# Patient Use of Electronic Methods to Self-Report Symptoms: An Integrative Literature Review

Sharyn Carrasco, RN, MSN, and Lene Symes, PhD, RN

PROBLEM IDENTIFICATION: Clinicians are unaware of most of their patients' symptoms. Symptoms may be poorly documented and their impact underestimated. Undertreatment of symptoms may lead to increased symptom distress and decreased quality of life. Improving the communication of symptoms to nurses is vital in symptom management and quality-of-life improvement. Electronic patient self-report of symptoms may be beneficial.

LITERATURE SEARCH: An integrative review of the literature was conducted to describe the use of electronic methods for symptom self-report by patients with cancer and to inform best practices.

**DATA EVALUATION:** The final sample for this integrative review consisted of 36 studies (32 quantitative and 4 qualitative).

SYNTHESIS: Data analysis was used to summarize the findings of the 36 studies. Patients with cancer found electronic self-report of symptoms to be feasible and the devices usable. Electronic symptom reporting may improve patient-clinician communication, leading to improved physical and psychosocial outcomes.

IMPLICATIONS FOR PRACTICE: In the studies that included an interactive communication component, oncology nurses were central in receiving, reviewing, and reporting changes to the provider. Patients expressed themselves more when consulting with nurses than with physicians.

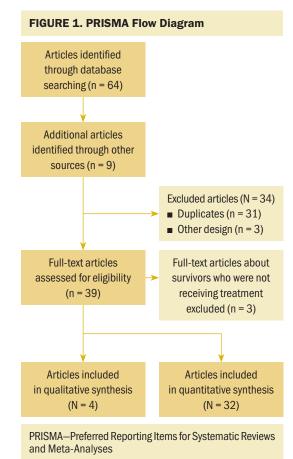
**KEYWORDS** electronic self-report; patient selfreport; patient-reported symptoms; integrative review *ONF*, *45*(3), 399-416. **DOI** 10.1188/18.ONF.399-416

atients with cancer experience acute and chronic symptoms caused by their disease and its treatment (Portenoy et al., 1994). However, clinicians are often unaware of patients' symptoms (Bruera, Sweeney, Calder, Palmer, & Benisch-Tolley, 2001; Butow, Brown, Cogar, Tattersall, & Dunn, 2002; Chang, Hwang, Feueurman, & Kasimis, 2000; Newell, Sanson-Fisher, Girgis, & Bonaventura, 1998) and fail to recognize 50%-80% of these symptoms (Epstein & Street, 2007; Farrell, Beaver, Heaven, & Maguire, 2001; Ryan et al., 2005). Even when symptoms are recognized, they may be underdocumented and undertreated, with their impact underestimated (McIntyre, 2015). Discordance exists between clinicians' findings during assessment and patients' reported symptoms (Basch et al., 2006; Petersen, Larsen, Pedersen, Sonne, & Groenvold, 2006), which leads to unmanaged symptoms. Inadequate management of treatment-related toxicities may increase symptom distress and negatively affect quality of life (Cella, 1997; Lee, 2008). Worsening symptoms may lead to emergency department visits and have a negative impact on patient outcomes, including survival (Barbera et al., 2013; Efficace et al., 2012). A vast array of instruments is being used to capture and measure symptoms, as well as to examine the complexity of caring for patients and treating and managing their symptoms (Basch et al., 2007; Berry et al., 2014; Blum et al., 2014; Cella et al., 2014; Fromme, Eilers, Mori, Hsieh, & Beer, 2004).

Reporting the prevalence, severity, and impact of symptoms is essential in oncology symptom management (White, McMullan, & Doyle, 2009). Reilly et al. (2013) concluded that any clinical study evaluating the impact of treatment on patients should consider including patient self-reporting of symptoms, which is also referred to as patient-reported outcomes.

The U.S. Food and Drug Administration and the National Cancer Institute have stated that a patient's own description of symptoms should be considered as the accepted benchmark (Dueck & Sloan, 2007). Increasing interest surrounds the use of electronic methods for patients to self-report their symptoms (Johansen, Henriksen, Berntsen, & Horsch, 2011).

Since the American Recovery and Reinvestment Act of 2009, which allocated significant funding to the implementation of electronic health records (EHRs), their use has spread widely. The integration of an electronic version of a validated symptom assessment into the EHR can enhance oncology practices and permit real-time patient assessment and management. Evidence supports the idea that the routine collection of patient symptoms, including the provision of timely feedback, enhances patient-clinician communication (Chen, Ou, & Hollis, 2013). The collection of patients' self-reported symptoms via electronic symptom assessment measures has been shown to be equivalent to paper-and-pencil measures (Gwaltney, Shields, & Shiffman, 2008). However, electronic assessment may offer other benefits. Bennett, Jensen, and Basch (2012) reviewed five electronic assessment systems commonly used in oncology,



finding that they support clinical activities, including symptom and toxicity assessment and symptom management. Because of growing interest in the electronic collection of symptoms, the number of studies about patients with cancer reporting their symptoms electronically has also increased. The purpose of this integrative review is to inform best practice by evaluating and synthesizing findings from studies about patients with cancer using an electronic method to self-report their symptoms.

# Methods

An integrative review (Whittemore & Knafl, 2005) framework was followed. This method allows for the exploration of quantitative, qualitative, and mixedmethod designs within one review, and it supports a comprehensive review of research. The sampling frame for this literature review consisted of research articles published in peer-reviewed journals from 2006–2016.

# Search Strategy

PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines were followed for this review (Moher, Liberati, Tetzlaff, & Altman, 2009) (see Figure 1). The first author of this article conducted a systematic literature search to identify studies in the PubMed, CINAHL<sup>®</sup>, and EMBASE electronic databases. Bibliographic searching was also performed. The search terms were unique to each database.

- PubMed search terms were self reported patient AND neoplasm.
- CINAHL search terms were self report AND symptoms AND cancer patients.
- EMBASE search terms were self report OR self evaluation AND neoplasm AND patient.
- The term *electronic* was added to the search in titles or abstracts. Filters were *adult*, *past 10 years*, and *English language*.

# Inclusion and Exclusion Criteria

Eligibility criteria included articles that described studies of adult patients who had access to a telephone or cell phone, were aged 18 years or older, had various types and stages of cancer, and were actively receiving treatment that included chemotherapy. The search was limited to studies reported in English. Literature reviews, articles unrelated to the oncology setting, pediatric studies, studies of cancer survivorship (related to long-term symptoms), and studies that focused only on a specific drug were excluded because their scope was too narrow for the purpose of this literature review.

The search resulted in 64 articles retrieved from the databases and 9 articles identified by hand search. Of these, 31 articles were duplicates and were removed. An additional three articles were removed after further review of the title and abstract because two articles described a methodologic design and one was a self-report of adherence; all three were determined to be irrelevant. The full text of the remaining 39 articles was reviewed, and another 3 articles were removed because 2 were about methodologic design and 1 concerned cancer survivors who were not actively receiving treatment. The final sample consisted of 36 empirical reports: 32 quantitative and 4 qualitative.

### **Data Evaluation**

The strength of evidence among the studies varied and consisted of levels II, III, and VI based on the Melnyk levels of evidence (Melnyk & Fineout-Overholt, 2011).

- Level II is a well-designed randomized, controlled trial.
- Level III is a well-designed nonrandomized, controlled trial or quasiexperimental trial.
- Level VI is a single descriptive or qualitative study. After the selection of the studies, the identified articles were again checked for inclusion criteria. All studies meeting the inclusion criteria were retained.

#### **Data Analysis**

The primary data analysis was conducted by the first author as part of the dissertation process and was guided by the method described by Whittemore and Knafl (2005). This method consists of data reduction, display, comparison, conclusion drawing, and verification. The data from the original sources were reviewed thoroughly, and the first author extracted data with consultation and collaboration provided by the second author. The extracted data were coded and then compared; similar data were categorized and grouped.

# Results

# **General Characteristics**

The data extracted from the reviewed studies are displayed in a methodologic matrix (see Table 1). The researchers also evaluated different devices and electronic software applications used in the studies. Of the 36 studies, access to the electronic software applications was available to the patients either in the clinic (14 studies) or remotely (16 studies). Six studies allowed remote and clinic access. In addition, as reported by Basch et al. (2007), 76% of patients had computers in their homes, but only 15% self-reported from home.

Nineteen of the 32 quantitative studies examined in this review were published from 2011–2016. In addition, 19 of these studies were conducted outside of the United States, with 16 of them performed in Europe. The studies looked at the acceptability or feasibility of electronically capturing patients' self-report of symptoms, as well as the impact on communication between the patient and the healthcare provider and/ or the patient's psychosocial well-being.

The methodologic matrix of the primary source data was closely examined to identify themes. A critical analysis of the data in the matrix was conducted. Similar themes were categorized and grouped. For accuracy, the themes were verified by returning to the primary source and reconfirming the findings.

# Acceptability, Feasibility, and Usability of Electronic Collection of Symptoms

Fourteen studies considered the patients' and/or clinicians' perspectives. Acceptability and feasibility of electronic assessment of symptoms directly by the patients was the focus of nine studies.

