scale questions, 5) multiple response options with participants choosing one or more options they feel are most applicable. The questionnaire focused on how nurse participants assessed BTPc in their own clinical setting, with responses sought based on their interactions with patients. The draft survey was sent to the CANO executive committee for comments and final approval. The executive committee approved the survey and offered its endorsement.

The insights we gathered related to current management of BTPc are presented in a companion article. A stipend was offered for completion of the survey that was within fair market value for the time anticipated.

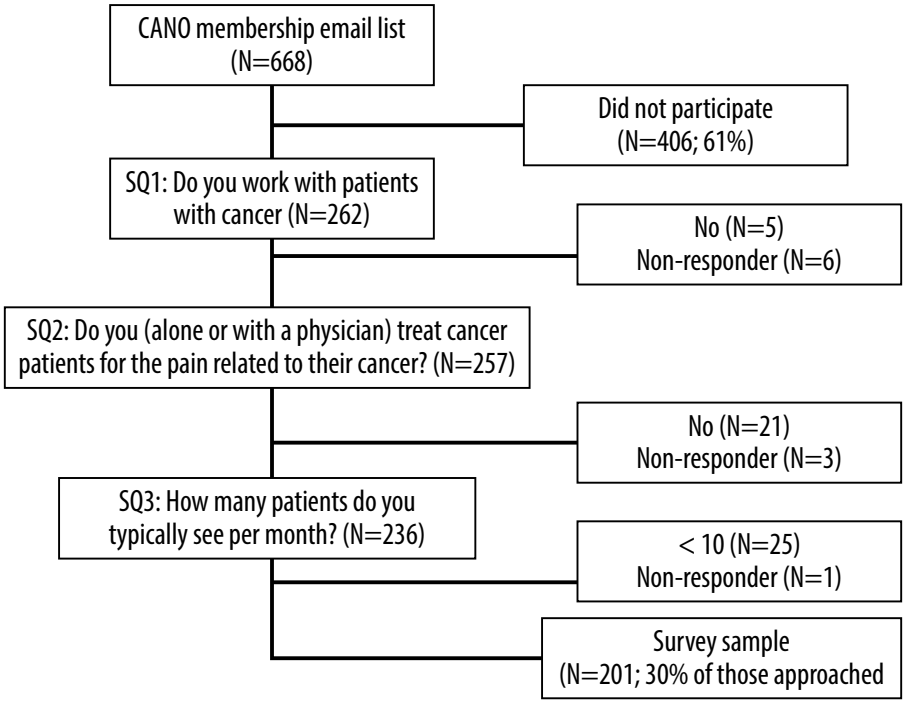

Figure 1: Selection process for eligibility of CANO members

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Table 1: Sociodemographic characteristics of survey respondents in the study	
Characteristics of respondents	**Number of respondents (n = 201) (absolute values [%])**
Age	
20-29 years	12 (6.0%)
30-45 years	59 (29.4%)
46-65 years	96 (47.8%)
NR	34 (16.9%)
Sex	
Females	162 (80.6%)
Males	5 (2.5%)
NR	34 (16.9%)
Region of practice	
British Columbia	12 (6.0%)
Alberta	18 (9.0%)
Saskatchewan	1 (0.5%)
Manitoba	8 (4.0%)
Ontario	73 (36.3%)
Quebec	25 (12.4%)
Nova Scotia	11 (5.5%)
New Brunswick	11 (5.5%)
Prince Edward Island	3 (1.5%)
Newfoundland	4 (2.0%)
Yukon	1 (0.5%)
NR	34 (16.9%)
Highest level of education	
Nursing diploma	45 (22.4%)
Nursing degree	70 (34.8%)
Masters	44 (21.9%)
Other	8 (4.0%)
NR	34 (16.9%)
Specialty education	
CON(C)	103 (51.2%)
Oncology nursing certificate	56 (27.9%)
Other	37 (18.4%)
No specialty education reported	5 (2.4%)
Work Status	
Full time	138 (68.7%)
Part time/casual	28 (13.9%)
NR	35 (17.4%)
Years in oncology nursing	
10 years and less	62 (30.8%)
11 to 20 years	59 (29.4%)
Greater than 20 years	41 (20.4%)
NR	39 (19.4%)
Note: NR = Non-responders	

Ethics approval was not required for the following reasons: 1) The survey was endorsed by the Canadian Association of Nurses in Oncology (CANO) and the process of data analysis and publication was stated clearly in the introduction; 2) Participation in the survey was considered to represent implicit consent for inclusion of individual data in the analysis; 3) No patient data were collected or included in the analysis.

