

Telephone Calls by Individuals With Cancer

Marie Flannery, RN, PhD, AOCN[®], Leanne McAndrews, LMSW, and Karen F. Stein, RN, PhD, FAAN

Assisting people with the management of symptoms associated with their disease and its treatment is not a new concern for researchers and clinicians in oncology. Since the 1980s, much has been learned about the symptom experience for patients with cancer including the scope, prevalence, and severity of commonly reported symptoms; the side-effect profiles associated with various treatment modalities; and the increased severity of symptoms often reported in later stages of disease (Barbera et al., 2010; Chen et al., 2010; Kirkova et al., 2006; Portenoy et al., 1994; Vainio & Auvinen, 1996; Yamagishi, Morita, Miyashita, & Kimura, 2009). Most of the evidence is a result of surveys using standardized symptom inventory tools administered to patients in the hospital or ambulatory care setting during scheduled visits (Kirkova et al., 2006). However, as oncology care is increasingly delivered in the outpatient setting, reporting symptoms by telephone has become a growing trend. These telephone reports differ from traditional face-to-face assessments by clinicians because they are initiated by the patient or family member and offer a unique opportunity to capture symptom reporting from a patient-centered perspective. Telephone reports of symptoms provide a window to examine the natural occurrence of symptom reporting and symptoms considered priority by the patient.

The importance or priority of a symptom to the individual has been identified as a crucial yet under-examined aspect of the cancer symptom experience (Barsevick, Whitmer, Nail, Beck, & Dudley, 2006; Cella et al., 2002, 2003; Miaskowski, Aouizerat, Dodd, & Cooper, 2007; Stromgren et al., 2006; Tishelman, Petersson, Degner, & Sprangers, 2007; Vainio & Auvinen, 1996; Yamagishi et al., 2009). Many associations have been proposed between symptom priority and a range of variables such as symptom severity, frequency, distress, interference with functional ability, and quality of life. Limited research has been done examining patient-reported priority in the symptom experience (Stromgren

Purpose/Objectives: To describe symptom type and reporting patterns found in spontaneously initiated telephone calls placed to an ambulatory cancer center practice.

Design: Retrospective, descriptive.

Setting: Adult hematology oncology cancer center.

Sample: 563 individuals with a wide range of oncology diagnoses who initiated 1,229 telephone calls to report symptoms.

Methods: Raw data were extracted from telephone forms using a data collection sheet with 23 variables obtained for each phone call, using pre-established coding criteria. A literature-based, investigator-developed instrument was used for the coding criteria and selection of which variables to extract.

Main Research Variables: Symptom reporting, telephone calls, pain, and symptoms.

Findings: A total of 2,378 symptoms were reported by telephone during the four months. At least 10% of the sample reported pain (38%), fatigue (16%), nausea (16%), swelling (12%), diarrhea (12%), dyspnea (10%), and anorexia (10%). The modal response was to call only one time and to report only one symptom (55%).

Conclusions: Pain emerged as the symptom that most often prompted an individual to pick up the telephone and call. Although variation was seen in symptom reporting, an interesting pattern emerged with an individual reporting on a solitary symptom in a single telephone call.

Implications for Nursing: The emergence of pain as the primary symptom reported by telephone prompted educational efforts for both in-person clinic visit management of pain and prioritizing nursing education and protocol management of pain reported by telephone.

Knowledge Translation: Report of symptoms by telephone can provide nurses unique insight into patient-centered needs. Although pain has been an important focus of education and research for decades, it remains a priority for individuals with cancer. A wide range in symptom reporting by telephone was evident.

et al., 2006; Tishelman, Degnar, & Mueller, 2000) and little is known about what motivates the individual to seek help via phone communication. The purpose of this

descriptive study was to address this gap. The results will contribute to the body of research on symptoms in oncology by examining spontaneous symptom reporting in the context of a self-initiated action to seek help and by using a novel existing data source of unprompted symptom reporting. Symptoms reported by telephone reflect patient prioritization because the individual determines whether a symptom is important enough to initiate a call. In addition, this knowledge will enhance clinician ability to anticipate patient care needs expressed via phone access, intervene promptly in the management of troubling symptoms, and provide continuity between visits.