**Symptoms Tracking and Reporting for Patients:** Electronic patient self-reporting was shown to be feasible by Basch et al. (2007) and Andikyan et al. (2012) using the Symptoms Tracking and Reporting for Patients (STAR), an online platform that contained five items from the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire–Core 30 (EORTC QLQ-C30) and the patient adaptation of the National Cancer Institute's Common Terminology Criteria for Adverse Events. STAR also triggered alerts for grade 3 and 4 toxicities. Most of the patients from both studies found STAR to be useful and said they would recommend it to other patients (Andikyan et al., 2012; Basch et al., 2007).

**Electronic Self Report Assessment–Cancer:** Studies by Chan et al. (2011) and Wolpin et al. (2008) used the Electronic Self Report Assessment–Cancer (ESRA-C), which is made up of the following four measures: the EORTC QLQ-C30, the 13-item Symptom Distress Scale, the single-item Pain Intensity Numerical Scale, and the 9-item Patient Health Questionnaire–Depression. Moderate to high acceptability was reported for the ESRA-C (Chan et al., 2011; Wolpin et al., 2008). Women reported higher acceptability scoress than men (p = 0.026), as did participants aged younger than 60 years compared to those aged older than 60 years (p = 0.048) (Wolpin et al., 2008).

TABLE 1 Deview of Literature About Electronic Methods for Symptom Solf Depart Categoria	od by Thoma
TABLE 1. Review of Literature About Electronic Methods for Symptom Self-Report, Categoriz	led by Theme

Study and Location	Purpose	Level of Evidence and Design	Electronic Tool	Major Findings		
Acceptable of	Acceptable or feasible					
Abernethy et al., 2008 (United States)	To determine if wireless tablet computers are feasible, acceptable, and valid for col- lecting research-quality data in academic oncology	<ul> <li>VI; pilot, single-arm trial of 66 outpatients with breast cancer</li> <li>FACT-B; FACT-G; FACIT; MDASI; self-efficacy</li> </ul>	Wireless tablet computer; clinic access	Wireless tablet computers offer a valid, feasible, and acceptable method for collecting research and quality PROs data in outpatient academic oncology.		
Andikyan et al., 2012 (United States)	To evaluate the feasibility of capturing PROs electronically and to identify the common distressing symptoms	<ul> <li>VI; prospective, single-arm pilot study of 49 patients with gynecologic cancer recovering from surgery</li> <li>Patient adaptation of the CTCAE, version 3.0; EORTC QLQ-C30, version 3.0</li> </ul>	Web-based STAR question- naire; remote access	Generated 43 alerts that resulted in 25 telephone contacts with patients, 2 emergency department referrals, 1 new appointment, and 1 pharmaceutical prescription; 80% of patients found STAR useful, and 85% would recommend it to others.		
Basch et al., 2007 (United States)	To assess willingness and ability of patients to self- report their symptoms	<ul> <li>VI; single-arm feasibility study of 107 outpatients with lung cancer receiving chemotherapy</li> <li>Patient adaptation of the CTCAE symptom items</li> </ul>	STAR online portal; clinic access with optional remote access	For consecutive visits, adherence was high, with an average of 78% of patients logging in. Reasons for failure to log in included having no reminder and having inadequate time. Satisfaction with the system was high (90%), but only 51% felt communication was improved.		
Blum et al., 2014 (Switzerland)	To examine the feasibility and acceptance of electronic monitoring of symptoms and syndromes using a PALM (handheld computer)	<ul> <li>VI; pilot phase (paper-based) was performed at a single insti- tution with 22 patients; single-arm feasibility study involved 62 patients; patients had advanced cancer and were located at four Swiss oncologic outpatient clinics.</li> </ul>	PALM; E-MOSAIC software; clinic access	The median time to complete the PALM-based assessment was 3 minutes. 49% of patients preferred the PALM, 23% preferred a paper version, and 28% had no preference. Paper versus PALM revealed no significant differences in symptoms, except nutritional (p = 0.013).		
Chan et al., 2011 (China)	To assess the feasibility and acceptability of using an elec- tronic self-report symptom assessment tool	<ul> <li>VI; single-arm, mixed-methods study of a convenience sample of 30 adult Chinese ambula- tory patients with cancer; the qualitative part was a major component of the study.</li> </ul>	ESRA-C appli- cation; clinic access	Moderately high acceptability in each subscale; participants took 17.5 minutes (SD = 8.9) to complete the ESRA-C. Qualitative interview data revealed that 25 participants found the ESRA-C to be useful and effective.		
Falchook et al., 2016 (United States)	To evaluate the feasibility of monitoring patient-reported symptoms via mobile devices	<ul> <li>VI; single-arm study of 22 patients with head and neck cancer receiving radiation ther- apy at a single institution</li> </ul>	Mobile device application using questions adapted from a validated instru- ment; remote access	Median reporting compliance was 71%, which did not meet the prespecified definition of feasibil- ity (80%). Patients reported high satisfaction with reporting their symptoms using the application on their mobile device.		

Continued on the next page

# TABLE 1. Review of Literature About Electronic Methods for Symptom Self-Report, Categorized by Theme (Continued)

Study and Location	Purpose	Level of Evidence and Design	Electronic Tool	Major Findings
Acceptable or	feasible (continued)			
Wintner et al., 2015 (Austria)	To evaluate the feasibility of electronic and web-based PRO assessment (clinic-ePRO and home-ePRO)	<ul> <li>VI; single-arm study of 168 patients from two institutions (clinic-ePRO, n = 113; home- ePRO, n = 55)</li> </ul>	Tablet computer with electronic version of EORTC QLQ-C30; remote and clinic access	Most patients indicated that reporting PROs is useful and that the method was adequate to report QOL; the majority did not experience problems and were satisfied.
Wolpin et al., 2008 (United States)	To explore the acceptability of asking symptom and QOL questions	<ul> <li>II; RCT with 342 patients who completed follow-up survey (45% medical oncology, 35% stem cell transplantation, 20% radiation oncology)</li> <li>ESRA-C at time 1 and time 2</li> </ul>	ESRA-C; clinic access	Patients were generally able to use the ESRA-C quickly and without difficulty in a real-world clinical setting; they were, overall, satisfied with the ESRA-C program. Significant differences were found in several acceptability areas in terms of demo- graphics and QOL measures.
Wu et al., 2016 (United States)	To evaluate the usability of PatientViewpoint	<ul> <li>VI; qualitative study of 42 pa- tients with breast and prostate cancer and their 12 clinicians; substudy of an RCT</li> </ul>	PatientViewpoint webtool; remote access	Patients primarily provided positive comments. A few clinicians were slow to adopt, but once engaged, all reported that it could be helpful. Cli- nicians preferred graphs over tables.
Usable or use	ful			
Head et al., 2009 (United States)	To use current best prac- tices for self-monitoring of symptoms	<ul> <li>II; RCT of 75 patients newly diagnosed with and undergoing treatment for head and neck cancer</li> <li>Compared telehealth inter- vention to a standard-of-care control condition</li> </ul>	Health Buddy; remote access	98% reported they had no problems setting up the device, and 86% reported it took 10 minutes or less to set up in their home. 85% said the device was very easy to use; 15% said it was easy to use. 65% reported being more satisfied with communi- cation with their doctor or nurse.
Mirkovic et al., 2014 (Norway)	To evaluate the usability of the Connect mobile appli- cation	<ul> <li>VI; mixed-methods, quantitative/qualitative study using semistructured interviews of 7 patients with cancer from a rural municipality in the north- ern part of Norway</li> </ul>	Connect mobile application; mobile access to the Connect system (formerly WebChoice); remote access	Average subjective usability ratings from the System Usability Scale ques- tionnaire were $71.25$ (SD = $14.8$ ) for the mobile phone application and 72.5 (SD = $15.3$ ) for the tablet appli- cation. Two themes emerged: mobile application user friendliness and usefulness of the Connect system.
Ruland, 2006 (Norway)	To evaluate clinicians' perceived usefulness of the CHOICE system	<ul> <li>VI; quantitative study guided by Roger's framework of 65 nurses and 12 physicians who had used CHOICE (N = 77)</li> </ul>	CHOICE; clinic access	Clinicians used information outputs from the CHOICE system about 50% of the time; nurses used them more. The system received high ratings on all aspects of usefulness by both groups. A strong, significant correla- tion was observed between patterns of use and perceived usefulness.