Data analysis

Data were collated via an online tool (www.simplesurvey.com) and imported into SPSS databases (IBM SPSS Statistics 17.0) by the data analysis team. Descriptive statistics (including frequencies [counts], percents, mean, standard deviation, and range [where applicable]) were used to describe the responses to each question. Descriptive analysis and cross-tabulations were performed using SPSS. Frequency distributions and percentages were calculated for each question. Cross-tabulations by each demographic question were performed, including age, education, years in oncology nursing, specialty education, work status, work setting, region, and patients seen per month.

Results

Sociodemographics

In total, 201 eligible subjects participated in the survey and answered at least one question in the main survey (response rate of 30%) (Figure 1). The margin of error was estimated at approximately 5.78%. As required for eligibility, all respondents were involved in the treatment of patients with cancer and related pain, and saw at least 10 patients per month. Surveyed nurses were mostly female, aged 46 to 65 years, worked full-time (Table 1), and approximately half (47.8%) had >20 years' experience in the nursing field (20.4% with >20 years' experience in the oncology nursing field), reflecting current trends in the broader Canadian nursing

Table 2: Descriptions deemed by participants to most accurately define BTPc

Descriptions of BTPc selected by respondents	Responses		Percent of cases (%)
	N	Percent	
Episodic pain that breaks through the stable background pain	159	24.1%	82.8%
Predictable incident pain	71	10.8%	37.0%
Spontaneous pain/ unpredictable incident	89	13.5%	46.4%
Transitory exacerbation pain	89	13.5%	46.4%
Pain is worsening over time	48	7.3%	25.0%
Pain that requires additional or adjustments to current pain medication	132	20.0%	68.8%
Anticipated pain associated with movement	70	10.6%	36.5%
Other	2	0.3%	1.0%

Note: Multiple responses were possible

workforce (Canadian Institute for Health Information [CIHI], 2010). The proportion of respondents practising within each of the provinces/Yukon Territory reflects regions of practice for nurses in the broader Canadian population (CIHI, 2010), except there were no participants from the Northwest Territories or Nunavut.

Identification of breakthrough pain in cancer

Sixty-four per cent of nurses surveyed reported that 41% to 80% of their patients experience breakthrough cancer pain. Most felt that their patients would generally rate the severity of BTPc as moderate to severe (88.1%), and only 3.5% would rate the pain as mild. About half the respondents estimated that patients experience BTPc at least twice a day, and 13% reported one episode a day or less. Overall, 37.0% were unsure of how often their patients experience BTPc each day—these were mainly nurses with more than 20 years of oncology experience (46.3%), compared to those in the younger age categories (27.1% of those with 11 to 20 years' experience; 41% of those with 5 to 10 years' experience; and 39.1% of those with 5 years and less). In contrast, 86.1% of respondents perceived that patients experience background pain most of the time. Approximately 30.0% of respondents reported difficulty distinguishing BTPc from end-of-dose failure, largely irrespective of the nurses' age. When given a choice of options, the characteristics selected to best describe BTPc varied between nurses surveyed (Table 2).

Characteristics of BTPc

Onset of BTPc was recognized by many respondents to occur during treatment (55.4%), development of metastases (84.8%), at end-of-life phases (64.1%), and/or less commonly during other stages of illness (20.1%). Nurses surveyed reported a median time for BTPc to peak of 11 to 20 minutes with a median duration of 31 to 60 minutes, but many respondents were unsure of how long it took for these episodes to reach peak intensity (40.3%), or their duration (36.3%). Most respondents selected a rating of 7 or 8 out of 10 to characterize the intensity of BTPc (Figure 2).

Impact of BTPc on quality of life

The majority of nurses surveyed indicated that BTPc has at least a significant impact on patients' QoL (Figure 3) and caused some (55.2%) or complete (43.6%) interference with patients' everyday activities.