Background

An extensive literature base on the symptom experience has been established in oncology. A review of symptom inventories in oncology by Kirkova et al. (2006) synthesized 22 symptom inventories that have been reported in the literature for capturing the scope and prevalence of symptoms. All of these measurements are structured with a closed response format except for two instruments with a single open response item (Kirkova et al., 2006). Evidence has been established on the wide range of symptoms experienced with cancer and its treatment, the prevalence of specific symptoms, the common experience of multiple concurrent symptoms, and patterns unique to specific cancer diagnoses. Symptom reporting by telephone is unique in that the calls are initiated by the individual and reflect patient centered concerns. Phone reporting presents a rare opportunity to examine symptom types that motivate the individual to seek help.

Measurement theory provides a framework for highlighting the uniqueness of data gathered from spontaneously initiated patient phone calls in contrast to using a structured questionnaire (Schaeffer & Dykema, 2011; Schwarz, Knauper, Barbel, & Stick, 2008; Strack & Schwarz, 2007). When a measurement instrument includes a specific list of symptoms, it provides prompts that serve to prime thought or memories, therefore directing, shaping, and limiting potential responses. The pre-established format primes the individual to a set response pattern. In addition, the use of such an instrument assumes the respondent has a formed position and knowledge of what is being asked. In contrast, measurement theory posits that data collected from an open-ended, unstructured approach will be inherently different than responses to a structured questionnaire such as a symptom inventory.

Spontaneous symptom reporting has been identified as one of three methods for studying symptoms that also include chart review and survey (Kroenke, 2001). However, because of the well-identified barriers to symptom

reporting established in oncology populations, the strategy of using spontaneous reporting under-represents the prevalence and scope of the symptom experience (Paice, 2004; Ward et al., 1993). The benefit of using an existing database of spontaneous reporting is that, despite barriers to symptom reporting, individuals do initiate symptom reports; examining this phenomenon can add to the understanding of the complex field of oncology symptoms.

In reviewing the literature, the authors were unable to find any research specifically designed to examine symptom reporting by telephone. Isolated descriptive research existed that reported on ambulatory adult oncology telephone calls; however, only three relevant studies were found. All of these studies analyzed data at the call level and did not report findings specific to the individual patient with cancer. Overall, those reports documented the prevalence and scope of oncology telephone calls as a component of practice with limited information provided on symptom reporting by telephone. In a foundational examination, Nail, Greene, Jones, and Flannery (1989) reported on 1,844 telephone calls collected over a six-month period from an ambulatory cancer center. They described multiple reasons why telephone calls were placed including continuity of care, request for prescription renewal, appointment clarification, procedural preparation, and self-care information. Using the American Nurses' Association and the Oncology Nursing Society's *Outcome Standards for Cancer Nursing Practice*, calls were categorized into 10 areas that can be approximated as symptom categories. For example, the most frequently cited areas were coping (anxiety, distress, emotional needs), comfort (pain, difficulty sleeping), nutrition (decreased appetite), and protective mechanisms (fever, symptoms of infection) (Nail et al., 1989).

In northern Ireland, Reid and Porter (2011) gathered descriptive information from 7,498 calls made during a one-year interval for a chemotherapy telephone help line specifically instituted for symptom support. Patients were given written information on the telephone service and were directed to call if they were unwell, and specifically to call for nausea and vomiting, bleeding, sore mouth or throat, diarrhea, shivering or flu-like symptoms, and high or low temperature. In this study, patients and their lay caregivers accounted for 77% of the calls and results were presented on the most common problems reported by all callers. Fifty percent of calls included one symptom only with a range of 1–6 symptoms per call. The most commonly reported problems were “unwell” (40%), pain (19%), infection (12%), blood problem (12%), and nausea and vomiting (11%). Reporting on one week of telephone calls placed to a community oncology practice, Lucia, Decker, Israel, and Decker (2007) noted that 20% of patient-initiated

Table 1. Sample Characteristics (N = 563)

Characteristic	\bar{X}	Range
Age (years)	60.5	20–73
Characteristic	n	%
Gender		
Female	317	56
Male	246	44
Race and ethnicity		
Caucasian	514	91
African American	38	7
Hispanic	5	1
Asian	4	1
Unknown	2	< 1
Cancer diagnosis		
Breast	153	27
Gastrointestinal	94	17
Hematology	90	16
Lymphoma	81	14
Thoracic	56	10
Genitourinary	46	8
Brain	24	4
Rare tumors or other	19	3

Note. Because of rounding, not all percentages total 100.

calls were for symptom management, but did not provide information on what symptoms were reported. All of these researchers analyzed data at the call level and did not focus on the call content as a unique opportunity to understand patient priorities in symptom experience and reporting. This study fills a gap by both focusing specifically on symptom reporting and by examining data at the individual rather than call level.