Continued on the next page

TABLE 1. Review of Literature About Electronic Methods for Symptom Self-Report, Categorized by Theme (Continued)

Study and Location	Purpose	Level of Evidence and Design	Electronic Tool	Major Findings
Use				
Ruland, Maffei, et al., 2013 (Norway)	To describe patients' use of a multicomponent eHealth application	<ul> <li>VI; qualitative study of 162 patients with breast and pros- tate cancer in the experimental group who had access to WebChoice</li> </ul>	WebChoice; remote access	103 patients (64%) actively used WebChoice (60 times on average). Used most were the following components: discussion forum and messages to the nurse. Communica- tion with the nurses was valued most.
Varsi et al., 2013 (Norway)	To investigate patients' views of an IPPC	<ul> <li>VI; qualitative study of 22 patients undergoing liver transplantation or autologous stem cell transplantation or having been diagnosed with testicular cancer or advanced cancer</li> <li>Part of a larger study to examine implementation of the WebChoice IPPC module</li> </ul>	WebChoice IPPC; remote access	Patients appreciated the availability and the possibility of using the IPPC, even if they did not use it. Reasons for not using the IPPC included the following: sufficient access to infor- mation, preference for other types of communication, and various hindrances (e.g., login issues).
Communicati	on: Symptom reporting, docu	mentation, or management		
Berry et al., 2011 (United States)	To determine likelihood of SQLIs being discussed between clinicians and patients	<ul> <li>II; RCT of patients with various cancer diagnoses and stages at 2 institutions; graphical summary (n = 327) versus control group without summary (n = 333)</li> </ul>	ESRA-C graph- ical summary; clinic access	When clinicians were provided with summary reports of patients' QOL and self-reported cancer symptoms, a positive impact was noted on patient- clinician communication. Clinic visits were similar in regard to duration.
Bock et al., 2012 (United States)	To investigate symptom reporting, physician docu- mentation of symptoms, and symptom management	<ul> <li>VI; single-arm questionnaire of 106 patients with breast cancer, stages I–III</li> </ul>	Secure online health ques- tionnaire; ISS software; remote and clinic access	Patients reported more symptoms using the online questionnaire (aver- age of 3.8) than were documented by the provider in clinic notes (average of 1.8). In 25% of charts where alco- hol consumption was noted, there was discordance between patient and clinician reporting.
Cleeland et al., 2011 (United States)	To examine more effective postoperative symptom control	<ul> <li>II; RCT of 100 patients receiving thoracotomy for lung cancer or lung metastasis</li> <li>An email alert was sent to the patient's clinical team; in the control group, no email alerts were generated.</li> </ul>	Automated telephone calls; remote access	The intervention group experienced greater reduction in symptom threshold events than did controls (19% versus 8%, respectively). A more rapid decline in symptom threshold events was also observed (p = 0.02).
Ekstedt et al., 2014 (Norway)	To explore the continuity of care and safety of patients with breast cancer	<ul> <li>VI; qualitative study of patients with breast cancer in their first year postdiagnosis</li> <li>Patients were part of a three-arm RCT (n = 325), with 200 random- ized to the WebChoice arm.</li> </ul>	OPNC part of WebChoice; remote access	The OPNC enabled quality assurance of information and coor- dination of care.
				Continued on the next page

Study and Location	Purpose	Level of Evidence and Design	Electronic Tool	Major Findings
Communicatio	on: Symptom reporting, docur	mentation, or management (cont	inued)	
Grimsbø et al., 2011 (Norway)	To explore patients' experi- ences of living with cancer as expressed through messages	<ul> <li>VI; qualitative content analysis of 276 messages by 60 pa- tients with breast and prostate cancer; part of an RCT (n = 325) testing WebChoice</li> </ul>	OPNC part of WebChoice; remote access	Themes emerged from patients' messages to the oncology nurses: living with symptoms and side effects, living with a fear of relapse, concerns for everyday life, and unmet information needs from healthcare providers.
Grimsbø, Ruland, & Finset, 2012 (Norway)	To investigate emotional cues and concerns of patients with cancer and how nurses responded to them	<ul> <li>VI; substudy of an RCT (n = 325) testing WebChoice; 283 electronic messages (n = 60; 38 patients with breast cancer and 22 patients with prostate cancer made up the experi- mental group and had access to WebChoice from their homes for 1 year) and 286 electronic responses (5 oncology nurses)</li> </ul>	OPNC part of WebChoice; remote access	Identified 102 cues and 33 con- cerns; expression of uncertainty or hope occurred in 39% of messages, followed by expressions of an unpleasant emotion that is clearly verbalized in 24% of messages. Nurses responded to 85% of patients' cues and concerns, and more than half of these were met witt a combination of providing informa- tion and expressing empathy.
Heyn et al., 2012 (Norway)	To test the number and type of cues and emotional con- cerns expressed by patients with cancer	<ul> <li>III; quasiexperimental design with convenience sample of 196 adult patients at 2 hospi- tals and 2 outpatient clinics</li> </ul>	CHOICE ITPA; clinic access	Identified 473 cues and 109 con- cerns, with an average of 3 (SD = $3.2$ ). The most frequent utterance (45%) was indicating expression of uncertainty or hope. More cues and concerns were noted in consulta- tions with the intervention group than the control group (p < 0.01) and with nurses than physicians (p < 0.001).
Heyn, Finset, Eide, & Ruland, 2013 (Norway)	To test patients' and clinicians' communication behaviors	<ul> <li>III; quasiexperimental design with convenience sample of 193 adult patients at 2 hospi- tals and 2 outpatient clinics</li> </ul>	CHOICE ITPA; clinic access	In the intervention group, sig- nificantly more symptoms were addressed, more questions were asked, and clinicians provided more information.
Heyn, Finset, & Ruland, 2013 (Norway)	To examine communication of emotional cues and concerns in terms of source of initiation, explicitness, and timing	<ul> <li>III; quasiexperimental design with convenience sample of 196 adult patients at 2 hospi- tals and 2 outpatient clinics</li> </ul>	CHOICE ITPA; clinic access	Significantly more frequent and more explicit expression of cues and concerns occurred in the CHOICE intervention group.
Kearney et al., 2009 (United Kingdom)	To provide a more accurate reflection of chemotherapy- related toxicity	<ul> <li>II; RCT with 112 patients with breast, lung, or colorectal cancer receiving outpatient chemotherapy</li> </ul>	Mobile telephone- based ASyMS; remote access	Higher reports of fatigue were observed in the control group than the intervention group. Hand-foot syndrome, on average, was reported less in the control group.
				less in the control group. Continued on the next p

# TABLE 1. Review of Literature About Electronic Methods for Symptom Self-Report, Categorized by Theme (Continued)

Study and Location	Purpose	Level of Evidence and Design	Electronic Tool	Major Findings
Communicatio	on: Symptom reporting, docur	mentation, or management (cont	inued)	
Kennedy Sheldon et al., 2011 (United States)	To explore healthcare provider cue-responding behaviors to patient cues of distress and socioemotional concerns	<ul> <li>VI; descriptive secondary analysis of a data set of audio recordings of oncology visits and reports of symptoms and QOL, with 31 randomly selected cases from a set of 590 audio recordings</li> </ul>	ESRA-C; clinic access	Providers acknowledged 57% of patient cues, exploring only 22% of all patient cues. The overall score for responsiveness to patient cues of distress was higher (more responsiveness) when providers had the printed ESRA-C summary report for use during patient visits.
LeBlanc et al., 2015 (United States)	To determine the most fre- quently reported symptoms and whether symptoms differ with proximity to death or with cancer anorexia-cachexia syndrome status	<ul> <li>VI; single-arm, longitudinal study of 99 patients with advanced non-small cell lung cancer</li> </ul>	Patient Care Monitor, version 2.0; clinic access	Functional concerns predominated, and the report of significant func- tional symptoms throughout, as well as the type and severity of symp- toms, varied by proximity to death. The most prevalent nonfunctional symptoms were severe dyspnea (29%) and fatigue (more than 50%).
Wagner et al., 2015 (United States)	To assess cancer-related symptoms with EHR integration, which enables communication of assess- ment results to the clinical team in real time	<ul> <li>VI; single-arm study with 636 patients, most of whom had ovarian (35%), uterine (28%), or cervical (7%) malignancies</li> <li>Patients completed clinical assessments through the Epic MyChart portal.</li> </ul>	PROMIS CATs; ePRO assessment that included PROMIS CATs and checklists; remote access	Mean T scores indicated a lower level of physical functioning and higher anxiety compared to the gen- eral population. Physical functioning impairment caused the most clinical alerts (4%).
Psychosocial	impact			
Basch et al., 2016 (United States)	To test whether systematic web-based collection of patient-reported symptoms during chemotherapy treat- ment improved health-related QOL	<ul> <li>II; nonblinded RCT with 766 patients with metastatic cancer (539 computer-experienced patients who were randomized 1:1 and 227 computer- inexperienced patients who were randomized 2:1 to web- based reporting of symptoms versus usual care)</li> </ul>	STAR, which included ques- tions adapted from CTCAE; remote and clinic access	Health-related QOL scores improved from baseline to 6 months (34% STAR versus 18% usual care) and worsened in the STAR arm (38% versus 53%). Improvement in health-related QOL was higher in the STAR arm (21% versus 11%). Mobil- ity (p = 0.02), self-care (p = 0.01), and anxiety/depression (p = 0.01) were all better with STAR compared to usual care.
Berry et al., 2014 (United States)	To determine the effect of a patient education and coaching intervention added to a self-report assessment with clinician summary on symptom/QOL outcomes	<ul> <li>II; RCT with 779 patients with a diagnosis of cancer in ambulatory care</li> <li>ESRA-C for self-report</li> </ul>	ESRA-C; remote and clinic access (patients self-identified as remote or clinic users)	A difference in distress was noted from baseline to the end of the study: 1.27 (SD = 6.7) in the control group (higher distress) versus 0.04 (SD = 5.8) in the intervention group (lower distress). Symptom Distress Scale-15 score was reduced (p = 0.02) in the intervention group.