Utility of assessment tools/guidelines

One-third (n = 67) of nurses reported that they do not use assessment tools/guidelines to help distinguish between background and BTPc. Nearly all of those who did use tools/guidelines found them to be somewhat (55%) or very (42%) useful. Of those using the tools or guidelines, most had achieved a nursing degree (43.2%) as their highest level of education, followed by a Master's degree (27.9%), nursing diploma (23.4%), or "other" (5.4%) designation. Use of assessment tools/guidelines was more common in respondents ages 46 to 65 years (75%) compared with 20 to 45 year olds (54.9%), but was irrespective of whether respondents had difficulties distinguishing BTPc from end-of-dose failure (66.7%) or not (64.2%). Respondents who were extremely confident in advising patients on how to manage BTPc were much more likely to report using an assessment tool/guidelines (84.4%) compared with those who did not report use of these methods (15.6%). Most of those who reported they were only slightly confident in advising patients (71.4%) did not use an assessment tool/guideline. The most commonly used tools noted by the nurses surveyed were the Edmonton Symptom Assessment System (ESAS) and Numerical Pain Rating Scale (scaled response items ranging from 1 to 10). A wide variety of other tools and guidelines were indicated—often, the same tools were identified by different names.

Discussion

Overall findings provide greater insight into how BTPc is perceived by oncology nurses, whose ability to evaluate pain is crucial to optimizing care. The survey supports published data (Davies et al., 2008; Davies et al., 2011; European Oncology Nursing Society, 2011a; European Oncology Nursing Society, 2011b) on the characteristics of the profile of a BTPc episode, the debilitating impact on patients, and the need to implement standardized, consistent approaches to assessment within Canadian practices.

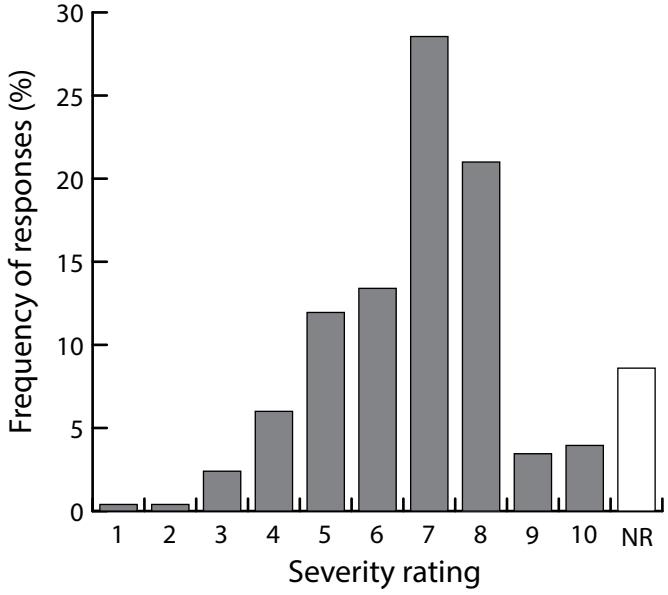

Figure 2: Severity rating of breakthrough pain in cancer
NR = No response

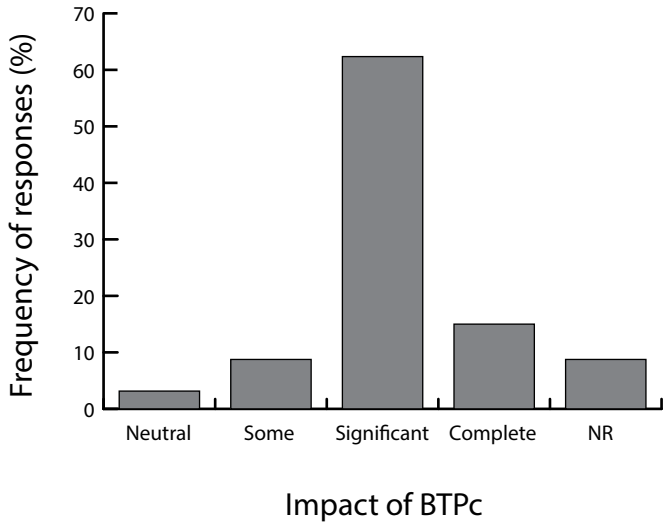

Figure 3: Impact of BTPc on quality of life
NR = No response

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Findings from the survey suggest that Canadian nurses in oncology recognize the serious burden of BTPc on the QoL and well-being of their patients. However, challenges are apparent in the identification of BTPc, recognition of characteristic features, distinction from other types of pain, and selection of assessment tools and guidelines.