As previously discussed, this study is based on theoretical assumptions consistent with Measurement Theory (Schaeffer & Dykema, 2011). Several philosophical assumptions underlie the study design. This includes the position that the individual is the best source of information about their symptom experience. An additional assumption consistent with measurement theory is that data collected from an open-ended, unstructured approach will be inherently different than responses to a structured questionnaire such as a symptom inventory.

The primary purpose was to describe symptom type and symptom reporting patterns found in spontaneously initiated telephone calls placed to an ambulatory cancer center practice.

Methods

Design

This was a retrospective, descriptive design. Results from this study have been published in another manuscript that focused on telephone call volume, reasons calls were placed, the nursing workload, and difference

in call volume by diagnosis (Flannery, Phillips, & Lyons, 2009). This manuscript includes data on symptoms and reporting patterns and does not overlap in content with the previous manuscript. Raw data were obtained from all RN-documented telephone calls placed to an ambulatory cancer center during a four-month interval. Research subject review board approval was obtained.

Sample

To examine data for this study, the inclusion criteria were restricted to calls placed by the patient, their significant other, or the community health nurse (acting as the patient proxy). In addition, individuals needed to have reported a symptom during the four-month interval. Calls were excluded if they were placed for reasons other than symptom reporting or they were initiated by pharmacists, other physicians, and laboratory or radiology personnel. The raw data included 1,489 patients with 5,238 telephone calls. After inclusion criteria were applied, the sample was 563 patients with 1,229 telephone calls.

Setting

The data were collected at Wilmot Cancer Center at the University of Rochester in New York. Data were collected from a four-month time period (May through August 2007). Care was organized into specialty services, including breast, thoracic, gastrointestinal (GI), genitourinary (GU), brain, lymphoma, and hematology. The practice included 11 oncologists, five nurse practitioners, and 26 RNs. All telephone calls came to a central number where a secretary recorded the primary reason for the call, and then the primary responsibility for answering telephone calls was centrally assigned to two RNs who rotated the assignment with some delegation of telephone calls to the practice team. A medical record form specific to telephone call documentation was in use at the setting. Information documented on the form included patient name, who was calling, the stated reason for the call, date and time received, a specific area for a narrative assessment, a specific area for a narrative intervention, a check box indicating teaching,

Table 2. Reported Pain Symptoms (N = 563)

Symptom	n	%
Pain	214	38
Headache	34	6
Myalgia and arthralgia	32	6
Dysphagia	31	6
Mucositis	24	4
Muscle spasms	18	3
Esophagitis	16	3

Note. Symptoms known clinically to cause pain are included in addition to report of "pain."

a section for prescription renewal requests, and the time the call was returned with an RN signature.

Instruments

Raw data were extracted from the medical record telephone form using a data collection sheet with 23 variables obtained for each phone call and collected using pre-established coding criteria. Pilot testing was conducted on the data collection form by four experienced ambulatory oncology nurses on 60 telephone calls with revisions made to the instrument to include all possible responses. The pre-established coding criteria and planned selection of variables to extract was coded on an investigator developed instrument that was based on the literature (Nail et al., 1989) and information that was present on the medical record telephone call documentation form in use in the setting. Detail was extracted on the reason for each call (e.g., if laboratory results were requested, imaging study results, appointment change, if a symptom or concern was reported). The responses for the item "What symptom, concern, or worry was reported?" were coded as 45 different symptoms identified from the Oncology Nursing Society Telephone Triage Manual (Hickey & Newton, 2005). An additional 17 responses were identified while coding after study implementation. Demographic and disease information also were collected from the electronic medical record including age, gender, race or ethnicity, insurance status, and cancer diagnosis.