Continued on the next page

Study and Location	Purpose	Level of Evidence and Design	Electronic Tool	Major Findings
Psychosocial	impact (continued)			
Berry et al., 2015 (United States)	To evaluate symptom distress	<ul> <li>II; RCT with 779 patients with a diagnosis of cancer in ambulatory care</li> <li>ESRA-C for self-report</li> </ul>	ESRA-C; remote and clinic access	The symptom distress score was reduced by an estimated 1.53 points (p = 0.01) in the interven- tion group versus the control group.
Børøsund et al., 2014 (Norway)	To compare an IPPC and WebChoice with usual care	<ul> <li>II; RCT with three groups (WebChoice group, WebChoice with IPPC group, usual care group); patients were recently diagnosed with breast cancer and were undergoing treatment (N = 167).</li> </ul>	WebChoice; WebChoice with IPPC included; remote access	The WebChoice group reported significantly lower symptom distress $(p = 0.001)$ , anxiety $(p = 0.03)$ , and depression $(p = 0.03)$ than the usual care group. The IPPC group reported significantly lower depression scores than the control group $(p = 0.03)$ .
Boyes et al., 2006 (Australia)	To examine the effectiveness of giving medical oncologists immediate feedback about the psychosocial well-being of patients with cancer	<ul> <li>III; pilot study of 80 patients with cancer attending one cancer center for their first visit; patients were alternately allocated to the intervention (psychosocial well-being summary reports were placed in the patient's chart) or the control group (usual care).</li> </ul>	Touchscreen computerized survey assessing psychosocial well-being; clinic access	Intervention group participants who reported a debilitating physical symptom at their second visit were significantly less likely to report a debilitating physical symptom at their third visit versus control group participants (p = 0.04).
Grimsbø, Engelsrud, Ruland, & Finset, 2012 (Norway)	To explore perspectives and experiences of patients with cancer	<ul> <li>VI; qualitative interviews were conducted with 10 infrequent (n = 2), medium (n = 5), and frequent (n = 3) IHCA users (6 women and 4 men with breast and prostate cancer)</li> </ul>	WebChoice; remote access	Patients expressed their experiences with WebChoice in various ways, depending on if they found it to be useful. Some described WebChoice as a friend, whereas others described it as a stranger. Some felt ambivalent, and some felt calmed down.
Hong et al., 2013 (United States)	To report and interpret health-related QOL change as measured by the EORTC QLQ- C30 and to determine the minimal clinically important difference	<ul> <li>II; 627 patients with any type of cancer who had started a new medical, radiation, or stem cell transplantation treatment, who were enrolled in the ESRA-C study, and who completed the EORTC QLQ-C30 at time 1 and time 2</li> </ul>	Electronic versions of the EORTC QLQ-C30; clinic access	Changes were found in QOL during treatment, with more than half of the patients undergoing stem cell transplantation reporting deteriorat- ing QOL. Among patients undergoing medical or radiation treatment, equal proportions perceived improvement (25%) and deterioration (26%).
Ruland et al., 2010 (Norway)	To examine symptom distress and patients' need for symp- tom management support	<ul> <li>II; RCT with an intervention group (ITPA plus assessment) and a control group (ITPA only); 145 patients were starting treatment for a new diagnosis of leuke- mia or lymphoma or starting treatment for a recurrence, with allogeneic or autologous stem cell support.</li> </ul>	Choice ITPA; clinic access	In the intervention group, more symptoms were addressed by physicians and nurses, leading to decreased symptom distress over time in 10 of 19 symptom/problem categories versus 2 categories in the control group.

Study and Location	Purpose	Level of Evidence and Design	Electronic Tool	Major Findings
Psychosocial	impact (continued)			
Ruland, Andersen, et al., 2013 (Norway)	To examine symptom distress	<ul> <li>II; 1-year repeated measures RCT with 325 patients with breast and prostate cancer; the experimental group had access to WebChoice, which is based on a comprehensive review of the scientific literature related to breast and prostate cancer, whereas the control group received URLs for publicly available cancer websites.</li> </ul>	WebChoice; remote access	Group differences on symptom distress were significant only for the Global Symptom Distress Index ( $p =$ 0.037). Significant within-group improvements in depression in the experimental group only and the control group indicated that self-efficacy and health-related QOL deteriorated significantly over time.

TABLE 1. Review of Literature About Electronic Methods for Symptom Self-Report, Categorized by Theme (Continued)

ASyMS—advanced symptom management system; CAT—computer adaptive test; CHOICE—Creating better Health Outcomes by Improving Communication about Patients' Experiences; CTCAE—Common Terminology Criteria for Adverse Events; EHR—electronic health record; E-MOSAIC—electronic monitoring of symptoms and syndromes associated with advanced cancer; EORTC QLQ-C30—European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire-Core 30; ESRA-C—Electronic Self-Report Assessment–Cancer; FACIT—Functional Assessment of Chronic Illness Therapy; FACT-B—Functional Assessment of Cancer Therapy–Breast; FACT-G—Functional Assessment of Cancer Therapy–General; IHCA—interactive health communication application; IPPC— Internet-based patient—provider communication service; ITPA—interactive tailored patient assessment; MDASI—MD Anderson Symptom Inventory; OPNC—online patient—nurse communication service; PRO—patient-reported outcome; PROMIS—Patient-Reported Outcomes Measurement Information System; QOL—quality of life; RCT—randomized, controlled trial; SQLI—patient-reported cancer symptom and quality-of-life issue; STAR—Symptoms Tracking and Reporting for Patients

In two studies, patients' symptoms were collected via assessments using paper and an electronic device (Abernethy et al., 2008; Blum et al., 2014). In both studies, no significant differences in symptoms were found.

**Wireless tablet computer:** The study by Abernethy et al. (2008) reported that patients felt that wireless tablet computers were easy to read (94%) and easy to respond to (98%).

**PALM:** In the Blum et al. (2014) study, 49% of the 84 participants preferred the PALM (handheld computer) to the paper-based assessment. Several studies reported high patient acceptability and feasibility regarding the electronic assessment of symptoms (Abernethy et al., 2008; Andikyan et al., 2012; Basch et al., 2007; Blum et al., 2014; Chan et al., 2011; Falchook et al., 2016; Wintner et al., 2015; Wolpin et al., 2008; Mu et al., 2016). Three studies (Head et al., 2009; Mirkovic, Kaufman, & Ruland, 2014; Ruland, Maffei, et al., 2013) considered the usability and usefulness of a device from the patient's perspective.

**Health Buddy:** In the Head et al. (2009) study (N = 75), the telecommunications device Health Buddy was described as an easy-to-use telehealth messaging device. The print on the screen was large and easy to read, and only four buttons were used to register the

responses. Compared to standard of care, the patients in the intervention group (n = 42) reported that the device was either easy or very easy to use, with 65%reporting improved satisfaction concerning communication with their healthcare providers.

**Connect and WebChoice:** The study by Mirkovic et al. (2014) involved usability testing of a highfidelity prototype of the Connect mobile application, which was developed to allow patients access to the Internet platform Connect. Seven patients evaluated the look and feel of the application while using it to report their symptoms; overall, patients found that the application was useful and that they would use it again.

Ruland, Maffei, et al. (2013) examined WebChoice, an interactive health communication application (IHCA) that is tailored to patients' individual needs and includes various components (e.g., discussion forum, healthcare team messaging, diary). Patientreported usefulness of WebChoice and its components differed with disease stage. Sixty-four percent of the participants actively used WebChoice (average of 60 times). The discussion forum and messages to the nurse components were used most, with large individual variations. The latter component was most valued by patients. WebChoice is a component of Connect.

CHOICE: A study by Ruland (2006) evaluated the clinicians' (65 nurses and 12 physicians) perceived usefulness of a system called Creating better Health Outcomes by Improving Communication about Patients' Experiences (CHOICE). CHOICE is an assessment tool for patients to report their cancerspecific symptoms; a summary report of these symptoms is then made available to clinicians to review and use for patient care planning. The clinicians highly rated all aspects of CHOICE's usefulness (e.g., patient involvement, assessment summaries), but the nurses consistently provided higher usefulness ratings than the physicians. The nurses reported feeling as though CHOICE improved care planning and provided them with a better understanding of patients' views. A strong significant correlation existed between patterns of use and perceived usefulness.

# Analysis

Berry et al. (2011) and Blum et al. (2014) reported that clinicians found the summary reports generated by the patient self-assessment systems (ESRA-C and E-MOSAIC, or electronic monitoring of symptoms and syndromes associated with advanced cancer, respectively) to be useful. Having a longitudinal and quantitative overview of patients' symptoms was viewed as being beneficial to clinicians (Blum et al., 2014). Most clinicians noted that the summary report was useful for identifying symptoms and quality-of-life issues, promoting patient-clinician communication, and identifying areas for referral (Berry et al., 2011; Blum et al., 2014).

Ruland, Maffei, et al. (2013) and Varsi, Gammon, Wibe, and Ruland (2013) looked at patients' frequency and patterns of use of the components of the WebChoice system. The patients in this study were part of a larger study (Ruland, Andersen, et al., 2013). Ruland, Maffei, et al. (2013) reported that patients with breast cancer logged in to the WebChoice system twice as often as patients with prostate cancer and that they also posted significantly more to the discussion forum. Patients visited the forum more often than they contributed messages to it, and the patients with prostate cancer preferred to send personal messages to the nurses rather than post to the discussion forum. The patients with breast cancer and the patients with prostate cancer sent a similar number of messages to the nurses. In addition, patients who had been diagnosed more than one year prior to entering the study wrote considerably more notes in the diary (which is part of the WebChoice system), sent more messages to the nurses, and visited the assessment section (which allows patients to self-monitor symptoms, problems, and priorities) more often than the patients who had been diagnosed more recently; however, the differences were not statistically significant.