Even though oncology nurses make up only 1.3% of the Canadian registered nursing workforce, respondent demographics generally reflected those of the Canadian nursing population overall including that most respondents were aged 46 to 65 years, consistent with the trend towards nurses graduating at ages ≥ 30 years (Canadian Institute for Health Information [CIHI], 2010) and the need for additional education in the specialized field of oncology (Canadian Association of Nurses in Oncology [CANO], 2012). However, a larger proportion of respondents achieved Master's degrees (21.9%) compared with the general Canadian nursing population (3.2%), and fewer held nursing diplomas (22.4% versus 60.1%, respectively), as their highest academic level (CIHI, 2010). Hence, this sample is considered to be a highly educated one.

The burden of BTPc to patients was well recognized by many respondents, with nurses' ratings reflecting those in a recent patient self-report survey suggesting most patients experienced moderate (37%) or severe (60%) episodes of BTP and a negative impact on QoL (Davies et al., 2011). Results from a European survey of oncology nurses also reported that BTPc had a significant impact on 75% of patients, affecting their enjoyment of life, mood, and sleep (European Oncology Nursing Society, 2011a).

Characteristics of BTPc noted by nurses in our survey generally reflected previous studies where approximately half of European nurses noted that patients experience BTPc two to three times a day (European Oncology Nursing Society, 2011a), and that patients experienced BTPc three times a day (Davies et al., 2011). Median time to peak and duration of BTPc episodes in our study were similar to those indicated in patient self-report studies (Davies et al., 2008; Davies et al., 2011), although the precise values varied somewhat in the literature (Portenoy, Bruns, Shoemaker, & Shoemaker, 2010; Portenoy, Payne, & Jacobsen, 1999). Nevertheless, we were surprised to find that many of the nurses surveyed—even those with more than 20 years' experience—were unsure of the basic characteristics of BTPc, indicating uncertainty when asked to define the frequency, time to peak, or duration of BTPc episodes. Evaluating the characteristics of pain such as frequency and duration was recommended as part of performing a comprehensive assessment in a recent position paper published by CANO (CANO/ACIO, 2011). However, uncertainties in defining BTPc, as suggested in our study by the variety of statements chosen to "best" describe BTPc, can impair its recognition. This problem is exacerbated by the lack of consensus about established definitions and consistent terminology in the literature (Haugen et al., 2010; Mercadante et al., 2002). In some ways, BTPc is still an emerging field, and clarity needs to be achieved. Challenges in recognizing characteristics of BTPc were also suggested by findings from a European-based study that reported 10% of oncology nurses were uncertain whether they had cared for patients with BTPc (European Oncology Nursing Society, 2011a).

Assessment tools and guidelines can help foster consistency in the approaches taken to diagnose, assess, and monitor BTPc. However, one-third of respondents did not use any tools/guidelines to help distinguish background from BTPc. Respondents in our survey most commonly reported using the Edmonton Symptom Assessment System (ESAS) and the Numerical Pain Rating Scale (with response items ranging from 1 to 10). Although the ESAS tool does screen for nine high-frequency symptoms, both the ESAS pain item and the Numerical Pain Rating Scale are single-item screening tools rather than comprehensive assessment tools. A standardized assessment tool that provides comprehensive assessment incorporates multiple items for pain (severity, location, intensity, impact, etc.), versus a single-item question on a tool such as the ESAS. There are also tools in use that have not been psychometrically validated. Such findings suggest a need for establishing a more standardized approach to assessing BTPc with greater awareness of appropriate tools and guidelines. Inconsistent and/or limited use of tools that specifically assess BTPc is not surprising, as a fully clinically validated instrument for independent assessment of BTPc intensity is not yet available (Haugen et al., 2010; Parlow et al., 2005), and a small minority of partially validated questionnaires are published in full in the literature (Haugen et al., 2010). Nevertheless, in our survey, those who used the tools available generally found them helpful, and were more confident in advising their patients about BTPc. Such increased confidence reflects reports that nurses value having access to tools that offer easily quantifiable measures related to delivery of care (Twycross, 2002). Integration of a tool for assessing pain was also found to be associated with increased confidence in a study of nurses caring for critically ill non-verbal patients, although it was difficult to decipher whether this effect was due to implementation of the tool itself, or the education provided to the nurses to support its use (Topolovec-Vranic et al., 2010). Another possibility is that the increased confidence in nurses who employed pain assessment tools or guidelines was influenced by their educational background. Survey respondents with a Master's or a nursing degree were more likely to use assessment tools than those with nursing diplomas or "other" educational backgrounds, suggesting that confidence in advising patients may be associated with education received. The tools selected by nurses for assessing pain should be those able to best interpret the patient experience since, according to McCaffery's (1968) definition, "pain is whatever the experiencing person says it is, existing whenever the experiencing person says it does" (McCaffery, 1968). Currently, there is an emerging approach in practice whereby there is a single-item screening question asked and, based on the answer, there would be a deeper assessment tool (set of questions) asked to further elaborate on the patient's experience with pain. Although selecting the appropriate tool is essential, it is only an initial step towards providing effective pain relief. The assessment of pain must lead to effective intervention to improve patient outcome. A recent study of health care providers (physicians, nurse practitioners and nurses) in an ambulatory care setting suggested that although knowledge of pain was related to providing a comprehensive pain assessment, it was not similarly associated with the amount of pain relief documented at the next clinic visit (Wells, McDowell, Hendricks, Dietrich, & Murphy, 2011). The findings highlight the need for the translation of a comprehensive pain assessment for effective delivery of care to optimize pain management.