Procedures

Raw data from the documented telephone call were alphabetized by patient, and a unique identification code was assigned to each patient. Each individual patient call medical record documentation form was reviewed, and data were extracted and coded on to the data collection instrument by research assistants. Extensive training was done for all coders by the principal investigator. Questions related to symptom reporting were verified by the first author

for all phone reports. The primary investigator personally reviewed the coding of the question on symptoms to ensure accuracy. Symptom reports were documented on the coding form using direct quotations from the call record. Descriptive statistics were generated to examine frequency distribution, means, mode, and range for all variables.

Table 3. Frequency and Distribution of Symptoms Reported by Call and Individual (N = 563)

Symptom	Calls Reporting		Individuals Reporting More Than Once	Maximum Times Reported by an Individual
	n	%	n	n
Pain	214	38	68	8
Fatigue	91	16	19	3
Nausea	89	16	20	4
Swelling	68	12	20	5
Diarrhea	67	12	11	4
Dyspnea	57	10	11	3
Anorexia	56	10	9	2
Weak or bedridden	55	10	10	4
Infection	53	9	10	3
Anxiety	52	9	6	5
Fever or chills	51	9	10	3
Bleeding or bruising	49	9	7	3
Dizzy, light headed, or faint	46	8	5	3
Vomiting	43	8	16	4
Emotional distress	40	7	4	3
Constipation	39	7	6	3
Lump or bump	39	7	3	3
Cough	37	7	9	3
Neuropathy	37	7	8	6
Skin breakdown	37	7	10	2
Sleep disturbance	36	6	9	3
Headache	34	6	8	4
Myalgia or arthralgia	32	6	5	3
Dysphagia	31	6	5	3
Urinary changes	29	5	5	4
Altered mental state	28	5	9	3
Rash	28	5	4	2

Results

The sample included 563 individuals reporting 2,378 symptoms recorded in 1,229 telephone calls (the same individual may have reported the same symptom more than once). For the 563 patients, 76% (n = 426) self-reported a symptom, significant others reported symptoms for 41% (n = 230), and community health nurses reported symptoms for 21% (n = 120). Most of the individuals were female and Caucasian, with a wide range of cancer diagnoses (see Table 1).

During the four months of data collection, a range of 1–49 total symptoms were reported for any individual (mode = 1, \bar{X} = 4.2, SD = 4.92). An abnormal distribution was found with the data skewed to the low end. Ninety-two percent of individuals reported 10 or fewer symptoms over the four-month interval, across all phone calls. In any individual telephone call, a range of 1–8 symptoms were recorded, with 45% reporting one symptom, 31% reporting two symptoms, 16% reporting three symptoms, and 4–8 symptoms reported in a single phone call less than 10% of the time. Finally, for each individual, a range of 1–18 telephone calls were made during the four month period with symptoms reported; 56% made one call only, 19% made two calls, and 25% made 3–18 calls.

Sixty-two unique symptoms were reported for the total sample. Symptoms reported for at least 10% of the sample included pain (38%), fatigue (16%), nausea (16%), swelling (12%), diarrhea (12%), dyspnea (10%), and anorexia (10%). Pain was reported by 214 different individuals (38%). In addition, 31% of individuals calling with pain reported pain more than once (2–8 reports) during the four-month interval. As displayed in Table 2, in addition to pain, other complaints commonly identified as painful were reported, including headache, myalgia, muscle spasms, dysphagia, mucositis, and esophagitis.

Tables 3 and 4 include additional details for symptoms reported by at least 5% of the sample. Also included are the number of individuals who reported the same

symptom more than once, and the range of times the symptom was reported for any individual. For example, the symptoms most likely to generate repeated telephone calls from the same individual were pain, neuropathies, nausea, and anxiety. Symptom reporting also was examined by diagnostic category as displayed in Figure 1. Six of the eight diagnostic groups reported pain most often. Variation in symptom report was noted among diagnostic groups, and differences in call volume also were present.

Discussion

Examination of naturally occurring patient initiated telephone calls provided a unique opportunity to expand the knowledge base on symptoms experienced by patients with cancer. The design provided the opportunity to examine spontaneous symptom reporting not primed by a closed-ended symptom checklist measure. Examination of symptom reporting by telephone for individuals with cancer revealed information on what symptoms motivated people to seek help.

Pain was the most frequent symptom; however, evidence of a wide range in the symptoms also were reported. Additional details emerged on how symptoms were reported by individuals, over time and in a single telephone encounter. For a subset of patients, a pattern emerged of calling only once and reporting only a solitary symptom.