Varsi et al. (2013) determined that patients appreciated the availability of the Internet-based patient-provider communication services (IPPCs) and the possibility of using such healthcare team messaging as needed, even if they did not actually use it. Their reasons for not using the IPPCs included the following:

- Had sufficient access elsewhere
- Preferred other types of communication (e.g., telephone, in person)
- Hindered in IPPC use (e.g., login problems)

Despite the variety of devices and symptom assessment tools used in the aforementioned studies, the participating patients and clinicians found electronic self-report of patient symptoms to be acceptable, feasible, and useful. Electronic collection of symptoms allowed for the generation of alerts to clinicians for grade 3 and 4 toxicities. Such alerts and summary reports may have led to increased acceptability, feasibility, and usability of the electronic method of symptom reporting by the patients. The summary reports were viewed as a benefit by clinicians and should be considered when implementing an electronic method of self-reporting symptoms. Understanding that patient use of the system may be dependent on various factors, including cancer type and time from diagnosis, is important.

#### Communication

Thirteen studies considered the effect of electronic patient self-report of symptoms on communication. Of those 13 studies, 6 considered the discussion between the patient and the clinician regarding symptoms, 1 examined the clinician's documentation of the symptoms, and 6 looked at the management of the self-reported symptoms. The type and capabilities of the electronic methods varied; several web-based patient assessment systems, including automated telephone systems set up to send alerts to the healthcare team, were examined.

**Symptom self-report:** In a study by Wagner et al. (2015) (N = 636), Patient-Reported Outcomes Measurement Information System computer adaptive tests (CATs) were completed by most of the patients at home (90%). They were then scored and reported via the Epic MyChart portal, with immediate integration into the EHR system. This real-time integration of patient-reported symptoms into the EHR permitted

identification of the need for and implementation of psychosocial and supportive care strategies.

**Symptom discussion:** When patients in a study by Heyn, Finset, and Ruland (2013) used CHOICE interactive tailored patient assessment (ITPA) prior to their consultation, they expressed more cues (utterances with an underlying emotional meaning) and concerns (p < 0.01) than did patients in the control group who did not use CHOICE ITPA. In addition, patients reporting to nurses expressed significantly more cues (p < 0.001) than did patients reporting to physicians (Heyn, Ruland, & Finset, 2012). More cues and concerns were expressed by patients early in clinician consultations (Heyn, Finset, & Ruland, 2013). The most frequent cue indicated expression of uncertainty and hope (Grimsbø, Ruland, & Finset, 2012; Heyn et al., 2012).

The symptom assessment summary report generated was provided to the clinician during the patient's visit; it prompted significantly more discussion of the patient's symptoms (Berry et al., 2011; Heyn, Finset, Eide, & Ruland, 2013). Among those in the intervention group, where patients had access to the healthcare messaging component and assessment summary, patients asked more questions, and clinicians provided more information during the visit (Heyn, Finset, Eide, & Ruland, 2013). On the whole, patient-clinician communication improved (Basch, et al., 2007; Berry et al., 2011; Blum et al., 2014; Heyn, Finset, Eide, & Ruland, 2013). These findings are consistent with those in a study by Detmar, Muller, Schornagel, Wever, and Aaronson (2002), who determined that the summary report provided a useful overview of patients' symptoms and facilitated communication between the patient and the physician. The summary report may have increased clinicians' acknowledgement of patients' socio-emotional concerns, as well as clinicians' overall responsiveness to patients' cues; however, the summary report did not increase clinicians' exploration of socio-emotional concerns, even when a prompt was provided (Kennedy Sheldon, Hilaire, & Berry, 2011). Exploration of concerns is necessary for complete assessment of patients' socio-emotional status (Maguire, Faulkner, Booth, Elliott, & Hillier, 1996). Patients who perceive their providers as acknowledging and exploring their socio-emotional status may have better emotional adjustment and decreased psychological distress compared to patients who do not perceive their providers as responding to these concerns (de Haes & Bensing, 2009).

**Documentation:** Patients with breast cancer in the Bock et al. (2012) study (N = 106) reported significantly more symptoms using a secure online questionnaire than were documented in the clinic notes by the clinician (p < 0.001); however, less than 40% of symptoms were managed. Exercise and alcohol consumption were reported 100% of the time in the online questionnaire but were documented in only 28% of the patients' charts. In 25% of the charts where alcohol consumption was documented, there was significant discordance between patient and clinician reporting.

**Symptom management:** An automated telephone system was used in the Cleeland et al. (2011) study in a postoperative setting to enable patients to rate their symptoms twice weekly for four weeks. An email alert was sent to a patient's clinical team when the symptom reached a predetermined severity threshold, and clinicians responded to 84% of those alerts. Among the alert group, a greater reduction was seen in the number of symptom threshold events, as well as a more rapid decline in these events, compared to the control group.

In a study by Kearney et al. (2009), a mobile telephone–based advanced symptom management system (ASyMS) allowed patients to remotely report symptoms and supported the management of symptoms in patients receiving chemotherapy. The preliminary findings suggest that the real-time reporting of symptoms facilitates a more accurate reflection of chemotherapy side effects, as well as better monitoring and management of them.

In a longitudinal study by LeBlanc et al. (2015), the Patient Care Monitor (PCM) was used by patients with advanced lung cancer to self-report their symptoms over time; the authors found that these patients experienced a substantial symptom burden that increased with proximity to death. Concerns related to physical movement or functioning were the most frequently reported moderate to severe issues. Collecting this detailed symptom assessment information and tracking symptoms in real time promoted an individualized supportive care approach.

Two qualitative studies (Ekstedt, Børøsund, Svenningsen, & Ruland, 2014; Grimsbø, Ruland, & Finset, 2012) and one quantitative study (Grimsbø, Finset, & Ruland, 2011) explored the healthcare team messaging component of WebChoice that allowed direct communication between a patient and the healthcare team. The patients in these three studies were part of a larger trial (Ruland, Andersen, et al., 2013).

The study by Ekstedt et al. (2014) looked at how the healthcare team messaging component of WebChoice

contributed to improving patient safety and continuity of care between treatment cycles. The messages allowed patients to communicate with the healthcare team and alert them to their symptoms and concerns, as well as ensure that quality information was being provided to the patients by confirming the information and sometimes providing further explanation (Ekstedt et al., 2014).

The study by Grimsbø et al. (2011) reviewed the content of the patients' electronic messages, and four main themes were identified: living with symptoms and side effects, living with fear of relapse, everyday life concerns, and the healthcare clinicians not meeting their needs for information. Nurses responded to most of the patients' cues and concerns in the electronic messages, and more than half of their responses provided information and empathy (Grimsbø, Ruland, & Finset, 2012).

Use of system components, including the electronic messaging component, differed by patient subgroup. For example, many patients with breast cancer used the WebChoice system for health-related information, and a number of patients with prostate cancer used features that helped them talk to their healthcare team. More active communication practices and information-seeking behaviors were observed in patients with a history of long-term illness than in those with a first-time diagnosis (Grimsbø, Engelsrud, Ruland, & Finset, 2012; Ruland, Maffei, et al., 2013). Patients with little social support and high levels of symptom distress and depression used the messaging and symptom self-management support components. Patient communication preferences and patterns are dependent on many factors and should be taken into consideration when identifying electronic methods that allow for patient-patient and patient-clinician communication.

# **Psychosocial Impact**

The following studies examined the use of the webbased ESRA-C by patients to report symptoms and quality of life. Berry et al. (2011) found that when clinicians were provided with summary reports of patients' self-reported cancer symptoms and quality of life, there was a positive impact on patientclinician communication. In a study by Berry et al. (2014), clinicians were given summary reports for all patients enrolled. The intervention group received education and coaching regarding their symptoms in addition to clinician provision of the summary report and reported lower distress than the patients who did not receive education and coaching. In addition, the intervention group reported lower distress compared to the control group (p = 0.02).

Basch et al. (2016) reported that health-related quality of life improved by 34% among patients who were reporting their symptoms via tablet and home computer versus an improvement of 18% among patients who were receiving usual care (symptom monitoring at the discretion of the clinician).

In a study by Hong, Bosco, Bush, and Berry (2013), the ESRA-C was used by patients (N = 627) to report their symptoms at two different time points within a 109-day period. Changes were found in quality of life during patients' treatment, with more than half of the patients undergoing stem cell transplantation (n = 191) reporting deteriorating quality of life. For the patients undergoing medical or radiation treatment (n = 436), equal proportions perceived improvement (25%) and deterioration (26%) of quality of life.

Berry, Blonquist, Patel, Halpenny, and McReynolds (2015) conducted a study to evaluate the fully automated ESRA-C. Patients in the intervention group had access to the teaching tips component of ESRA-C. For any symptom or quality-of-life issue that was rated as moderate or severe, the patient would receive teaching tips. Participants who were undergoing radiation treatment were more likely than those who were undergoing medical treatment or transplantation to use the tips. Symptom distress was reduced (p = 0.01) for those who used the teaching tips.

The intervention group in a study by Ruland et al. (2010) involved the sending of a summary report to clinicians after patients rated and prioritized their self-reported symptoms; the control group did not include provision of this report. In the intervention group, more symptoms were addressed by physicians and nurses, leading to decreased symptom distress over time in 10 of 19 symptom/problem categories versus 2 categories in the control group.