Limitations to this study included the use of the CANO members' email list for recruiting respondents, rather than random sampling of the broader Canadian oncology nurse population, although the basic characteristics of the survey sample were comparable to the broader population of oncology nurses in Canada. As with any survey conducted online, responses could reflect the demographics of individuals who are computer literate and have high Internet usage. Reliance on nurses' perception and recall of the patient experience rather than direct patient self-report may also have introduced bias, but allows comparison of this pivotal group of stakeholders with results from other nurse surveys and patient-based survey studies. The 39% response rate (including screen failures) may be considered low for a survey sample, but could, in part, reflect the choice of some nurses not to respond to a screening question if they anticipated they would not qualify for the study. A 39% response rate (i.e., including screen failures) was obtained and, as with online surveys in general, inherently reflects, in part, server

rejections, out-of-office/automated replies, and the use of spam filters (Dobrow et al., 2008). The response rate achieved was consistent with that of a previous CANO members' questionnaire (Bakker & Fitch, 1998). Response rates to nurses' surveys are notoriously low, but may be increased with endorsement by a legitimizing local, state or national professional association (VanGeest & Johnson, 2011) such as with distribution to CANO members in this study. Other recommended approaches followed for this survey included ensuring multiple contacts with potential responders to improve response rates (Dillman, 2007). Perhaps response rate may have been boosted by selecting to distribute the surveys by mail or telephone, which are generally shown to improve nurses' participation over web-based distribution (VanGeest & Johnson, 2011).

Clinical implications

The quality, consistency, and confidence in BTPc assessment must be advanced, with tools implemented to improve assessment practices, intervention, and patient education. Pain assessment is an area that is thought to be inadequately addressed in the nursing curricula, and specialized training is considered important for increasing confidence in managing pain (Grant et al., 2011; Holley, McMillan, Hagan, Palacios, & Rosenberg, 2005). In this survey, nurse respondents who reported the use of pain assessment tools/guidelines were more confident in advising patients on BTPc.

Research implications

If standard tools were developed and successfully implemented, allowing nurses to use these assessment tools routinely, their confidence in pain assessment would likely increase with experience. This increased confidence would result in improved outcomes for patients, especially if nurses can engage in patient teaching programs to address patients' basic pain information needs. It would be interesting to examine more closely the extent to which implementing standard tools for assessing BTPc enhances nurses' confidence level and whether this translates to improvement in patient outcomes.

Educational implications

The lack of a standardized definition for BTPc makes it challenging to implement a standardized, consistent approach to assessment within Canadian practices. Without a standard definition, clinicians and nurses across health care practices are basing their care on different vantage points or criteria for assessment of BTPc. Regardless of which assessment tools may be used, a consistent definition of BTPc is essential so that all practitioners are aligned in their identification of BTPc. Ongoing education for health care professionals must, then, include a clear definition of BTPc.

As noted in this survey, if nurses believed that a large proportion of patients suffered with both background and BTPc pain, there is a need for nurses to differentiate the two types of pain experiences to bolster their assessment skills and ability to advocate for patients to receive the appropriate level of analgesia to alleviate the specific type of pain. Further, the high prevalence of patients experiencing moderate to severe BTPc in nurses' daily practices, as indicated in this survey, reinforces the need for patient education sessions on how to cope with this pain. If nurses are aware that BTPc interferes with patients' daily activities, they should educate patients on the use of BTPc medication in anticipation of the activities that are likely to precipitate a pain event.

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