A striking finding of this study was that pain emerged as the primary symptom that prompted a phone call. More than twice the number of individuals reported pain compared to any other symptom. Pain was the most frequently reported symptom by cancer diagnosis for six of eight groups (breast, thoracic, GI, GU, rare tumor types, and hematology) and, for the remaining two diagnostic groups (lymphoma, brain), pain ranked as the second and fifth most frequently reported symptom, respectively. Pain also was the symptom most likely to be reported more than once during the four-month interval. Examining this finding in light of the limited published

reports, the frequency of pain reported is consistent with past findings, but even more prevalent. Reid and Porter (2011) reported that 19% of total calls included a report of pain, the most common symptom after feeling unwell. The finding on pain prevalence in that study was particularly interesting because study participants received written direction to call for a range of symptoms; however, pain was not specified. Alterations in comfort were reported in 32% of telephone calls for medical oncology patients (Nail et al., 1989). In a study

Table 4. Reported Symptoms by Cancer Diagnosis

Diagnosis	n	\bar{X}	SD	Range	Maximum Calls With Symptoms	Unique Symptoms Reported
Brain	24	9.83	11.4	1–49	17	42
Breast	153	4.54	5.4	1–42	18	58
Gastrointestinal	94	4.3	4.34	1–25	12	48
Genitourinary	46	3.72	4.66	1–27	11	47
Hematology	90	2.86	2.59	1–13	8	49
Lymphoma	81	3.64	3.46	1–21	13	43
Rare tumor	19	3.26	2.33	1–8	5	25
Thoracic	56	4.6	3.73	1–19	9	44



Figure 1. Top Five Most Commonly Reported Symptoms by Cancer Diagnosis Group

comparing symptom response to an open-ended question followed by completion of a symptom checklist, pain was more likely to be volunteered than any other symptom, and was reported more than twice as often as any other symptom (Homsí et al., 2006). This finding also is congruent with qualitative work in which individuals with lung cancer identify pain as the most important symptom (Tishelman et al., 2000).

The frequent report of pain can be reviewed as good and bad news—good news that individuals are calling when pain is not relieved, bad news that pain is not being relieved. For example, patients may experience new or worsening pain prior to scheduled visits and calling to report that pain is good news. Although researchers and clinicians have been focused on the experience of cancer pain for more than three decades, these findings indicate that cancer pain remains a priority and frequently unrelieved symptom. Pain also has been identified as a commonly occurring symptom when research is conducted with symptom inventories, although not the most prevalent. The emergence of pain as by far the most frequently called-about symptom in a naturally occurring data set reinforces the widely held belief that pain is a sentinel symptom and, when present, it may be a priority and be associated with an increased symptom profile and worse experience and outcomes (Barsevick et al., 2006). Pain was deemed as important enough to prompt action to pick up the telephone and spontaneously report to healthcare providers, possibly indicating that the symptom of pain is a naturally occurring priority.

Although pain was clearly the most frequently reported symptom, a wide range of symptoms also was reported, indicative of the complexity of the symptom experience for individuals with cancer. All 45 of the symptoms listed in the *Oncology Nursing Society Telephone Triage Manual* (Hickey & Newton, 2005) were reported during the four-month interval, although some by only

a few individuals. Symptom prevalence reported via telephone did vary by cancer diagnostic category. This finding is consistent with past research that has identified different symptom profiles specific to primary cancer diagnosis.

One intriguing pattern of symptom report by telephone was found. The modal response was to call only one time and to report only one symptom (55%). This finding is similar to that reported by Reid and Porter (2011), who noted that 50% of telephone calls contained only one symptom. The majority of individuals reporting only a solitary symptom also are consistent with past researchers who have demonstrated that, when a general question is asked, a patient is most likely to report a single symptom and, when given a symptom checklist, more symptoms will be reported (Barsevick, 2007; Homsí et al., 2006). Results across studies indicated that patients tend to spontaneously report a single symptom, which suggests that patients focus on a single symptom as most important or disruptive. This raises some interesting questions about the nature of the symptom experience from the patient perspective. Individuals may experience a single symptom as most disruptive and, therefore, most important for reporting and a priority for seeking relief.