In a study by Boyes, Newell, Girgis, McElduff, and Sanson-Fisher (2006), a summary report was provided to clinicians after patients completed a computerized survey of their physical symptoms, as well as the 14-item Hospital Anxiety and Depression Scale and a shortened version of the Supportive Care Needs Survey. The intervention group received a report with clinician feedback. The patients in the intervention group who had reported a debilitating physical symptom at their second visit were significantly less likely to report this at their third visit versus control group participants (p = 0.04).

Patients with access to WebChoice or the healthcare team messaging component reported

lower symptom distress over time (p = 0.001), including less depression and anxiety (p = 0.03), compared to the group who did not have access to electronic self-reporting or messaging (Børøsund, Cvancarova, Moore, Ekstedt, & Ruland, 2014). Even in the group with access to only the messaging component, the patients reported lower depression scores than those in the standard care group (Børøsund et al., 2014).

The study by Ruland, Andersen, et al. (2013) randomized patients to use WebChoice and any of its components, including the messaging component, for one year. The control group received only an information sheet listing publicly available cancer-related Internet sites. Symptom distress was significantly less, as measured by the Memorial Symptom Assessment Scale–Short Form (Børøsund et al., 2014; Ruland, Andersen, et al., 2013). Scores improved in the intervention group compared to the control group for depression, self-efficacy, quality of life, and social support (Ruland, Andersen, et al., 2013).

Patients' experiences with WebChoice varied (Grimsbø, Engelsrud, Ruland, & Finset, 2012). Ten patients were interviewed about their interactions with WebChoice; some described WebChoice as feeling either like a trusted friend or a remote stranger, and a range of emotions (including feeling calmed down, upset, or like their normal selves) were reported.

# Discussion

A variety of electronic devices and software were evaluated in the studies. Applications for tablet computers with touch screens, mobile telephones, personal digital assistants, and the web represent the primary technologies considered. Growing evidence exists to support the idea that routinely collecting patient-reported outcomes electronically is feasible and acceptable to the patient. For instance, a high percentage of patients used the various components of WebChoice, such as the discussion forum, and appreciated the availability of the IPPC, even if they did not use it (Varsi et al., 2013). Such findings are consistent with a Cochrane database review on the effects of IHCAs; users were more knowledgeable than non-users, and they also felt socially supported and may have experienced improved behavioral and clinical outcomes (Murray, Burns, Tai, Lai, & Nazareth, 2005). Clinicians discussing the summary report findings directly with their patients led to increased communication and the early addressing of symptoms and problems (Berry et al., 2011). Realtime review of symptoms by clinicians who provide timely feedback (including interventions to manage

#### **KNOWLEDGE TRANSLATION**

- Most patients find electronic methods to be acceptable and feasible to self-report their symptoms.
- Real-time symptom assessment and management positively affects patient-reported quality of life.
- Oncology nurses are vital to receiving, reviewing, and reporting changes in patient status, as well as responding to patients with quality information and with empathy and coordinating care.

symptoms) enhances patient-clinician communication and decreases distress (Boyes et al., 2006).

Qualitative methods should be considered when the researcher is interested in capturing patients' experiences. Additional qualitative studies with patients undergoing cancer treatment could enhance understanding concerning different types of electronic self-report of symptoms and their impact on symptom management.

# Limitations

Challenges existed in identifying and retrieving all relevant research on patient-reported symptoms in oncology. As a result, different terms were used to search individual databases. The search was limited to studies published from 2006–2016 and to Englishlanguage articles; gray literature and unpublished studies were excluded. Studies published prior to 2006 may contain important findings. The studies selected for inclusion used different data collection methods, as well as varied in the devices and assessment tools considered and in the sampling methods used. Some of the studies used the same data set, and many studies were single-institution experiences specific to a certain type of cancer diagnosis, which may limit the generalizability of the results.

# Implications for Nursing Practice and Research

Patient-reported outcomes improve symptom detection and management, enhance quality of care, and promote patient satisfaction (Basch, 2014). Electronic methods are being used by patients to self-report these outcomes, and most patients find electronic methods to be acceptable and feasible for reporting symptoms. Realtime self-reporting via an interactive patient–clinician communication component improved patient–clinician communication and decreased symptom distress. This should be considered when evaluating tools for patients to self-report their symptoms. Other features that increase the usefulness of an electronic method for collecting patient symptoms include the following:

- Has mechanisms for real-time self-reporting of symptoms
- Generates alerts for selective grade 3 or 4 side effects
- Has a patient-clinician communication portal
- Has the capability to produce symptom summary reports
- Tracks symptoms over time
- Has a patient information portal with the capability to access the patient blog

In addition, oncology nurses were found to be central in receiving, reviewing, and reporting changes to the provider, as well as in responding to patients and providing them with quality information and expressing empathy. They were also significant in care coordination. Patients expressed themselves more when consulting with nurses versus physicians (Heyn, Finset, & Ruland, 2013).

Finding or developing new ways for nurses to manage patient symptoms is vital to improving patients' quality of life (National Institute of Nursing Research, 2016). Communication of patient-reported outcomes to nurses is key to symptom management. Electronic methods featuring interactive components that permit patient–clinician communication are becoming important tools for nurses to support patients with cancer. Nurses should consider making available an approach where patients can report their symptoms as they are experienced so assessment and management can occur in real time.

This literature review uncovered the lack of information that exists regarding patients' experiences of reporting their symptoms and their preferences related to symptom-reporting method; consequently, this is an area for future research. Understanding the ways in which patients prefer to report their symptoms may influence the likelihood that patients will report those symptoms and report them in a timely manner.

The 2013 Oncology Nursing Society Research Priorities Survey identified the use of interventions that employ technology to address symptoms, self-management to improve symptom control, and symptom management interventions as top priorities for oncology nurses (LoBiondo-Wood et al., 2014). Studies with larger and more diverse samples are needed to explore the use of various technologies to assess patient-reported symptoms and to improve the understanding behind the use of these technologies for symptom management and self-management. Future studies exploring the electronic capture of symptoms should consider a platform that includes interactive components, allowing for patient-clinician communication and real-time symptom assessment and management. Using qualitative methods to uncover what it means to electronically report symptoms would adequately capture patients' experiences. This understanding will then need to be incorporated into future research, with the aim of improving symptom reporting and patient interventions, including self-management of symptoms.

#### Conclusion

The studies included in this integrative review employed a variety of symptom assessment measures and electronic methods for patient self-report of symptoms. Electronic assessment of patient-reported symptoms was considered to be acceptable and feasible in most of the studies. In the studies that evaluated the usefulness and usability of electronic or telephonic methods, patients reported that the systems were easy to use, and the clinicians found the information reported by patients to be useful. Considerations should be made based on how usage of the patient communication components of electronic systems varied according to cancer type, disease stage, illness burden, and length of illness. Patients with recurrent or metastatic disease tended to communicate more often and sent more messages to nurses, demonstrating varied needs for patient support. Incorporating patient symptom reporting into clinical practice improves symptom detection and management, enhances quality of care, and improves patient satisfaction.

Clinicians reported better communication when using the software systems that generated summary reports. EHR integration of patient-reported symptoms may help to improve patient-clinician communication, thanks to real-time delivery of communications and assessment by the healthcare team, including automated triage for supportive care. Using web-based systems with an integrated patientclinician communication service led to less patient distress because the healthcare team was able to focus on addressing symptoms of concern and then tracking those symptoms over time.

Sharyn Carrasco, RN, MSN, is a senior medical science liaison for Array BioPharma in Morrisville, NC, and a graduate student in the College of Nursing at Texas Woman's University in Houston; and Lene Symes, PhD, RN, is a professor in the College of Nursing at Texas Woman's University in Houston. Carrasco can be reached at scarrasco@twu.edu, with copy to ONFEditor@ons.org. (Submitted October 2017. Accepted January 3, 2018.)

No financial relationships to disclose.

Carrasco completed the data collection and provided statistical support. Both authors contributed to the conceptualization and design, provided the analysis, and contributed to the manuscript preparation.

#### REFERENCES

- Abernethy, A.P., Herndon, J.E., 2nd, Wheeler, J.L., Patwardhan, M., Shaw, H., Lyerly, H.K., & Weinfurt, K. (2008). Improving health care efficiency and quality using tablet personal computers to collect research-quality, patient-reported data. *Health Services Research*, 43, 1975–1991.
- Andikyan, V., Rezk, Y., Einstein, M.H., Gualtiere, G., Leitao, M.M., Jr., Sonoda, Y., . . . Chi, D.S. (2012). A prospective study of the feasibility and acceptability of a Web-based, electronic patient-reported outcome system in assessing patient recovery after major gynecologic cancer surgery. *Gynecologic Oncology*, 127, 273–277.
- Barbera, L., Atzema, C., Sutradhar, R., Seow, H., Howell, D., Husain, A., . . . Dudgeon, D. (2013). Do patient-reported symptoms predict emergency department visits in cancer patients? A population-based analysis. *Annals of Emergency Medicine*, 61, 427–437. https://doi.org/10.1016/j.annemergmed.2012.10.010
- Basch, E. (2014). The rationale for collecting patient-reported symptoms during routine chemotherapy. American Society of Clinical Oncology Educational Book, 2014, 161–165.
- Basch, E., Iasonos, A., Barz, A., Culkin, A., Kris, M.G., Artz, D., ... Schrag, D. (2007). Long-term toxicity monitoring via electronic patient-reported outcomes in patients receiving chemotherapy. *Journal of Clinical Oncology*, 25, 5374–5380. http://doi.org/10 .1200/JCO.2007.11.2243
- Basch, E., Iasonos, A., McDonough, T., Barz, A., Culkin, A., Kris, M.G., . . . Schrag, D. (2006). Patient versus clinician symptom reporting using the National Cancer Institute Common Terminology Criteria for Adverse Events: Results of a
- questionnaire-based study. *Lancet Oncology*, 7, 903–909. Basch, E.M., Deal, A.M., Kris, M.G., Scher, H.I., Hudis, C.A.,
- Sabbatini, P., . . . Schrag, D. (2016). Symptom monitoring with patient-reported outcomes during routine cancer treatment: A randomized controlled trial. *Journal of Clinical Oncology*, *34*, 557–565. https://doi.org/10.1200/JCO.2015.63.0830
- Bennett, A.V., Jensen, R.E., & Basch, E. (2012). Electronic patientreported outcome systems in oncology clinical practice. CA: A Cancer Journal for Clinicians, 62, 336–347. https://doi.org/10.3322/ caac.21150
- Berry, D.L., Blonquist, T.M., Patel, R.A., Halpenny, B., & McReynolds, J. (2015). Exposure to a patient-centered, web-based intervention for managing cancer symptom and quality of life issues: Impact

on symptom distress. Journal of Medical Internet Research, 17, e136. https://doi.org/10.2196/jmir.4190

- Berry, D.L., Blumenstein, B.A., Halpenny, B., Wolpin, S., Fann, J.R., Austin-Seymour, M., . . . McCorkle, R. (2011). Enhancing patient–provider communication with the electronic self-report assessment for cancer: A randomized trial. *Journal of Clinical Oncology*, 29, 1029–1035.
- Berry, D.L., Hong, F., Halpenny, B., Partridge, A.H., Fann, J.R., Wolpin, S., . . . Ford, R. (2014). Electronic self-report assessment for cancer and self-care support: Results of a multicenter randomized trial. *Journal of Clinical Oncology*, 32, 199–205.
- Blum, D., Koeberle, D., Omlin, A., Walker, J., Von Moos, R., Mingrone, W., . . . Ribi, K. (2014). Feasibility and acceptance of electronic monitoring of symptoms and syndromes using a handheld computer in patients with advanced cancer in daily oncology practice. *Supportive Care in Cancer*, 22, 2425–2434.
- Bock, M., Moore, D., Hwang, J., Shumay, D., Lawson, L., Hamolsky, D., . . . Melisko, M. (2012). The impact of an electronic health questionnaire on symptom management and behavior reporting for breast cancer survivors. *Breast Cancer Research and Treatment*, 134, 1327–1335. https://doi.org/10.1007/s10549-012-2150-1
- Børøsund, E., Cvancarova, M., Moore, S.M., Ekstedt, M., & Ruland, C.M. (2014). Comparing effects in regular practice of ecommunication and web-based self-management support among breast cancer patients: Preliminary results from a randomized controlled trial. *Journal of Medical Internet Research*, 16(12), e295.
- Boyes, A., Newell, S., Girgis, A., McElduff, P., & Sanson-Fisher, R. (2006). Does routine assessment and real-time feedback improve cancer patients' psychosocial well-being? *European Journal of Cancer Care*, 15, 163–171. https://doi.org/10.1111/j.1365-2354 .2005.00633.x
- Bruera, E., Sweeney, C., Calder, K., Palmer, L., & Benisch-Tolley, S. (2001). Patient preferences versus physician perceptions of treatment decisions in cancer care. *Journal of Clinical Oncology*, 19, 2883–2885. https://doi.org/10.1200/JCO.2001.19.11.2883
- Butow, P.N., Brown, R.F., Cogar, S., Tattersall, M.H., & Dunn, S.M. (2002). Oncologists' reactions to cancer patients' verbal cues. *Psycho-Oncology*, 11, 47–58. https://doi.org/10.1002/pon.556
- Cella, D. (1997). The Functional Assessment of Cancer Therapy-Anemia (FACT-An) Scale: A new tool for the assessment of outcomes in cancer anemia and fatigue. *Seminars in Hematology*, 34(Suppl. 2), 13–19.
- Cella, D., Choi, S., Garcia, S., Cook, K.F., Rosenbloom, S., Lai, J.-S., . . . Gershon, R. (2014). Setting standards for severity of common symptoms in oncology using the PROMIS item banks and expert judgement. *Quality of Life Research*, *23*, 2651–2661.
- Chan, C.W., Tam, W., Cheng, K.K., Chui, Y.Y., So, W.K., Mok, T., . . . Berry, D.L. (2011). Piloting electronic self-report symptom assessment-cancer (ESRA-C) in Hong Kong: A mixed method approach. *European Journal of Oncology Nursing*, 15, 325–334.
- Chang, V.T., Hwang, S.S., Feueurman, M., & Kasimis, B.S. (2000). Symptom and quality of life survey of medical oncology patients

at a veterans affairs medical center: A role for symptom assessment. *Cancer*, 88, 1175–1183.

- Chen, J., Ou, L., & Hollis, S.J. (2013). A systematic review of the impact of routine collection of patient reported outcome measures on patients, providers and health organizations in an oncologic setting. BMC Health Services Research, 13, 211. https:// doi.org/10.1186/1472-6963-13-211
- Cleeland, C.S., Wang, X.S., Shi, Q., Mendoza, T.R., Wright, S.L., Berry, M.D., . . . Vaporciyan, A.A. (2011). Automated symptom alerts reduce postoperative symptom severity after cancer surgery: A randomized controlled clinical trial. *Journal of Clinical Oncology*, 29, 994–1000. https://doi.org/10.1200/JCO.2010.29.8315
- de Haes, H., & Bensing, J. (2009). Endpoints in communication research, proposing a framework of functions and outcomes. *Patient Education and Counseling*, 74, 287–294. https://doi.org/ 10.1016/j.pec.2008.12.006
- Detmar, S.B., Muller, M.J., Schornagel, J.H., Wever, L.D., & Aaronson, N.K. (2002). Health-related quality-of-life assessments and patient-physician communication: A randomized controlled trial. JAMA, 288, 3027–3034.
- Dueck, A.C., & Sloan, J.A. (2007). Meeting on the FDA draft guidance on patient-reported outcomes. *Value in Health*, 10(Suppl. 2), S64–S65. https://doi.org/10.1111/j.1524-4733.2007.00268.x
- Efficace, F., Cartoni, C., Niscola, P., Tendas, A., Meloni, E., Scaramucci, L., . . . Mandelli, F. (2012). Predicting survival in advanced hematologic malignancies: Do patient-reported symptoms matter? *European Journal of Haematology*, *89*, 410–416. https://doi .org/10.1111/ejh.12004
- Ekstedt, M., Børøsund, E., Svenningsen, I.K., & Ruland, C.M. (2014). Reducing errors through a web-based self-management support system. Studies in Health Technology and Informatics, 201, 328–334.
- Epstein, R.M., & Street, R.L., Jr. (2007). Patient-centered communication in cancer care: Promoting healing and reducing suffering. Retrieved from https://bit.ly/2vhvjiG
- Falchook, A.D., Tracton, G., Stravers, L., Fleming, M.E., Snavely, A.C., Noe, J.F., . . . Chera, B.S. (2016). Use of mobile device technology to continuously collect patient-reported symptoms during radiation therapy for head and neck cancer: A prospective feasibility study. Advances in Radiation Oncology, 1, 115–121. https:// doi.org/10.1016/j.adro.2016.02.001
- Farrell, C., Beaver, K., Heaven, P., & Maguire, P. (2001). Identifying the concerns of women undergoing chemotherapy treatment for cancer. *European Journal of Cancer*, 37(Suppl. 6), S390. https://doi .org/10.1016/S0959-8049(01)81894-3
- Fromme, E.K., Eilers, K.M., Mori, M., Hsieh, Y.-C., & Beer, T.M. (2004). How accurate is clinician reporting of chemotherapy adverse effects? A comparison with patient-reported symptoms from the Quality-of-Life Questionnaire C30. *Journal of Clinical Oncology*, 22, 3485–3490. https://doi.org/10.1200/JCO.2004.03.025
- Grimsbø, G.H., Engelsrud, G.H., Ruland, C.M., & Finset, A. (2012). Cancer patients' experiences of using an interactive health communication application (IHCA). *International Journal of*

Qualitative Studies on Health and Well-Being, 7, 15511. https://doi .org/10.3402/qhw.v7i0.15511