Although a modal pattern of reporting a solitary symptom occurred, symptom reporting behaviors varied. For example, a very wide range (1–49) occurred in the total number of symptoms that were reported for any one individual during the four-month interval. Similarly, a wide range of telephone calls (1–18) occurred during the four-month interval to report symptoms. Finally, in any individual telephone call, a range of 1–8 symptoms was reported. The amount of time data were collected influenced the results; a longer time period would have captured wider ranges. This finding is similar to that reported by Reid and Porter (2011) and Homsí (2006) who noted a range of 1–6 symptoms reported.

One intriguing explanation for the variation in pattern of symptom reporting is that individuals with cancer fall into two groups: those that report a single symptom and those that have more variable symptom reporting behaviors. If so, the two groups of individuals may require different interventions. Individuals focused on reporting a single symptom may benefit from an intervention tailored to their prioritized concern. Individuals reporting a single symptom also were experiencing other symptoms, and this design could not capture that phenomenon. However, these individuals may only attend to one symptom or priority at a time and interventions need to be consistent with this patient-centered frame of the cancer symptom experience. For those who focus on a solitary symptom, the standard approach of symptom checklists may not correspond to the patient's orientation to symptom relief and may not be a helpful approach. When presented with a symptom inventory, individuals will report multiple symptoms; however, the authors do not know if the checklist may in some cases effect an individual conceptualization of symptoms by priming a specific cognitive response.

Limitations

The study has certain limitations. First of all, an existing data set was used that did not include telephone calls placed after hours to on-call personnel, and was dependent on documented information that may not have included all symptom-related content of the telephone calls. In addition, it was conducted at a single site and, therefore, results may not be generalized to settings with different practice patterns. The sampling strategy included all patients from the cancer center practice with variability in stage of disease, treatment status, and prognosis. Although the variability in the sample could be either a benefit or a limitation, it does provide one explanation for the range of symptoms reported and the variance in symptom reporting patterns. In addition, some variables important to the symptom experience, such as stage of disease and treatment status, were not collected. Importantly, the data set did not include any information on the symptom experience of people who did not call.

Implications for Practice

The use of existing data documented on telephone calls can provide patient-centered insight into the prevalence and pattern of symptom reporting specific to an oncology setting. These results on the symptom experience can be of assistance in any ambulatory oncology setting for quality improvement initiatives. Awareness of the specific symptoms that are spontaneously reported in a practice can be used to analyze

what information is provided during visits and what instructions individuals with cancer are given for contacting the cancer center in between visits. Identification of practice implications from this study are most appropriate for the specific setting in which it was conducted. In this study's cancer center, the emergence of pain as the primary symptom reported by telephone prompted educational efforts for both in-person clinic visit management of pain and prioritizing nursing education and protocol management of pain reported by telephone.

Future Research

Although extensive research has been conducted on the oncology symptom experience, many aspects require additional study. One specific gap is the knowledge of patient-identified priority in the symptom experience. Telephone reporting of symptoms provides a unique opportunity to consider patient-identified priority in the symptom experience. Continued examination of factors that influence symptom reporting is warranted because the reasons individuals with cancer choose to call or not call to report a symptom are not known. Individuals may choose to report a symptom because they were specifically instructed to report the symptom, because they find the symptom distressing or unmanageable, because they believe an intervention could help relieve the symptom, or because recommendations were not made for symptom relief when they were at their scheduled visit. Patient-centered care begins with an understanding of the symptom experience from the patient's perspective. The preponderance of pain as the primary symptom reported in telephone calls provides evidence of the priority of pain from a patient perspective. The intriguing finding of telephoning to report a solitary symptom versus a cluster of symptom complaints warrants additional investigation as researchers seek to understand the symptom experience from patient experiences and priorities.

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Marie Flannery, RN, PhD, AOCN[®], is an assistant professor in the School of Nursing and James P. Wilmot Cancer Center at the University of Rochester; and Leanne McAndrews, LMSW, is a doctoral student, and Karen F. Stein, RN, PhD, FAAN, is the Brody Endowed Chair and Professor, both in the School of Nursing at the University of Rochester; all in New York. Support for this research was provided through a University of Rochester School of Nursing Faculty Research Support Grant. Flannery can be reached at marie_flannery@urmc.rochester.edu, with copy to editor at ONFEditor@ons.org. (Submitted October 2012. Accepted for publication January 8, 2013.)

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