- Grimsbø, G.H., Finset, A., & Ruland, C.M. (2011). Left hanging in the air: Experiences of living with cancer as expressed through e-mail communications with oncology nurses. *Cancer Nursing*, 34, 107–116. https://doi.org/10.1097/NCC.ob013e3181eff008
- Grimsbø, G.H., Ruland, C.M., & Finset, A. (2012). Cancer patients' expressions of emotional cues and concerns and oncology nurses' responses, in an online patient–nurse communication service. *Patient Education and Counseling*, 88, 36–43. https://doi .org/10.1016/j.pec.2012.01.007
- Gwaltney, C.J., Shields, A.L., & Shiffman, S. (2008). Equivalence of electronic and paper-and-pencil administration of patientreported outcome measures: A meta-analytic review. Value in Health, 11, 322–333. https://doi.org/10.1111/j.1524-4733.2007 .00231.x
- Head, B.A., Studts, J.L., Bumpous, J.M., Gregg, J.L., Wilson, L., Keeney, C., . . . Pfeifer, M.P. (2009). Development of a telehealth intervention for head and neck cancer patients. *Telemedicine and e-Health*, 15, 44–52. https://doi.org/10.1089/tmj.2008.0061
- Heyn, L., Finset, A., Eide, H., & Ruland, C.M. (2013). Effects of an interactive tailored patient assessment on patient-clinician communication in cancer care. *Psycho-Oncology*, 22, 89–96. https://doi .org/10.1002/pon.2064
- Heyn, L., Finset, A., & Ruland, C.M. (2013). Talking about feelings and worries in cancer consultations: The effects of an interactive tailored symptom assessment on source, explicitness, and timing of emotional cues and concerns. *Cancer Nursing*, 36, E20–E30. https://doi.org/10.1097/NCC.ob013e318254af66
- Heyn, L., Ruland, C.M., & Finset, A. (2012). Effects of an interactive tailored patient assessment tool on eliciting and responding to cancer patients' cues and concerns in clinical consultations with physicians and nurses. *Patient Education and Counseling*, 86, 158–165. https://doi.org/10.1016/j.pec.2011.04.024
- Hong, F., Bosco, J.L., Bush, N., & Berry, D.L. (2013). Patient self-appraisal of change and minimal clinically important difference on the European Organization for the Research and Treatment of Cancer Quality of Life Questionnaire Core 30 before and during cancer therapy. *BMC Cancer*, 13, 165.
- Johansen, M.A., Henriksen, E., Berntsen, G., & Horsch, A. (2011). Electronic symptom reporting by patients: A literature review. Studies in Health Technology and Informatics, 169, 13–17.
- Kearney, N., McCann, L., Norrie, J., Taylor, L., Gray, P., McGee-Lennon, M., . . . Maguire, R. (2009). Evaluation of a mobile phone-based, advanced symptom management system (ASyMS<sup>®</sup>) in the management of chemotherapy-related toxicity. *Supportive Care in Cancer*, 17, 437–444.
- Kennedy Sheldon, L., Hilaire, D., & Berry, D.L. (2011). Provider verbal responses to patient distress cues during ambulatory oncology visits. Oncology Nursing Forum, 38, 369–375. https://doi .org/10.1188/11.ONF.369-375

LeBlanc, T.W., Nickolich, M., Rushing, C.N., Samsa, G.P., Locke, S.C.,

& Abernethy, A.P. (2015). What bothers lung cancer patients the most? A prospective, longitudinal electronic patient-reported outcomes study in advanced non-small cell lung cancer. *Supportive Care in Cancer*, 23, 3455–3463. Lee, J. (2008). *Exploring chemotherapy-induced nausea and vomiting*:

- The symptoms, interventions, and relationship to functional status (Doctoral dissertation). Retrieved from ProQuest Dissertations and Theses Global. (UMI No. 3311334)
- LoBiondo-Wood, G., Brown, C.G., Knobf, M.T., Lyon, D., Mallory, G., Mitchell, S.A., . . . Fellman, B. (2014). Priorities for oncology nursing research: The 2013 national survey. *Oncology Nursing Forum*, 41, 67–76. https://doi.org/10.1188/14.ONF.67-76
- Maguire, P., Faulkner, A., Booth, K., Elliott, C., & Hillier, V. (1996).
  Helping cancer patients disclose their concerns. *European Journal* of Cancer, 32A, 78–81.
- McIntyre, P. (2015, March 1). Side effects of targeted treatments: Clinicians' perceptions, patients' realities. *Cancerworld*. Retrieved from https://bit.ly/2HzoJpA
- Melnyk, B.M., & Fineout-Overholt, E. (2011). *Evidence-based practice in nursing and healthcare: A guide to best practice* (2nd ed.). Philadelphia, PA: Lippincott Williams and Wilkins.
- Mirkovic, J., Kaufman, D.R., & Ruland, C.M. (2014). Supporting cancer patients in illness management: Usability evaluation of a mobile app. *JMIR mHealth and uHealth*, 2(3), e33. https://doi.org/ 10.2196/mhealth.3359
- Moher, D., Liberati, A., Tetzlaff, J., & Altman, D.G. (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA statement. PLOS Medicine, 6(7), e1000097.
- Murray, E., Burns, J., Tai, S.S., Lai, R., & Nazareth, I. (2005). Interactive health communication applications for people with chronic disease. *Cochrane Database of Systematic Reviews*, 4, CD004274.
- National Institute of Nursing Research. (2016). The NINR strategic plan: Advancing science, improving lives. A vision for nursing science. Retrieved from https://bit.ly/2vlMVdi
- Newell, S., Sanson-Fisher, R.W., Girgis, A., & Bonaventura, A. (1998). How well do medical oncologists' perceptions reflect their patients' reported physical and psychosocial problems? Data from a survey of five oncologists. *Cancer*, 83, 1640–1651.
- Petersen, M.A., Larsen, H., Pedersen, L., Sonne, N., & Groenvold, M. (2006). Assessing health-related quality of life in palliative care: Comparing patient and physician assessments. *European Journal* of Cancer, 42, 1159–1166.
- Portenoy, R.K., Thaler, H.T., Kornblith, A.B., Lepore, J.M., Friedlander-Klar, H., Coyle, N., . . . Scher, H. (1994). Symptom prevalence, characteristics, and distress in a cancer population. *Quality of Life Research*, *3*, 183–189. https://doi.org/10.1007/bf00435383
- Reilly, C.M., Bruner, D.W., Mitchell, S.A., Minasian, L.M., Basch, E., Dueck, A.C., . . . Reeve, B.B. (2013). A literature synthesis of symptom prevalence and severity in persons receiving active cancer treatment. *Supportive Care in Cancer*, 21, 1525–1550. https:// doi.org/10.1007/s00520-012-1688-0

Ruland, C.M. (2006). Clinicians' perceived usefulness of a support

system for patient-centered cancer care. Studies in Health Technology and Informatics, 124, 624-630.

- Ruland, C.M., Andersen, T., Jeneson, A., Moore, S., Grimsbø, G.H., Børøsund, E., & Ellison, M.C. (2013). Effects of an internet support system to assist cancer patients in reducing symptom distress: A randomized controlled trial. *Cancer Nursing*, *36*, 6–17.
- Ruland, C.M., Holte, H.H., Røislien, J., Heaven, C., Hamilton, G.A., Kristiansen, J., . . . Ellison, M.C. (2010). Effects of a computersupported interactive tailored patient assessment tool on patient care, symptom distress, and patients' need for symptom management support: A randomized clinical trial. *Journal of the American Medical Informatics Association*, 17, 403–410.
- Ruland, C.M., Maffei, R.M., Børøsund, E., Krahn, A., Andersen, T., & Grimsbø, G.H. (2013). Evaluation of different features of an eHealth application for personalized illness management support: Cancer patients' use and appraisal of usefulness. *International Journal of Medical Informatics*, 82, 593–603. https://doi .org/10.1016/j.ijmedinf.2013.02.007
- Ryan, H., Schofield, P., Cockburn, J., Butow, P., Tattersall, M., Turner, J., . . . Bowman, D. (2005). How to recognize and manage psychological distress in cancer patients. *European Journal of Cancer*, 14, 7–15. https://doi.org/10.1111/j.1365-2354.2005.00482.x
- Varsi, C., Gammon, D., Wibe, T., & Ruland, C.M. (2013). Patients' reported reasons for non-use of an internet-based patient– provider communication service: Qualitative interview study. *Journal of Medical Internet Research*, 15(11), e246. https://doi .org/10.2196/jmir.2683
- Wagner, L.I., Schink, J., Bass, M., Patel, S., Diaz, M.V., Rothrock, N., . . . Cella, D. (2015). Bringing PROMIS to practice: Brief and precise symptom screening in ambulatory cancer care. *Cancer*, 121, 927–934. https://doi.org/10.1002/cncr.29104
- White, C., McMullan, D., & Doyle, J. (2009). "Now that you mention it, doctor . . .": Symptom reporting and the need for systematic questioning in a specialist palliative care unit. *Journal of Palliative Medicine*, 12, 447–450. https://doi.org/10.1089/jpm.2008.0272
- Whittemore, R., & Knafl, K. (2005). The integrative review: Updated methodology. *Journal of Advanced Nursing*, 52, 546–553. https://doi .org/10.1111/j.1365-2648.2005.03621.x
- Wintner, L.M., Giesinger, J.M., Zabernigg, A., Rumpold, G.,
  Sztankay, M., Oberguggenberger, A.S., . . . Holzner, B. (2015).
  Evaluation of electronic patient-reported outcome assessment
  with cancer patients in the hospital and at home. *BMC Medical Informatics and Decision Making*, 15, 110.
- Wolpin, S., Berry, D., Austin-Seymour, M., Bush, N., Fann, J.R., Halpenny, B., . . . McCorkle, R. (2008). Acceptability of an electronic self-report assessment program for patients with cancer. *Computers, Informatics, Nursing, 26*, 332–338.
- Wu, A.W., White, S.M., Blackford, A.L., Wolff, A.C., Carducci, M.A., Herman, J.M., & Snyder, C.F. (2016). Improving an electronic system for measuring PROs in routine oncology practice. *Journal* of *Cancer Survivorship*, 10, 573–582. https://doi.org/10.1007/s11764 -015-0503-6